Hope in palliative care: A longitudinal qualitative study

Olsman, E.

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Hope in Palliative Care describes hope of persons with a life-threatening illness, their family members, friends and healthcare professionals. It addresses ethical, spiritual and psychological issues and offers practical tools for healthcare professionals.

Erik Olsman graduated cum laude in Theology and this book is his PhD Thesis. His main area of interest is meaningful communication in tragic situations.
Hope in Palliative Care

A Longitudinal Qualitative Study

Erik Olsman
Hope in palliative care.
A longitudinal qualitative study
PhD Thesis, Academic Medical Center, University of Amsterdam


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Hope in Palliative Care

A Longitudinal Qualitative Study

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad van doctor

aan de Universiteit van Amsterdam

op gezag van de Rector Magnificus

prof. dr. D.C. van den Boom

ten overstaan van een door het College van Promoties ingestelde commissie,
in het openbaar te verdedigen in de Aula der Universiteit

op vrijdag 26 juni 2015, te 13:00 uur

door

Hendrik Jan Olsman

geboren te Den Ham
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Faculteit der Geneeskunde
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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**


Chapter 2: Three Perspectives on Hope

This chapter was published as: Olsman E, Leget C, Onwuteaka-Philipsen B and Willems D. Should palliative care patients’ hope be truthful, helpful or valuable? An interpretative synthesis of literature describing healthcare professionals’ perspectives on hope of palliative care patients. *Palliat Med* 2014; 28 (1): 59–70. [http://pmj.sagepub.com/content/28/1/59](http://pmj.sagepub.com/content/28/1/59)

**Abstract**

**Background:** Healthcare professionals’ perspectives on palliative care patients’ hope influence communication. However, these perspectives have hardly been examined.

**Aim:** To describe healthcare professionals’ perspectives on palliative care patients’ hope found in the literature.

**Design:** The interpretative synthesis consisted of a quality assessment and thematic analysis of included articles.

**Data sources:** Literature search of articles between January 1980 and July 2011 in PubMed, CINAHL, PsycINFO and EMBASE and references of included studies. Search strategy: (palliat* or hospice or terminal* in title/abstract or as subject heading) AND (hope* or hoping or desir* or optimis* in title or as subject heading).

**Results:** Of the 37 articles, 31 articles were of sufficient quality. The majority of these 31 articles described perspectives of nurses or physicians. Three perspectives on hope of palliative care patients were found: 1) realistic perspective – hope as an expectation should be truthful, and healthcare professionals focused on adjusting hope to truth, 2) functional perspective – hope as coping mechanism should help patients, and professionals focused on fostering hope, and 3) narrative perspective – hope as meaning should be valuable for patients, and healthcare professionals focused on interpreting it.

**Conclusions:** Healthcare professionals who are able to work with three perspectives on hope may improve their communication with their palliative care patients, which leads to a better quality of care.
Introduction

Hope of palliative care patients is related to their psycho-spiritual well-being (1) and can be defined, for example, as finding meaning in life, future-oriented goals or a way of being hopeful (2,3). Several reviews, meta-studies and meta-synthesis studies have mainly examined this topic from the perspective of palliative care patients (1–6), but healthcare professionals’ perspectives have hardly been scrutinized.

Among the exceptions, Clayton et al. (7) systematically reviewed studies on healthcare professionals, patients and families. Focusing on sustaining hope during prognostic and end-of-life issue discussions with terminally ill patients and their families, they suggested that healthcare professionals should balance hope with honesty. Hope was best engendered, among other strategies, by framing it in a wider context than the medical context (7). This systematic review has not explored healthcare professionals’ definitions of hope and only focused on prognostic and end-of-life issue discussions.

It is important, however, to systematically describe healthcare professionals’ perspectives on hope of palliative care patients, without limiting these perspectives to discussions on prognosis or end-of-life issues. This is important since palliative care patients may not limit hope to the medical domain (8), and one cannot assume that professionals’ and patients’ perspectives are identical (9). Moreover, healthcare professionals’ perspectives on hope influence what they do. For example, healthcare professionals describing hope merely as something that should be maintained may delay end-of-life discussions (10–13).

The aim of our study was to describe healthcare professionals’ perspectives on hope of palliative care patients. The results may support healthcare professionals to reflect on how their perspectives influence communication with palliative care patients. Our study will furthermore contribute to understanding similarities and differences between patient and professional perspectives on hope, which may increase healthcare professionals’ sensitivity during encounters with palliative care patients (14).

Our literature synthesis question was as follows: what are healthcare professionals’ perspectives on hope of palliative care patients? Since
perspectives, according to a pragmatist approach (15), influence what healthcare professionals do, we examined not only their definitions of hope but also how healthcare professionals reacted on palliative care patients' hope.

**Method**

Our literature synthesis aimed at describing the complex, interpretative and normative elements of the multiple perspectives on hope and hence implied a qualitative methodology (16). More specifically, we conducted an interpretative synthesis of the literature, which in contrast to an integrative synthesis does not summarize results of studies but aims at the production of theory (17).

This was appropriate because a synthesis of healthcare professionals' perspectives on hope was still lacking and because hope research was characterized by a diversity of concepts, perspectives and methods (3,18,19).

**Literature Search and Selection Procedure**

We searched for references in PubMed, CINAHL, PsycINFO and EMBASE by making use of the following words as subject heading or in title/abstract: palliat* or hospice or terminal*. Then, we searched for references with the following words as subject heading or in title: hope* or hoping or desir* or optimis*. These two searches were combined with the Boolean operator AND. The references of the included articles were also screened (for details, see Figure 1). The procedure was checked by an experienced clinical librarian.

We excluded references that in their results do not discern between healthcare professionals and patients. However, studies that describe healthcare professionals working with both palliative care patients and chronic or curative patients were included because the transition to palliative care is not always a clearly demarcated moment (20). In addition, we included ethnographic studies that describe practices within which healthcare professionals discussed hope with palliative care patients. We furthermore only included peer-reviewed articles, and we excluded case studies and non-empirical studies.
Figure 1. Flow Chart.

**Databases:** CINAHL, EMBASE, PsycINFO, PubMed consulted 1 August 2011

**Strategy:**
1. subject headings: palliat* or hospice or terminal*
2. abstract/title: palliat* or hospice or terminal*
3. subject headings: hope* or desir* or optimis*
4. title: hope* or hoping or desir* or optimis*
   
   (1 OR 2) AND (3 OR 4)

**Search limited to:** items with abstract, peer reviewed, had studied human beings, articles from January 1980

**CINAHL (n=219); EMBASE (n=288); PsycINFO (n=178); PubMed (n=2991)**

   n = 3676 (total)

   **Duplicates excluded: n = 438**

**Numbers of references identified for screening title/abstract: n = 3238**

Inclusion criteria: written in Dutch/English/German; abstract was present; peer reviewed; described what professionals said about or did with hope of palliative care patients

**Excluded: n = 3177**

133 not empirical
17 not original research
15 case studies
3012 not inclusion criteria

**Number of references identified for screening full-text: n = 61**

**Excluded: n = 29**

14 not/hardly on hope
7 not/hardly on professionals
5 on hope of professionals
2 on parents (pediatrics)
1 not English/German/Dutch

**Number of references included in the synthesis: n = 32**

**Screening cross references on title: n = 5**

**Total numbers of references included in the synthesis: n = 37**
**Data Analysis**

The characteristics of the included studies were summarized and a quality assessment was performed (see Table 1). The quality of the qualitative (54–56) and mixed-methods studies (57) was assessed (E.O.), and in case of doubt or when studies were neither of obviously good nor of poor quality, another researcher independently assessed the quality (C.L.). Both researchers discussed their findings until they reached consensus. The quality of the quantitative studies, which were all survey studies, was assessed as well (B.O.–P.) (58). The same procedure was followed here as with the qualitative and mixed-methods studies (E.O. as second researcher). For details on the quality assessment, see Supplementary Appendices 1 and 2 (Supplementary Appendices can be found in the electronic version of this article, available from pmj.sagepub.com).

We then summarized the results of the included studies and thematically analyzed them (59) with regard to 1) concepts, that is, healthcare professionals’ definitions of palliative care patients’ hope and 2) actions, that is, how they responded to their patients’ hope. In order to remain sensitive to the context within which hope was described, we also thematically analyzed the content of hope and related themes (see Supplementary Appendix 3).

Since our aim was to produce theory, we went beyond a summary of original studies (17). In order to maintain rigor, however, we went back and forth to the results of the studies during all phases of the analysis. In addition, we intensively discussed results with each other and repeatedly consulted four other researchers from different backgrounds: neurology, pedagogy, sociology/nursing and humanistic studies.

Our thematic analysis showed that the synthesized studies frequently mentioned two concepts and two actions. Analysis of these themes led to the formulation of two perspectives. However, these two perspectives excluded results of our thematic analysis, of which many related to the meaning of hope for patients (see Supplementary Appendix 4). Searching literature on this theme, we found narrative theories (60–62) on hope (63,64), which helped us to interpret the thematic results on meaning from a theoretical point of view (17).
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<th>Q Risk of Bias</th>
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<td>Annunziata et al (21)</td>
<td>To determine the influence of socio-demographic and professional factors on physicians' attitudes to the terminally ill</td>
<td>Surv</td>
<td>Phys, N=605</td>
<td>Var</td>
<td>Var</td>
<td>Italy</td>
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<td>To examine the attitudes and practices of oncologists in disclosure of unfavorable medical information to cancer patients</td>
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<td>Hosp</td>
<td>Ca</td>
<td>Various</td>
<td>+ Questionnaire distributed on a congress; no desription of response rate</td>
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<td>Benzein &amp; Saveman (23)</td>
<td>To describe nurses' perception of hope among cancer patients in palliative care</td>
<td>Interv</td>
<td>Nurs, N=9</td>
<td>Hosp</td>
<td>Ca</td>
<td>Sweden</td>
<td>+ Data collection in only one setting</td>
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<td>Boroujeni et al. (24)</td>
<td>To explore the nurse–patient interaction in terminally ill situation in acute care, focusing on the nurses' preparation for loss</td>
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<td>Nurs, N=18</td>
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<td>Commun</td>
<td>Ca</td>
<td>UK</td>
<td>+ Poor description of reflexivity and influence of research team on findings</td>
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<td>Browall et al (25)</td>
<td>To explore healthcare staff's opinions about what existential issues are important to cancer patients and staff's responsibility when existential issues are raised by patients</td>
<td>F Group</td>
<td>Nurs, N=23</td>
<td>Var</td>
<td>Ca</td>
<td>Sweden</td>
<td>+ X</td>
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<td>Buiting et al (11)</td>
<td>To examine health professionals’ experiences and attitudes towards the provision of chemotherapy to patients with end stage cancer</td>
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<td>Nether-lands</td>
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<td>Carter et al (26)</td>
<td>To compare responses of health professionals to MS and MND and the issues regarding critical caring for MND and MS patients</td>
<td>Surv</td>
<td>Var</td>
<td>Var</td>
<td>MND,</td>
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<td>Var</td>
<td>Ca</td>
<td>Australian</td>
<td>+ Poor description of theoretical orientation researchers and data collection procedure</td>
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<td>Cutcliffe (28)</td>
<td>To describe how nurses inspire and instil hope in terminally ill HIV patients</td>
<td>Interv</td>
<td>Nurs,</td>
<td>Hosp</td>
<td>HIV</td>
<td>UK</td>
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<td>HIV</td>
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<td>Delvecchio Good et</td>
<td>To explore oncologists’ descriptions of conversations about diagnosis, prognosis and treatment, how they maintain hope and how they cope with the limits of their own hopefulness</td>
<td>Interv</td>
<td>Oncol,</td>
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<td>Duggleby et al. (30) b</td>
<td>To explore the congruence of one dominant interpretation of hope in newspapers with the hope of older palliative care patients, significant others and primary nurses</td>
<td>Interv</td>
<td>Nurs, N=3</td>
<td>Pal, Home Care</td>
<td>Ca</td>
<td>Canada</td>
<td>+ Small sample</td>
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<td>Fadul et al. (31)</td>
<td>To determine the perception of the impact of the name <em>palliative care</em> compared with <em>supportive care</em> on patient referral and to determine whether there was an association between demographic factors and the perceptions of the two names by medical oncologists and their midlevel providers at a comprehensive cancer centre</td>
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<td>Hospic, Nurs Home</td>
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<td>UK</td>
<td>- Aim and sample size suggest qualitative approach; presentation of results in discussion section</td>
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<td>Herth (34)</td>
<td>To identify and compare use and effectiveness of hope-engendering interventions of hospice nurses and home healthcare nurses</td>
<td>Surv</td>
<td>Nurs, N=158</td>
<td>Hospic, Nurs</td>
<td>Ca, Var</td>
<td>USA</td>
<td>+ X</td>
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<td>Hirai et al. (35)</td>
<td>To identify the components of a Japanese 'good death' through qualitative interviews with cancer patients, their families, physicians and nurses</td>
<td>Interv</td>
<td>Nurs, Phys, N=40</td>
<td>Hospit</td>
<td>Ca</td>
<td>Japan</td>
<td>+ Aim may suggest quantitative approach</td>
</tr>
<tr>
<td>Hunt (36)</td>
<td>To explore scripts nurses present to their patients (and families) and the latter's response to these influences</td>
<td>Taped conversations</td>
<td>Nurs, N=5</td>
<td>Commun Ca</td>
<td>UK c</td>
<td>+ Small sample; poor description of data analysis</td>
<td></td>
</tr>
<tr>
<td>Kierners et al. (37)</td>
<td>To describe oncologists' attitudes to palliative care and hospice services, about informing their patients about the incurable nature of the disease, and the option of issuing advance directives</td>
<td>Surv</td>
<td>Oncol, N=176</td>
<td>Hospit</td>
<td>Ca</td>
<td>Austria</td>
<td>+ Low response rate (23%) but non-response analysis done</td>
</tr>
<tr>
<td>Mahlengulu &amp; Uys (38) b</td>
<td>To describe the phenomenon of spirituality from the perspective of nurses and patients / clients with the aim of generating a middle range theory of spiritual care in nursing</td>
<td>Interv, F Group</td>
<td>Nurs, N=40</td>
<td>Hospit, PC</td>
<td>South Africa</td>
<td>+ Presented quotations do not distinguish nurses and patients</td>
<td></td>
</tr>
</tbody>
</table>

(Continued)
<table>
<thead>
<tr>
<th>References</th>
<th>Objective</th>
<th>Methods</th>
<th>Participants</th>
<th>Work Setting</th>
<th>Patients</th>
<th>Country</th>
<th>Q</th>
<th>Risk of Bias</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maxwell et al. (39)</td>
<td>To provide a description of medical students' hospice experience</td>
<td>Reflection papers N=49</td>
<td>Med stud, N=49</td>
<td>Hospic PC USA</td>
<td>+ X</td>
<td></td>
<td></td>
<td>Low response rate (24%) and limited non-response rate done</td>
</tr>
<tr>
<td>McCahill et al. (40)</td>
<td>To evaluate current practices and attitudes regarding palliative surgery</td>
<td>Surv Surge, N=419</td>
<td>Hospit Ca, Var</td>
<td>USA various</td>
<td>+</td>
<td>-</td>
<td></td>
<td>Presentation results (table) suggests quantitative approach; poor description of data analysis</td>
</tr>
<tr>
<td>Miyaji (41)</td>
<td>To examine physicians' views about their own practices regarding truth-telling and their ethical standpoints</td>
<td>Interv Phys, N=32</td>
<td>Hospit Var</td>
<td>USA</td>
<td>+</td>
<td></td>
<td></td>
<td>Influence of research team on findings and study design</td>
</tr>
<tr>
<td>Mok et al. (42)</td>
<td>To explore the phenomenon of existential distress in patients with advanced cancer from the perspective of healthcare professionals</td>
<td>F Group Var, N=23</td>
<td>PC Unit Ca</td>
<td>Hong Kong</td>
<td>- Poor description of reflexivity and influence of research team on findings and study design</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mok et al. (43)</td>
<td>To explore the meaning of hope to advanced cancer patients from their professionals' perspective</td>
<td>F Group Var, N=23</td>
<td>PC Unit Ca</td>
<td>Hong Kong</td>
<td>+ Poor description of data collection procedure</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nolan (44)</td>
<td>To understand how palliative care chaplains work with patients when active treatment has been ceased</td>
<td>Interv, F Group Chapl, N=19</td>
<td>Hospic PC Unit</td>
<td>PC UK</td>
<td>+ Poor description of reflexivity and influence of research team on findings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Norton &amp; Talerico (45)</td>
<td>To examine provider behaviors that facilitated the process of decision-making near the end of patients' lives</td>
<td>Interv Nurs, Phys, N=15</td>
<td>Var Var USA</td>
<td>+ Poor description of reflexivity and influence of research team on findings</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Continued)
<table>
<thead>
<tr>
<th>Methods</th>
<th>Participants</th>
<th>Setting</th>
<th>Country</th>
<th>Q, Risk of Bias</th>
</tr>
</thead>
<tbody>
<tr>
<td>Owen (46)</td>
<td>N=6</td>
<td>Nurs., Hosp.</td>
<td>USA</td>
<td>+ Small sample</td>
</tr>
<tr>
<td>Pang (47)</td>
<td>N=105</td>
<td>Nurs., Mixed Hosp.</td>
<td>China</td>
<td>- Poor description of qualitative data analysis</td>
</tr>
<tr>
<td>Perakyla (48)</td>
<td>Ethno, Hospital</td>
<td>PC</td>
<td>Finland</td>
<td>- Poor description of data analysis</td>
</tr>
<tr>
<td>Pfeifer et al. (12)</td>
<td>Med, Interv Phys.</td>
<td>PC</td>
<td>USA</td>
<td>- Poor description of research team and reflexivity and study design</td>
</tr>
</tbody>
</table>

Table 1. (Continued)

To develop a beginning understanding of the meaning of hope for cancer patients' by focusing on clinical nurses specialists' vivid descriptions of hopeful patients’ perceptions and carry out their responsibilities to do with safeguarding patients’ best interests when there is a question of disclosing information to vulnerable patients to aim of the article’s empirical part.

To study the social meanings of death in the hospital.

To identify primary care patients' and physicians' beliefs, attitudes, preferences, and expectations regarding discussions of end-of-life medical care and to identify factors limiting the quality and frequency of these discussions.
<table>
<thead>
<tr>
<th>References</th>
<th>Objective</th>
<th>Methods</th>
<th>Participants</th>
<th>Work Setting</th>
<th>Patients</th>
<th>Country</th>
<th>Q Risk of Bias</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reinke et al. (49)</td>
<td>To describe nurses’ perspectives on meeting patients' needs for hope and illness information</td>
<td>Interv</td>
<td>Nurs, N=22</td>
<td>Hosp</td>
<td>COPD, Ca</td>
<td>USA</td>
<td>+ X</td>
</tr>
<tr>
<td>Rittman et al. (50)</td>
<td>To describe the shared practices of oncology nurses caring for dying patients</td>
<td>Written stories</td>
<td>Nurs, N=6</td>
<td>Hosp</td>
<td>Ca</td>
<td>USA c</td>
<td>+ Claims to study practices, but does not (studies perspectives)</td>
</tr>
<tr>
<td>Schulman-Green et al. (13)</td>
<td>To identify common obstacles to nurses’ discussions of prognosis and referral to hospice care with terminally ill patients in the hospital setting</td>
<td>Open-ended surv</td>
<td>Nurs, N=174</td>
<td>Hosp</td>
<td>Var</td>
<td>USA</td>
<td>+ X</td>
</tr>
<tr>
<td>Sellers &amp; Haag (51) a</td>
<td>To explore what nursing interventions oncology, parish and hospice nurses implement to enhance the spirituality of clients and how they learned about these interventions</td>
<td>Surv</td>
<td>Nurs, N=224</td>
<td>Var</td>
<td>Var</td>
<td>USA</td>
<td>+ Low response rate (30%) and no non-response analysis; no description of justification methodology</td>
</tr>
<tr>
<td>The et al. (52) b</td>
<td>To discover and explore the factors that result in 'false optimism about recovery' observed in patients with small-cell lung cancer</td>
<td>Ethno</td>
<td>Phys</td>
<td>Hosp</td>
<td>Ca</td>
<td>Nether-lands</td>
<td>+ Poor description of data analysis</td>
</tr>
</tbody>
</table>

(Continued)
<table>
<thead>
<tr>
<th>References</th>
<th>Objective</th>
<th>Methods</th>
<th>Participants</th>
<th>Work Setting</th>
<th>Patients</th>
<th>Country</th>
<th>Q Risk of Bias</th>
</tr>
</thead>
<tbody>
<tr>
<td>Thulesius et al. (53) b</td>
<td>To describe the main problem of end-of-life cancer care today and what patients and caregivers are doing to resolve it</td>
<td>Mixed</td>
<td>Nurs, Phys, Var</td>
<td>Ca</td>
<td>Sweden</td>
<td>+</td>
<td>No general research question; poor description of influence of researchers on findings</td>
</tr>
</tbody>
</table>

**General**: PC, palliative care; Var, various; a) focus article was not only on palliative care; b) palliative care professionals were not the only respondents; c) country was not made explicit in article; ?: not mentioned

**Methods**: Ethno, ethnography; F Group, focus group; Interv, interview; Surv, survey;

**Participants**: Chapl, chaplains; GP, general practitioners; Hospit wards, hospital wards; Med stud, medical students; Nurs, nurses; Oncol, oncologists; Phys, physicians; Surg, surgeons

**Work Setting**: Commun, community; Hospic, hospice; Hospit, hospital; Med, medical; Unspec, unspecified

**Patients**: Ca, cancer; COPD, chronic obstructive pulmonary disease; MND, motor neurone disease; MS, multiple sclerosis

**Q**: quality of study; (+) sufficient; (-): insufficient
We were then able to distinguish a third perspective. Meanwhile, we compared the three perspectives to the results of the thematic analysis in order to refine them.

Yet, there still remained themes in the thematic analysis that had not been included in our three perspectives. We therefore reasoned back and forth between the three perspectives and the remaining results of the thematic analysis. This led to the finding that some healthcare professionals took two or three different perspectives at the same time.

**Results**

**Healthcare Professionals’ Perspectives on Hope of Palliative Care Patients**

Table 2 presents the results of our analysis: a realistic, functional and narrative perspective on hope.

<table>
<thead>
<tr>
<th>Perspective</th>
<th>Realistic</th>
<th>Functional</th>
<th>Narrative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concept</td>
<td>Expectation</td>
<td>Coping</td>
<td>Meaning</td>
</tr>
<tr>
<td>Action</td>
<td>Adjust</td>
<td>Foster</td>
<td>Interpret</td>
</tr>
<tr>
<td>Criterion</td>
<td>Truthful</td>
<td>Helpful</td>
<td>Valuable</td>
</tr>
</tbody>
</table>

Concept: professionals' definition of hope; Action: professionals' behavior in relation to hope; Criterion: standard by which professionals judge hope.

**Realistic Perspective.** Particularly, physicians and nurses said that hope was an expectation that should be truthful because they wanted their palliative care patients to avoid futile treatments and help them focus on what had to be done before dying (11,27). However, hope could be destroyed by the truth (27), disclosure of medical information (24) or use of the word ‘palliative care’ (31). Oncologists in several studies, in addition, stated that hope could be destroyed by disclosure of prognosis (22,33) or discussions on death and dying (11). Primary care physicians in another study mentioned that discussions on advance/end-of-life care could destroy hope (10).
In order to maintain hope and to be honest, healthcare professionals generally focused on adjusting hope to truth, which was a process of weighing words and balancing truth and hope (11,27,36,40,41,53). This process of balancing was especially difficult for hospital nurses in an Iranian study, who had to deal with family's wish not to inform the patient about approaching death (24). A qualitative study in Japan, in addition, found that maintaining hope was a far more important element of a good death for patients and families than for physicians and nurses (35).

**Functional Perspective.** Nurses and physicians in several studies mentioned that palliative care patients' hope was a way of coping with the impact of the disease. Hospital nurses who worked with cancer patients defined hope, for example, as a positive attitude (46). Swedish healthcare professionals in another study saw hope as motivation and well being required to live a normal life (53). Oncologists in an American interview study, in addition, described hope as something patients could psychologically hang on to (33).

Hope was considered as good because it helped palliative care patients. For example, most of the included 605 Italian physicians in a survey believed in the beneficial effects of hope in terminally ill patients (21), and various healthcare professionals in a Hong Kong study stated that hope helped palliative care patients to keep on living (42). In addition, American oncology nurses in another study said that hope helped their patients to face an uncertain future and to undergo treatment (50). The latter was confirmed by American oncologists in an American study (33).

Healthcare professionals focused on fostering hope by strategies like offering treatment (33), providing comfort or pain relief (34), or talking about (quality of) life (27). Most of these hope-fostering strategies were described in studies that had been conducted within the United States.

**Narrative Perspective.** Various healthcare professionals and nurses described hope as meaning. For example, American hospital nurses who cared for dying cancer patients (46,50) or who cared for cancer and chronic obstructive pulmonary disease (COPD) patients (49) described hope in terms of meaning. Swedish hospital nurses in another study described the
importance of hope as the achievement of events (23). Healthcare professionals, in addition, related hope to spirituality, like a fundamental faith (25) or a vision of an afterlife (42), while others saw spirituality as a source of hope (27,38).

Hope was good when it was valuable for palliative care patients. That is, hope should be in line with the patient’s life narrative, who (s)he is and what is important to him or her. American nurses who worked with advanced cancer and COPD patients therefore tried to interpret hope by asking patients about their hopes (49), and Canadian palliative home care nurses in another study searched for new meanings beyond hope for cure (30).

However, only a few of the Australian healthcare professionals in another study discussed hope as spiritual/existential meaning with their palliative care patients (27), although the study did not provide a reason for this scarcity. The narrative perspective, in addition, was absent in studies that exclusively focused on physicians.

More than One Perspective. The above perspectives were not mutually exclusive because healthcare professionals could take more than one perspective at once, which led to the formulation of new definitions of hope. For example, hope as peace or acceptance could imply both a realistic and a narrative perspective on hope. That is, American oncology nurses in a qualitative study (46) and American medical students who had visited a hospice, in another study (39), described hope as peace, which meant realistic acceptance. American hospital nurses (49) and chaplains in the United Kingdom (44) in two other studies tried to be present in a hopeful and accepting way. This presence implied that they attuned to individual narratives of palliative care patients.

Discussion
Main Findings
The results of our study suggest that healthcare professionals can take three perspectives on the hope of their palliative care patients. From a realistic perspective, hope is an expectation that should be in line with the truth, and healthcare professionals therefore focus on adjusting hope to
truth. From a functional perspective, hope is a form of coping that should help palliative care patients. In this instance, healthcare professionals focus on fostering hope. Healthcare professionals who take a narrative perspective see hope as meaning that should be valuable for palliative care patients. In that case, healthcare professionals focus on interpreting hope. The findings of our study also suggest that healthcare professionals may take more than one perspective at the same time.

**Strengths and Limitations**

While most review or synthesis studies generally focus on patient perspectives, our interpretative synthesis contributes to the description of healthcare professionals' perspectives. The strength of this specification is that it clarifies one domain in the diverse field of hope research (3,18,19), without limiting this field to, for instance, hope and truth-telling (65). It consequently helps us not only to see hope in relation to honesty and truth, like Clayton et al. (7) generally did in their systematic review, but also to distinguish three different perspectives on hope, each with its own implications for clinical practice. In addition, our comprehensive search resulted in the inclusion of more studies on healthcare professionals than earlier reviews (3,7).

However, our interpretation of the included studies leaves open the possibility for further revision or further validation because our synthesis includes studies with different methods and epistemological foundations. In our view, this multiplicity may reinforce the transferability of the findings (66), although there are different opinions on combining results of studies with different methods (17). In addition, the original studies have been conducted within different countries and mainly within Western countries, which restricts the generalizability or transferability to non-Western cultures. Another limitation of our study is that most of the original studies have approached healthcare professionals who work with advanced cancer patients, which leaves unexamined healthcare professionals' perspectives on hope of palliative care patients other than cancer. A last limitation of our study is that most of the included quantitative studies have only measured hope and consequently not examined professionals' definitions of hope.
Other Studies

We found a realistic perspective among healthcare professionals, while synthesis and review studies that focused on palliative care patients did not describe this as an explicit perspective (1–6). In addition, the narrative perspective was absent in our included physician studies. The narrative perspective was also hardly described in the systematic review of Clayton et al. (7).

These differences may suggest that palliative care patients and healthcare professionals take different perspectives on hope or emphasize different elements of hope. One explanation for this difference may be that palliative care patients do not (always) restrict hope to the medical domain in which realism is a central value (8). The cultural tendency towards truth-telling during disclosure practices (67), which is based on respect for patient autonomy (65), however, may reinforce healthcare professionals’ realistic perspectives on hope.

However, there were similarities between palliative care patients’ and healthcare professionals’ perspectives as well. For example, hospice patients defined hope as a process that helped them to endure suffering (4), which parallels our finding of a functional perspective. A meta-study in the field of spirituality furthermore linked hope to meaning and purpose (2), which parallels our finding of a narrative perspective. In addition, a review on psycho–spiritual well-being in advanced cancer patients found that living with meaning and hope was related to psycho–spiritual well-being (1), which may parallel an integration of healthcare professionals’ functional and narrative perspectives.

Clinical Implications

Healthcare professionals should be able to work with all the three perspectives on hope, which may contribute to helpful communication with palliative care patients. Their ability to work with three perspectives may, for example, increase their sensitivity (14), openness and active listening (68), flexibility (69) or adaptation to changing informational and emotional needs of palliative care patients (70). However, healthcare professionals do not have to be experts in all perspectives on hope. They may, for example,
sometimes refer a patient to a colleague with a different professional background.

For example, if healthcare professionals communicate with an incurably ill patient who hopes for physical cure through God’s intervention, they should weigh different perspectives. From a functional perspective, her hope is a coping mechanism that should help her to function well. In that case, they may foster her hope by mentioning that, although unlikely, miracles do happen. From a narrative perspective, her hope is a way of giving meaning (to life), which should be valuable for her. Then, they may interpret this meaning in relation to who she is, her biography and her socio-religious context. If they look at their patient’s hope from a realistic perspective, they see it as an unrealistic expectation and may try to alter it into more realistic hope.

Their ability to work with three perspectives on hope requires that healthcare professionals take into account their own hope (71). For example, they could ask themselves why they sometimes hope to maintain palliative care patients’ hope and how their own hope relates to themes like losing control (72) or to the hope of their palliative care patients (11,48,52).

**Future Research**

Future research should synthesize studies on healthcare professionals’ own hope in order to better understand professional perspectives on hope. In addition, healthcare professionals’ perspectives on hope of family members should be synthesized, like the hope of parents (73,74). Third, while our synthesis has mainly included studies that have been conducted in Western countries, future studies should examine the perspectives of healthcare professionals with non-Western backgrounds in order to shed light on cultural values that inform perspectives on hope. Finally, more research on healthcare professionals is needed to validate or revise our model of three perspectives. Such research may also show what impact the three perspectives have on healthcare professionals during their encounters with patients.
Conclusion

In summary, our model of three perspectives on hope may help healthcare professionals to improve their communication with palliative care patients, which leads to a better quality of care for people who are in the final phase of their life.

Acknowledgements

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References


33. Gordon EJ and Daugherty CK. ‘Hitting you over the head’: oncologists’


Chapter 3: Metaphors of Hope


Abstract

Context: Hope is important in palliative care. However, palliative care professionals’ perspectives on hope are not well understood. Metaphors of hope are a way of better understanding these perspectives.

Objectives: To describe palliative care professionals’ perspectives on hope by examining their hope metaphors they spontaneously used to describe their own hope and their perspectives on the hope of patients and their families.

Methods: Semi structured interviews with palliative care professionals were recorded, transcribed, and analyzed using a narrative approach. Results were discussed until the researchers reached consensus and reinforced by other healthcare professionals and by observing several palliative care settings.

Results: The 64 participants (mean age, 48.42 years; standard deviation, 9.27; 72% female) were physicians (41%), nurses (34%), chaplains (20%), or other professionals (5%), working in Canada (19%) or The Netherlands (81%). Participants described the hope of patients, their families, or themselves as a 1) grip, which implied safety; 2) source, which implied strength; 3) tune, which implied harmony; and 4) vision, which implied a positive perspective. Compared with Dutch participants, Canadian participants generally put more emphasis on spirituality and letting go of their own hope as a grip (safety). Compared with other included professionals, physicians used hope as a grip (safety) most often, whereas chaplains used hope as a tune (harmony) most often.
Conclusion: Our findings help to increase the understanding of hope and contribute to improving the communication skills of palliative care professionals.

Introduction

Hope is important for palliative care professionals (1,2), their patients and patients' families (3). Within the context of communication on prognosis and end-of-life issues, however, health-care professionals (HCPs) perceive patients' hope as difficult (4–6). They sometimes experience an ethical dilemma between maintaining patients' hope and truth-telling, which may diminish hope (7,8). However, a recent synthesis study describing professionals' perspectives on the hope of palliative care patients indicated that “either maintaining or diminishing hope” was just one way of framing the ethics of hope. Hope could be judged from a variety of perspectives as truthful, helpful, or valuable for patients (9). The results of this synthesis study are helpful in understanding HCPs' perspectives on hope and reframing the ethics of hope. However, HCPs’ implicit perspectives on hope were not addressed, and additional studies are needed to determine how the findings of this synthesis relate to patients' perspectives on hope.

One way of understanding HCPs' implicit perspectives on hope is to analyze their spontaneous use of hope metaphors. A metaphor is figurative language use that “reduces two terms to their shared characteristics, enabling the linguistic transference of one to the other” (10). Metaphors may both hinder and facilitate palliative care communication (11–13), and they show, among other things, cultural values and perceptions of a phenomenon (10,12,14,15). As a consequence, metaphor analysis offers a way to understand hope and the implications of metaphor use for clinical practice. The aim of our study was to describe palliative care professionals' perspectives on hope by examining their spontaneous use of hope metaphors with respect to their own hope and their perspectives on the hope of patients and patients' families. Our central question was What metaphors of hope do palliative care professionals use?
Methods

Theoretical Underpinnings

Our study was underpinned by narrative theory, in which hermeneutics and language use are important (16–21). Hermeneutics is the study of the interpretation of texts. Hermeneutics within a narrative approach means that people interpret the world and themselves by making use of language, for instance, by telling their story (19,20). In their stories, people give meaning to their lives by making use of (shared) language. However, this shared language involves assumptions that include and exclude certain groups, as shown in narrative research among minority groups (22). Metaphors are one form of language use that makes possible certain interpretations while excluding others.

Participant Recruitment and Data Collection

Semi-structured interviews were conducted with HCPs in The Netherlands and in Alberta, Canada. Participants were 18 years of age or older and working clinically with palliative care patients for at least the prior six months. Sampling aimed to obtain variation in age, professional background, and gender. Eligible participants were informed about the study through a variety of approaches, such as e-mail listservs and newsletters, and they were sent detailed information by e-mail. Snowball sampling also was used (23). Canadian participants signed an informed consent form, whereas Dutch participants were only required to give oral consent (24).

An interview guide (Appendix I, available from jpsmjournal.com) of open-ended questions was used and participants were invited to share their experiences without being limited to definitions of hope (25) or definitions of palliative care (1). All interviews were audio recorded and were approximately 45–75 minutes in length. Participants were not asked for metaphors of hope. Rather, data analysis focused on participants’ spontaneous and implicit use of metaphors of hope to achieve the study aims. Interview data were transcribed, and to establish trustworthiness, differences in intonation also were noted (26). In addition, the interviewer wrote field notes, which contributed to an ongoing reflexivity during the research process.
Data Analysis

Metaphors of hope and metaphors that described how HCPs dealt with hope were analyzed by E.O. (all interviews), five Dutch researchers (eight Dutch interviews), and W.D. (two Canadian interviews). Although metaphors may be used in a dynamic way (26), the analysis revealed that several metaphors referred to the same bodily dimensions and values. These then became the basis for clustering metaphors together (see Appendix II, available at jpsmjournal.com, for an example). Saturation was reached after approximately 30 interviews, but all interviews were analyzed to further refine the findings.

During all stages, the authors discussed the results until they reached consensus (26). In addition, all researchers had experience with palliative care settings, which helped them to understand contextual factors that shape metaphors of hope in palliative care (27). The findings were further reinforced by presenting them during oral presentations to approximately 100 Dutch palliative care professionals who were not involved in the study (27). The results presented in this article were affirmed during these presentations.

Results

Participants

A total of 64 HCPs participated in the study. Demographic information is provided in Table 1.

Metaphors of Hope

Participants generally spoke about hope as something positive. The clustering of hope metaphors led to four central metaphors 1) hope as grip, which implied safety; 2) hope as a source, which implied strength; 3) hope as a tune, which implied harmony; and 4) hope as a vision, which implied seeing a positive perspective or a positive future. A common feature of these metaphors was that they referred to the body: inside (source) or outside (grip) or at the crossing between inside and outside (tune and vision). Findings are summarized in Table 2.
### Table 1. Characteristics of Participants

<table>
<thead>
<tr>
<th>Demographics</th>
<th>N</th>
<th>%</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years</td>
<td>48.42</td>
<td>9.27</td>
<td>29–64</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years experience</td>
<td>18.69</td>
<td>9.39</td>
<td>1–43</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>46</td>
<td>72</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>18</td>
<td>28</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Canadian</td>
<td>12</td>
<td>19</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dutch</td>
<td>52</td>
<td>81</td>
<td></td>
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<tr>
<td>Profession</td>
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</tr>
<tr>
<td>Medical Doctor</td>
<td>26</td>
<td>41</td>
<td></td>
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<tr>
<td>Registered Nurse</td>
<td>22</td>
<td>34</td>
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<td></td>
</tr>
<tr>
<td>Chaplain</td>
<td>13</td>
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*Hope as a Grip Implied Safety.* A grip can be defined as “a strong and tenacious grasp” (28). Participating HCPs stated how hope provided stability for themselves, their palliative care patients, and patients’ families.
in an unstable situation. They also described hope as holding onto something. “Hope and grip always mix a bit with each other” (participant 60). “Sometimes you meet people who have so much hope (...) holding onto life (...) [a patient] hoped to celebrate New Year’s Eve (...) but he rapidly deteriorated” (participant 41).

Participants also told how letting go of hope could cause themselves or their patients to fall or to feel down. “Well, if that hope drops, people often collapse, literally and figuratively” (participant 58). “[My patient’s cancer had metastasized:] That knocked me down (...). It was totally unexpected for her and for me (...). Well, and talking about hope, her situation had actually been full of hope” (participant 19).

Other participants spoke about relationships between the hope of HCPs and their patients’ hope as a grip: “The physician continues to hang onto his treatment mode (...) in order not to take away all his [patient’s] hope” (participant 47). “As long as we try things, there is hope (...). We are a sort of a straw to clutch at, you know” (participant 38).

According to participants, hope as a grip implied safety: grasping hope helped participants, patients, and patients’ family members feel stable and safe in their unstable and unsafe situation. “It’s like you’re sweeping from side to side in public transport (...). You need to hold onto that [signals grasping of a handle above] together with them. You need to offer safety” (participant 15). “I think that [different doctors who contradict each other] may disturb the development of hope, because there is a lot of confusion and lots of insecurity. (...) No grip” (participant 17).

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<th>Value of Hope</th>
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**Table 2. Palliative Care Professionals’ Metaphors of Hope**

Hope as a Source Implied Strength. Participating HCPs also described hope as a source that helped themselves, their palliative care patients, and patients’ families to deal with difficult situations. They stated that hope
was an internal source of energy that helped them to keep going, such as fuel in a gas tank or the heart in the body. “I think hope is one of the most important sources of energy here [in hospice]” (participant 25). “I didn’t think he was completely drained of resources (...). [If you are completely in despair, you have] nothing in your gas tank” (participant 01). “If people aren’t feeling hopeful and you come with a hopeful idea or a positive idea, that is such a disconnect to their heart that they just reject it” (participant 07).

Some participants mentioned that the relationship with their patients could be a source of hope for patients and their families. “We are a sign of hope and a source of hope because through our existence as a – as a part of the community that’s dedicated to helping folks in this situation” (participant 04). “That connection that you made (...) I don’t know if you would call it hope (...). People who have been discharged from specialists (...) feel very empty and they’re upset and angry (...). But from a system point of view, you have to make room for the people” (participant 03).

Participants stated that hope as a source implied strength that allowed both participants and their patients to cope with difficult situations. “Hope immediately makes me think of the strength that is behind all movement. It is a source of strength” (participant 20). “It lightens me up inside. It gives me something positive and strength when I see how some [older] people are. That gives me hope” (participant 48).

**Hope as a Tune Implied Harmony.** A tune is defined as “a series of musical notes that produce a pleasing sound” (28). Participating HCPs often did not describe a strict division between their own hope and their palliative care patients’ hope. “For me it [hope] is about accompanying people to see how you could alleviate their suffering” (participant 42). “Talking about the role of hope, the biggest fault could be, talking about attuning to each other, that the one focuses on the short line and the other on the long line” (participant 25).

Some HCPs related hope to a piece of music in which they accompanied patients or their families. “The orchestra [of the Titanic] still played in the midst of that, and you can either focus on how to get off the boat, or (...): ‘Let’s stop for a minute and listen to this.’ (...) Well, I think I need (...) to
help look for it [hope] with others” (participant 10). “You need a sort of polyphonic instrument. At the one moment being totally open and searching for: (...) what is the despair, the lack of hope, actually? While at another moment an intervention is very suitable” (participant 13).

Hope as a tune implied harmony, which, according to participants, reflected their own or their patients’ inner being, or their relationship with patients. “I try to enter neutrally, sense the atmosphere and to attune to that. Well, that’s a piece of rest that I try to bring (...). You need rest yourself too. And hope” (participant 53). “I think it takes some work on our part to – to make some peace with, um, with where we stand (...). And often for me, a hopeful side is that (...) there still is capacity for love and relationship” (participant 07).

Hope as a Vision Implied a Positive Perspective. Hope as a vision meant that the participating HCPs and their palliative care patients were able to look forward to something positive in the future. The visual dimension of hope became clear when some participants spoke about “being a sign of hope” (see above) or about “letting patients see.” “Hope means that there is a future perspective again” (participant 49). “Whenever I think about hope in my palliative care patients, it’s one of the things I, I don’t know if I try to let them see” (participant 02).

Hopeful patients, who looked forward with open eyes, gave one participant hope. “That actually gives me hope (...) when I see that there are people who are receiving things peacefully. And with open eyes looking forward” (participant 48).

Participants considered hope to be something positive because it meant their perspective and that of their patients, was positive. “If you try to see perspective, together with people, and to live towards something, which can be very simplistic, but people, well em, they like that, that you keep that hope” (participant 31). “Or they [specialist physicians] continue to make appointments: ‘(...) I let him visit me in six weeks. Probably he won’t be alive anymore by then. But then he has at least something to look forward to.' Well, talking about hope [laughs]” (participant 47).
Differences between Groups

Physicians used patients' hope as a grip more often than other participants, nurses regularly used this metaphor, whereas chaplains used it the least. The chaplains referred to hope as a tune more often than nurses and physicians. Compared with Dutch participants, Canadian participants paid relatively more attention to two topics: letting go of their own hope as a grip and spirituality. One Canadian participant suggested that spirituality was different in the participant's Western European country of origin and another Canadian participant stated that spirituality and hope were not always valued in the hospital setting: "[Patients in my Western-European country of origin] were not connected as much to religion as people seem to be here, and um, yeah, this might play a role with hope (...). That even if people [here in Canada] don't feel connected to – to a certain religion, that they – yeah, it seems to be easier for them to express, um, what their spirituality is like" (participant 05). "[Some patients have an] intimate, everyday connection to the Creator, and I think that, um, that is not seen here or not valued here [in the hospital]" (participant 11).

Discussion

Our findings suggest that palliative care professionals perceive hope as a grip that implies safety, a source that implies strength, a tune that implies harmony, and a vision that implies seeing a positive future or a positive perspective. Participants used all metaphors of hope to describe both their own hope and their perspectives on patients' hope.

Strengths and Limitations

A strength of this study is the diversity of participants' work settings and professional backgrounds. In addition, one author interviewed all participants, providing a relatively constant factor in the comparison of different groups: this is also a limitation because various interviewers may reinforce the validity of a qualitative study. However, he was an experienced interviewer and had constantly striven for reflexivity within the research team. Another strength of our study is the involvement of several researchers with various professional backgrounds and from various countries (29,30).
Our study was limited, however, as there were fewer Canadian than Dutch participants and fewer chaplains than physicians. In addition, Canada and The Netherlands could both be considered as Western countries. Future research should focus on the hope metaphors in non-Western countries. Moreover, the findings with respect to differences between groups cannot be generalized. However, they are an important step toward the formulation of hypotheses that could be tested in future studies.

**Implications for Ethics of Hope**

The ethical discourse on hope, mainly drawing from principle ethics (31), focused on two values: respect for patient autonomy, which meant diminishing patients’ hope, versus beneficence, which implied maintaining patients’ hope (7). However, a recent synthesis study has added the values of truthfulness, helpfulness and meaningfulness (9), and our study adds safety, strength, harmony, and perspective. Future studies could compare, contrast, or synthesize these values.

In addition, the ethical discourse has too easily construed hope as a patient’s individual possession (32), leaving unnoticed HCPs’ own experiences (33). More importantly, our findings suggest that hope also can be a co-construction or common process among patients, their families, and HCPs. Other studies addressed the common process of hope between patient and HCP (34–36) and emphasized the relational dimensions of hope as well (3,37). The ethical discourse on hope, which has primarily focused on the individual, therefore needs to be balanced with relational and social constructionist approaches in ethics (38–43). Both approaches help to explain how hope can be part of a relational process.

HCPs’ moral reflection could be guided by our findings when they ask themselves the following: What offers me (or us) safety, strength, harmony, or perspective?; Do I feel empty or rather filled with hope (source)?; Will I fall down when I have to let go of this hope and how will I respond (grip)?; How do I, in relation to my patient’s hope, play a hopeful melody or attune as a second voice (tune)?; and What positive future do I see ahead of me or us (vision)? The overall aim of these reflective questions is not to discredit
any of the perspectives on hope but rather to broaden a too limited framing of hope; this is particularly important in hopeless situations (44).

**Implications for Clinical Practice**

Our findings support the widening of HCPs' communicative repertoire. For example, HCPs may use metaphorical language that easily brings up hope as a theme. They could ask their palliative care patients or patients' family members questions such as What keeps you upright or stable (grip)?; What fills you with energy (source)?; How do you want me to accompany you or attune to you (tune)?; or What path do you see ahead of you: one full of bumps, a smooth path, or something in–between (vision)?

Furthermore, asking questions about hope may facilitate conversations about spirituality, as the two concepts are linked (45). Asking the questions above may allow HCPs to explore, for example, what hope and spirituality mean for an individual patient and her/his family. This is important because our findings indicate that hope and spirituality may play unique roles within different cultural and institutional contexts. In addition, as religion has given way to spirituality (46), asking for the individual experience of spirituality is appropriate in Western countries.

HCPs should take into account their own dominant perspectives on hope when asking these questions. For example, our findings suggest that physicians, compared with other HCPs, used patients' hope as a grip most often. If HCPs can only frame hope as a grip, which offers patients safety while fighting against their disease, HCPs may inadvertently force their patients to interpret physical decline as a personal failure (13). However, using various metaphors of hope may help HCPs to be flexible (47) and attune to patients' individual needs (48).

The insights into palliative care professionals' use of hope metaphors gained through this study have added an in–depth understanding to the perceptions of hope and offer possibilities for improving palliative care communication. Future studies could focus on the perspectives of patients and their family members on hope, develop communication models, and study communication practices between patients and HCPs, ultimately leading to better care for palliative care patients and their families.
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Chapter 4: The Dynamics of Hope over Time

This chapter was accepted for publication as: Olsman E, Leget C, Duggleby W and Willems D. A singing choir: understanding the dynamics of hope, hopelessness and despair in palliative care patients. A longitudinal qualitative study. Palliat Support Care 2014.

Abstract

Objective: Hope, despair and hopelessness are dynamic in nature, however, they have not been explored over time. The objective of this study was to describe hope, hopelessness and despair over time, as experienced by palliative care patients.

Method: A qualitative longitudinal method based on narrative theories was used. Semistructured interviews with palliative care patients were prospectively conducted, recorded and transcribed. Data on hope, hopelessness and despair were thematically analyzed, which led to similarities and differences between these concepts. The concepts were then analyzed over time in each case. During all stages the researchers took a reflexive stance, wrote memos, and did member checking with the participants.

Results: Twenty-nine palliative care patients (mean age, 65.9 years; standard deviation, 14.7; 14 females) were included. Eleven suffered from incurable cancer, ten from severe chronic obstructive pulmonary disease, and eight from severe heart failure. They were interviewed a maximum of three times. Participants associated hope with gains in the past or future, such as physical improvement or spending time with significant others. They associated hopelessness with past losses, like loss of health, income or significant others, and despair with future losses, which included the possibility of losing the future itself. Over time hope, hopelessness and despair changed when participants' physical condition changed. These dynamics could be understood as voices in a singing choir that could sing together, alternate with each other, or sing their own melody.

Significance Results: The findings offer insight into hope, hopelessness and despair over time and the metaphor of a choir helps to understand the
co-existence of these concepts. The findings also help healthcare professionals to address hope, hopelessness and despair during encounters with patients, which is particularly important when patients' physical condition has changed.

Introduction

Hope is important for palliative care patients and has been associated with their psycho-spiritual well-being (1–3). The existential being of hope described as “living with hope” has been distinguished from hope as a goal-oriented phenomenon (1), and patients may lose hope but find new hope when they are able to shift perceptions and see positive possibilities (4–7). In addition, despair and hopelessness include the word “hope” in several languages and are therefore related, although these concepts have been defined in various ways (8–12).

Hope, hopelessness and despair may furthermore change over time. These changes may be understood in terms of stage models, in which for instance despair may be followed by hopelessness or hope. However, stage models have normative end stages and they may press people into directions that they do not want to go (13,14). Moreover, recent qualitative studies suggest that palliative care patients are able to and do live with contradictions around hope, like hope for cure and preparation for death (15), or the co-existence of hopelessness and hope (16). A description of hope, hopelessness and despair, which acknowledges these contradictions and helps to understand them over time is lacking.

The objective of our study was to describe hope, hopelessness and despair over time, as experienced by palliative care patients. The central question was: How can palliative care patients' hope, hopelessness and despair be understood over time? The results of our study may help healthcare professionals to recognize patterns over time of hope, hopelessness and despair in their patients. Healthcare professionals may also better recognize hopelessness in severely ill patients, which has been associated with negative health outcomes, like depression (17–19). In addition, while hope has been perceived as a barrier for end-of-life discussions (20–22), the results of our study may support healthcare
professionals to address death and dying while acknowledging patients’ hope.

**Method**

A qualitative longitudinal approach was used, which enables understanding of change over time (23,24).

**Theoretical Underpinnings**

This study was underpinned by narrative and postmodern identity theories, which are able to acknowledge paradoxes in identities and stories (25–27) and in which voice is a central concept (28,29). These theories approach human beings as relational beings instead of isolated, detached individual beings (14,28), which is important because relational dimensions of hope have been found to be significant (1).

**Data Collection**

Semi-structured interviews with palliative care patients in The Netherlands were conducted, audiotaped and transcribed. The researchers purposively sampled aiming at variation in gender, age, living place and disease. The following diseases were chosen because they are in Western countries some of the most prevalent causes of death and because they follow different illness trajectories (30): severe heart failure (HF), New York Heart Association (NYHA) III or IV, severe Chronic Obstructive Pulmonary Disease (COPD), Global initiative for chronic Obstructive Lung Disease (GOLD) 3 or 4, and incurable cancer. Physicians, nurses and chaplains working in different healthcare settings were informed about the sampling strategy and were asked to approach eligible participants. During the process of inclusion, healthcare professionals were informed about groups that were underrepresented, like very old patients, or patients with severe HF.

Based on the literature and three pilot interviews, a topic list with open-ended questions was developed. Interviews started with the open question: “Could you tell me what your first ideas were when you heard about the topic of this research: hope?” In some instances we varied on this question, for example when participants had told, prior to the interview, that they
found it a difficult topic because they experienced “a lack of hope”. Topics also included questions about hopelessness and despair. For the topic list see Supplementary File 1 (page 76).

Hospice patients were interviewed every month because of their limited prognosis, whereas the other participants were interviewed every six months. Participants were interviewed a maximum of three times and all of them agreed to be called every six weeks. During telephone conversations they were asked whether something around their hope, hopelessness or despair had changed. If this appeared to be the case, a next interview was planned earlier than six months (24). During all stages memos were discussed within the research team about, for instance, interview setting, research questions and preliminary findings. In addition, the constant factor of one interviewer (E.O.) established trust between participants and interviewer, which is important in longitudinal qualitative research (23).

*Research Ethics*

According to Dutch law, a review of the study by an ethics committee was not necessary, which was confirmed by the ethics committee of the Academic Medical Center, Amsterdam. Palliative care patients may benefit from participating in research (31–33). However, risks include intrusion into participants' lives and difficulties around serial consent, and a risk for the main researcher was the potential for emotional distress (23,34). The risks and benefits were discussed within the research team. Being also an experienced non-denominational chaplain in psychiatry, the researcher easily attuned to participants' needs.

Eligible participants were informed orally and by letter about the study and words like "palliative care" were avoided in order not to confront participants with medical information. Participants signed an informed consent form and in a few cases they were unable to do so. In these cases the form was read aloud and participants confirmed orally, which was audiotaped, and a witness could confirm voluntary participation. Main reasons for non-participation or drop out were death and fatigue. The interviewer regularly checked the status of the participant during the interviews and, if possible, the last interview included an evaluation of the interviews.
Data Analysis

Hope and derivatives were not defined prior to the study because of the multiplicity of definitions and approaches to hope in healthcare (1,35–37), but most of all because we wanted to start from the participants’ concepts of hope, hopelessness and despair. Each case was first thematically analyzed by hand, and then the analysis focused on data, in which the words hope, hopelessness or despair were used. For an example of the identification of similarities and differences between the concepts, see Supplementary File 2 (page 77). Then, the three concepts were used to analyze each case over time. Specific attention was paid to what led to changes within or between the three concepts over time. For data summaries reflecting the three concepts over time, see Supplementary File 3 (page 78).

The researchers worked together with researchers from different professional backgrounds in order to sharpen their understanding of interview transcripts and their synthesis of findings (38). The first author of this article analyzed all interviews and researchers with backgrounds in neurology, nursing/sociology, humanistic studies, medicine, ethics, religious studies and general practice analyzed a total of eighteen interviews. Transcripts were sent to participants and interpretations of transcripts were checked during subsequent interviews and telephone conversations (23,38). Saturation was reached after approximately twenty-four participants had been included. That is, there appeared no new themes around (the dynamics of) hope, hopelessness and despair. However, in order to further refine the findings, inclusion continued until twenty-nine participants had been included.

Results

Participants

Twenty-nine patients were included. For demographic information, see Table 1. Between December 2010 and November 2012, fifty-two interviews were conducted, which lasted around one hour (range 14–101 minutes). The first interview took place at participants’ home (n=19), home care institution (n=3) or hospice (n=7) and participants were interviewed alone (n=21) or with someone else, like their partner (n=8). The present paper
only highlights patients’ stories. Seventeen participants were interviewed for a second time, after an average of 6.9 months (range 0.5–13 months), and six were interviewed for a third time after an average of 5.3 months (range 1.5–8 months).

**Table 1. Characteristics of Participants (n=29)**

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COPD, Chronic Obstructive Pulmonary Disease; GOLD, Global initiative for chronic Obstructive Lung Disease; HF, Heart Failure; NYHA, New York Heart Association

**Hope, Hopelessness and Despair**

Similarities and differences between hope, hopelessness and despair were found, which are presented in Table 2. These characteristics will be elucidated in the following paragraphs.
Hope: Gains in the Future and the Past. Participants hoped for a future gain, like spending time with others or physical improvement. One participant stated: “You’ve got the hope to experience certain events, to see your grandchild growing, to stay longer with him [partner]” (female, 60, cancer). Another participant favored the zoo and the market: “You hope that you’re able to do these things several times again” (female, 37, HF). Another participant explained: “I just hope that I will gain many more years” (male, 60, cancer).

Participants also spoke about hope in relation to the past, which expressed how they (had) received hope as a gift. One participant looked back on beautiful experiences in his life: “That is hope that isn’t oriented towards something in the future but more a feeling of hope that you get by looking back” (male, 60, cancer). The treatments of another participant had been effective for a long period: “It was stable. And then you get hope” (female, 60, cancer). Another participant had received love and care from his children, which he described as hope: “My children are my hope (...). They are so close to my heart” (male, 88, HF).

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</table>

Hopelessness: Losses in the Past. Participants associated hopelessness with past losses, which ultimately meant that they had lost their (meaningful) future. One participant concluded that he felt constantly hopeless because he had lost several family members: “And I lost my job. Well, you know, I’ve got social security benefit, so [I lost] my income. My health.” (male, 63, HF). Another participant felt often hopeless because there had been no curative treatments available: “So the hospital has already written me off as well” (female, 60, COPD). Particularly participants with COPD and some with HF (had) experienced hopelessness. One participant defined hopelessness as follows: “If you feel hopeless, you’re
not up to anything at all, you don’t do anything, you just remain seated and then you easily sink down” (male, 69, COPD).

**Despair: Losses in the Future.** Participants related despair to possible future losses, ultimately indicating (the risk of) losing the future itself: “Well, I really despaired, that’s the way to put it. I thought: this has been my life. I won’t manage anymore. I’m losing the fight” (female, 50, COPD). Another participant stated that despair would be further metastasis of his tumor: “Despair in my situation would be that they make the diagnosis that it [treatment] doesn’t work anymore and that it will start to metastasize” (male, 60, cancer). Several participants expressed the uncertainty of the future, when talking about despair: “I’ve got moments of fear, moments of despair, like: o my god, where will this lead to? Because you don’t know anything” (female, 51, cancer). Some participants described despair as lasting shorter than hopelessness although the findings were not univocal in this regard.

**Dynamics of Hope, Despair and Hopelessness**

Participants often associated the dynamics between hope, despair and hopelessness with changes of physical condition. The metaphor of a singing choir is helpful in understanding these dynamics, in which hope, despair and hopelessness are three voices. For data summaries reflecting the three voices over time, see Supplementary File 3 (page 78).

**Co–Existing Voices.** Over time the voices could co–exist and they sometimes mutually reinforced each other. One participant expressed how despair and hope for cure mutually reinforced each other. She compared her situation with being thrown into the sea: “I’ll have to go to the bottom of the sea. But I hope against hope, which is of course in desperation. But I still have hope for reaching the surface” (female, 51, cancer).

In another participant’s story hopelessness co–existed with hope. During “bad days” he felt hopeless, which made him hope for a better day tomorrow: “Today it may be good and tomorrow it may be bad. Often it is bad. And then I always hope that tomorrow will be better” (male, 61, COPD).
Alternating Voices. Hope could also alternate with despair or hopelessness. One participant told how he had experienced despair when he was about to lose his life: “That’s why I say: hope played no role. It was despair because they tell you your death-sentence” (male, 76, HF). However, some months later he physically improved. He drew hope from the geriatrician who confirmed his experiences: “Hope is that the geriatrician hasn’t said: this stuff is ready for the scrap heap.” He started to take nutrition supplements: “You hope for that future!”

Another participant (female, 48, cancer) had received the message that the heavy treatment had had no effect: “Well, you hope that there will be a bit positivity. But well, then it’s a very raw deal when you hear that it has had no effect.” The days after that she felt hopeless. However, her hope increased when she was about to start a next chemotherapy: “Monday I will start with a new chemotherapy. Then you try to find the hope to go for it.”

Unrelated Voices. Hope, hopelessness and despair could also be understood as co-existing voices singing unrelated melodies, without attuning to each other. One participant for instance told that his situation, from a medical point of view, was hopeless. However, he and his wife hoped for a miracle cure through God’s intervention: “From the first day onwards there is hope” (male, 39, cancer).

Another participant expressed how he kept hope apart from hopelessness and fear: “Hope just stays the same. It remains hope because I separate it. If I wouldn’t separate it, I would feel insecure about that hope” (male, 60, cancer).

Discussion
The results of our study suggest that palliative care patients relate hope to a gain in the past or future, despair to a future loss, and hopelessness to a past loss, and that over time the physical condition plays a central role in the dynamics of hope, hopelessness and despair. Our findings also suggest that over time the three concepts can be best understood as singing voices in a choir.

One of the strengths of this study is its longitudinal character, which allowed the researchers to do member checking with participants. Another
strength is that it reflects the tendency to increasingly include non-cancer patient populations in palliative care (research) (39,40). However, future studies in other patient groups, like those suffering from progressive neurological diseases, are necessary to revise or confirm our findings. Our study was also limited in that it only included Dutch patients, which restricts the generalizability to other cultures. Future studies should therefore examine hope, hopelessness and despair in other languages and cultures. In addition, our study focused on hope, hopelessness and despair, and future research should examine relationships with other themes, such as acceptance, fear and faith.

Some of our findings are in line with those of other studies. For example, loss as characteristic of despair has been reported by a synthesis study on hope and despair within the context of human immunodeficiency virus (8), and ‘losing’ and ‘receiving’ may reflect our findings of losses and gains (41). The co-existence of contradicting concepts, in addition, has been found in terminally ill cancer patients (16) and the association between (changes of) physical condition and (changes around) hope has been reported by several others (4,5,42).

The temporal dimensions of hope, hopelessness and despair, in addition, suggest that while living in the present and telling their story, palliative care patients connect their past and future. This may be in line with the difference found by a synthesis study on hope in palliative care, which found two overarching themes of patients’ hope that were not separate contents: hoping for something as future– and goal–oriented phenomenon, and living with hope, which included the presence of confirmative relationships (1). Future studies should further scrutinize the temporal dimensions of hope, hopelessness and despair. In this regard, narrative analyses may be particularly helpful because of their focus on the temporal dimensions of stories (27).

Furthermore, our findings suggest that particularly patients with severe COPD or severe HF may suffer from hopelessness. Hopelessness has been associated with depressive symptoms, and these symptoms are indeed common in patients with severe COPD or HF (43–46). In addition, hope has often been interpreted as barrier for end–of–life discussions (20–22), and healthcare professionals may not start end–of–life discussions because

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they are afraid of triggering anxiety and depression in their patients (47). However, the results of our study suggest that palliative care patients may hope for cure while acknowledging that they are approaching death, which was also found in other studies (15). The metaphor of a singing choir may support healthcare professionals in attuning to hope, hopelessness and despair in their patients (48,49).

Contrary to the stage models of coping with dying (13), approaching hope, hopelessness and despair as voices in stories of patients, offers possibilities for healthcare professionals to recognize dominant voices and see how voices are separated from each other or resonate with each other (28,29). For example, when hope for cure is a dominant voice in patients’ stories, healthcare professionals may say: “I understand that this hope for cure (or improvement) is very important for you. Would it be okay for you to talk once or twice about other scenarios?” Questions like this one are important when patients have experienced physical changes, which, as our findings suggest, may lead to changes around hope, hopelessness and despair.

In conclusion, the results of our study have reinforced the understanding of hope, despair and hopelessness over time, as experienced by palliative care patients. The results offer new possibilities for clinical practice and future studies should provide healthcare professionals with tools, which they can use to attune to hope, hopelessness and despair in their palliative care patients. Future studies should also evaluate the use of these tools in clinical practice, ultimately leading to better care for people in the last phase of their lives.

References


Supplementary File 1. Topic list

The topic list was based on the literature and three pilot interviews. This paper mainly focuses on the results of the topics 1 – 3.

1. Opening
   a) Could you tell me what your first ideas were when you heard about the topic of this research: hope?
   b) Answers (and stories) were further explored by explorative questions: ‘What do you mean by …?’ ‘Could you tell something more about…?’ et cetera.

2. Concept of hope
   a) What does hope mean for you and what is its relation to hopelessness or despair?
   b) Are there other themes related to hope?

3. Dynamics of hope
   a) Have there been changes in your hope? Prompts: If yes, in what way?
      Did your hope, for example, increase, decrease, or remain the same? Could you tell me more about that?
   b) Have there been changes in your hopelessness? Prompts: If yes, in what way?
   c) Have there been changes in your despair? Prompts: If yes, in what way?
   d) Did other themes play a role in these changes? Prompts: If yes, which themes?

4. Social dimensions of hope
   a) What is the role of other persons in your hope? Prompts: which actions, responses or relationships help you to keep hope? Who threatens your hope? How did other respond to (changes in) your hope?
   b) Is hope the same for you, your family and healthcare professionals? If not, in what way is it different and how do you deal with that difference? If yes, how do you notice that it is the same?

5. Ethics of hope
   a) What do you see as a good way of dealing with (changes in) hope?
   b) What do you see as a good way of dealing with hopelessness?
   c) What do you see as a good way of dealing with despair?
      Prompts: Could you give an example? Could you tell me more about that?
### Supplementary File 2. An Example of the Code Tree: Hope, Hopelessness and Despair

<table>
<thead>
<tr>
<th>Quotations</th>
<th>Hope</th>
<th>Hopelessness</th>
<th>Despair</th>
<th>Summary</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;This is also my hope, to finish it [my life] in a good way. But well, what do I call good?&quot;</td>
<td>to finish life</td>
<td></td>
<td>hope for future gain</td>
<td></td>
</tr>
<tr>
<td>&quot;I've felt hopeless, once in my life. Then I really was hopeless. After the disease of my wife [who died].&quot;</td>
<td></td>
<td>after loss of wife</td>
<td>hopeless: past loss</td>
<td></td>
</tr>
<tr>
<td>&quot;Well, it's a fact that I'm not done yet with treatments, that she [oncologist] hasn't said like: 'We can't do anything anymore.' (...) Now you have hope to go for it.&quot;</td>
<td>&quot;we can do something&quot; – leads to hope</td>
<td></td>
<td>(near) past gain fosters hope</td>
<td></td>
</tr>
<tr>
<td>&quot;I really feel desperate when I have hyperventilation (...). Then I think: oh, my god, maybe it (...) will fail.&quot;</td>
<td></td>
<td>oh my god, maybe it will</td>
<td>despair: possible future – loss</td>
<td></td>
</tr>
<tr>
<td>&quot;It [hope] has to do with what you have experienced, and what you expect of the future.&quot;</td>
<td>past and future</td>
<td></td>
<td>hope: past experiences, expectation</td>
<td></td>
</tr>
<tr>
<td>&quot;Despair is like: Help me! Help me! (...) Like: 'Oh my god, what should I do? Help me!'&quot;</td>
<td></td>
<td>What should I do?</td>
<td>despair: possible future loss?</td>
<td></td>
</tr>
<tr>
<td>&quot;[Hopelessness and despair] are like a day that I think: I feel such a tight chest. This life is no longer worth living it.&quot;</td>
<td>tight chest; life not worth living it</td>
<td>tight chest; life not worth living it</td>
<td>loss of importance of life</td>
<td></td>
</tr>
<tr>
<td>&quot;I hope that I may live for another ten years because they told me ten years ago: 'You have another two years and then you're gone.' But now I'm ten years later. So you don't know. It's not in your hands, not in my hands.&quot;</td>
<td>derive hope from past of unexpectedly living longer</td>
<td></td>
<td>past gain fosters hope for future</td>
<td></td>
</tr>
</tbody>
</table>
**Supplementary File 3. Data Summaries Reflecting Hope, Hopelessness and Despair over Time**

<table>
<thead>
<tr>
<th>0 year</th>
<th>0.5 year</th>
<th>1 year</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Female, 51, cancer</strong></td>
<td><strong>Female, 91, COPD</strong></td>
<td><strong>Male, 76, HF</strong></td>
</tr>
<tr>
<td>HOPE: to be cured; DESPAIR: hope against hope, while despairing</td>
<td>HOPE: to complete my life in a good way</td>
<td>HOPE: that my wife will do well; being happy, while looking back; DESPAIR: that my death is near</td>
</tr>
<tr>
<td><strong>Female, 60, COPD</strong></td>
<td><strong>Male, 42, cancer</strong></td>
<td></td>
</tr>
<tr>
<td>HOPELESSNESS: that I can't do anything and feel like a plant; HOPE: Maybe they can offer me new lungs some day</td>
<td>HOPE: for living as long as possible with best quality of life; DESPAIR: panic, something is going terribly wrong</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>0 year</th>
<th>0.5 year</th>
<th>1 year</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Female, 51, cancer</strong></td>
<td><strong>Male, 76, HF</strong></td>
<td></td>
</tr>
<tr>
<td>HOPE: for cure; increases when I feel physically well; DESPAIR: oh my god, where does this lead to? HOPELESSNESS: feeling lost</td>
<td>[no longer the hope of waking up next morning]</td>
<td>HOPE: that the predicted life won't come true; derive hope from being able to work in the garden again</td>
</tr>
<tr>
<td><strong>Female, 60, COPD</strong></td>
<td><strong>Male, 42, cancer</strong></td>
<td></td>
</tr>
<tr>
<td>HOPELESSNESS: in fact you can't do anything; DESPAIR: when I feel shortness of breath</td>
<td>HOPE: that the time that is left for us as family, that we will spend that as good as possible</td>
<td></td>
</tr>
</tbody>
</table>

**1 year**

| **Female, 51, cancer** | **Male, 76, HF** |  |
| HOPE: for better quality of life, even when it means that I will die earlier | HOPE: that I may last for a while, like it is now | HOPE: You improve and then you start to get hope; Hope that my present life will continue |
| **Female, 60, COPD** | **Male, 42, cancer** |  |
|  | [only two interviews] | (only two interviews) |

The most dominant voice (hope, hopelessness or despair) was described as first one
Chapter 5: A Relational Ethics of Hope

A modified version of this chapter was accepted for publication as: Olsman E, Willems D and Leget C. Solicitude: balancing compassion and empowerment in a relational ethics of hope. An empirical-ethical study in palliative care. Med Health Care Philos 2015.

Abstract
The ethics of hope has often been understood as a conflict between duties: do not lie versus do not destroy hope. However, such a way of framing the ethics of hope may easily place healthcare professionals at the side of realism and patients at the side of (false) hope. That leaves unexamined relational dimensions of hope. In addition, the relational-ethical dimensions of hope have hardly been explored empirically. The objective of this study was to describe a relational ethics of hope based on the perspectives of palliative care patients, their family members and their healthcare professionals. Semi-structured interviews on hope were conducted with twenty-nine palliative care patients, nineteen friends or family members, and fifty-two healthcare professionals. Several researchers thematically analyzed data on hope and interpretations of hope were checked with participants. When participants spoke about hope, they referred to power, like the powerful bonding of hope between patients and physicians. They also associated hope with the loss of hope and suffering. Several participating healthcare professionals tried to balance both sides, which involved acknowledgment of hope and suffering. Moral philosophies were used to articulate the ethical dimensions of the empirical findings. Hope and power were reflected in the ethical concept of empowerment, whereas suffering and the loss of hope were reflected in the ethical concept of compassion. Empowerment and compassion can be balanced in solicitude. In conclusion, a relational ethics of hope requires solicitude, in which healthcare professionals are able to weigh empowerment and compassion within particular relationships.
**Introduction**

The ethics of hope has often been described within the context of truth telling, for instance when healthcare professionals have to break bad news. They may have to tell patients that a treatment failed to work or that patients suffer from a serious disease. In situations like these, healthcare professionals may want to tell the truth and respect patient autonomy, while simultaneously maintaining patients’ hope (1,2). This perspective may be connected to deontological theories, in which healthcare professionals experience a conflict of duties.

However, “hope versus truth” only reflects a realistic perspective on hope (3), which may easily place healthcare professionals at the side of realism and patients at the side of (false) hope. That leaves unexamined relational processes underlying shared hope (4,5). Furthermore, only a few authors have addressed relational–ethical dimensions of hope (6–8), and these dimensions have hardly been examined empirically.

The objective of our study was to describe a relational ethics of hope based on the perspectives of palliative care patients, their family members and their healthcare professionals. The central question was as follows: what does a relational ethics of hope consist of? Our approach was informed by the ethics of care and narrative ethics, in which relational dimensions, among other dimensions, are significant (9–14). The research question was answered from an empirical–ethical point of view (15,16), which involved that we examined what participants stated about hope within relationships. Moral philosophies were used to articulate the ethical dimensions of these findings.

The findings of this study may help healthcare professionals to see various sides of what is at stake when they work with hope, which may widen their reflective equilibrium (17). Furthermore, the results may support healthcare professionals to deal with hope in such a way that the quality of their relationship with patients is maintained or reinforced.

**Method**

Being part of a longitudinal qualitative study on hope in palliative care
(18), this paper focuses on the ethics of hope.

**Data Collection**

Semi-structured interviews on hope were conducted with palliative care patients, their family members and healthcare professionals. Sampling of participants aimed to obtain variation in gender and age. Eligible participants were eighteen years of age or older and they were informed about the study both orally and by letter.

Nurses, chaplains and physicians were approached through newsletters and palliative care networks. During the interview they were asked to tell about their own hope and the hope of their palliative care patients and patients’ family members. Then, participating healthcare professionals were informed about the sampling of patients and they were asked to approach eligible patient participants. When patients agreed to be approached by the researchers, they received information about the study. They were asked for their preference for being interviewed alone or with a family member or friend. In the latter case, the friend/family member was also informed about the study. After the interview they were asked for written and oral consent for interviewing their healthcare professional and/or their family members about them.

Palliative care patients were included when they suffered from incurable cancer, severe chronic obstructive pulmonary disease (COPD), or from 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. These three diseases were selected because they are some of the most prevalent causes of death in Western countries and because they follow different trajectories (19).

Interview guides were developed on the basis of three pilot interviews and on the basis of literature on hope in healthcare (see Supplementary File 1, pages 95–97). The interviews were audiotaped and transcribed. Definitions of hope were not formulated prior to the study because of the various definitions and approaches of hope in healthcare and philosophy (20–25), and mainly because the researchers were interested in participants' ideas about hope.
Participants were interviewed a maximum of three times with average intervals of six months. One interviewer (E.O.) interviewed all participants, which provided a relative constant factor in the research process and was important for building trustful relationships with participants (26). He was an experienced interviewer and had followed several courses on qualitative data collection and analysis.

Research Ethics

According to Dutch law our study did not need an ethics review (27). Although severely ill patients may benefit from participating in research, risks include the potential for emotional distress in participants and the main researcher, and difficulties around serial consent (26,28). These risks were discussed within the research team and the main researcher constantly attuned to the needs of patients and patients’ family members.

Eligible participants received information about the study both by letter and orally, and when they took part in the study, patient and family participants signed an informed consent form. In The Netherlands healthcare professionals only have to give oral consent (27). In a few cases patient participants were unable to sign an informed consent. In these cases the informed consent was read aloud and patients gave oral consent, which was audiotaped, and a witness confirmed that patients participated voluntarily. Issues of confidentiality were explained to participants and patient participants were asked for written and oral consent for interviewing their healthcare professional and/or their family members about them.

In order to guarantee the anonymity of all participants in this paper, demographics are presented collectively (Table 1), and the characteristics of two participants in this paper were changed. However, these changes did not affect the presentation of the findings.

Data Analysis

Fragments, in which participants explicitly referred to the word “hope” and derivatives thereof, like hopelessness and despair, which include the word “hope” in the Dutch language, were thematically analyzed. MAXqda
software was used to analyze the data. For examples of the code trees, see Supplementary Files 2 (page 98) and 3 (page 99). The main researcher (E.O.) analyzed the interviews and six researchers (four females) with backgrounds in sociology/nursing, religious studies, general practice/ethics, humanistic studies/ethics, or neurology co–analyzed a total of twenty–six interviews. Results were discussed until researchers reached consensus.

In many instances, interpretations of participants' hope were checked by telephone or during subsequent interviews. Transcripts were returned to participants and memos were used to reflect, analyze and capture ideas on hope. Saturation was reached when no new themes appeared in the data and when around twenty–four patient participants had been included. Inclusion of patients continued until twenty–nine patients had been included (26,29).

Results
Participants

Of the participating patients (n=29), eleven suffered from incurable cancer, ten from severe COPD, and eight from severe HF. Nine partners, four friends, three children, two brothers, and one sister–in–law were interviewed (n=19). Around one half of the friends/family members were interviewed together with the patient participants. The included healthcare professionals (n=52) were twenty–four physicians, among whom general practitioners, geriatricians and specialist physicians, eighteen nurses, among whom community, hospice, and specialist nurses, and ten chaplains with a Protestant, Roman Catholic, non–denominational, humanistic, or Muslim background. See Table 1 for demographic information.

The semi–structured interviews lasted an average of one hour and took place between December 2010 and November 2012. Patient and family interviews took place at their living place, like home, hospice or home care institution, whereas most interviews with healthcare professionals took place at their work place. Reasons for dropping out and non–participation of patient participants were fatigue and death, whereas the main reason for non–participation of healthcare professionals was a lack of time.
Hope and Suffering

When patients, patients’ family members and healthcare professionals in our study addressed hope, they often spoke about power. They also associated hope with suffering and loss of hope. For examples of the code trees, see Supplementary Files 2 (page 98) and 3 (page 99).

Hope and Power. Talking about hope, participants often referred to power. The wife of one of the included patients spoke about hope: “It has to do with a sort of power” (family 12). One of the patient participants addressed power as well and related it to healthcare professionals’ ethical obligation to give hope: “You always have to give your patient hope, offer him something to cheer him up by telling him: ‘Have confidence! Be open for the forces and powers that accompany you’” (patient 6).

Several healthcare professionals described hope as a powerful bonding between specialist physicians and patients. One healthcare professional referred to hope and told about this bonding: “The specialist physicians say: ‘Well, the patient asks for it, you know, to go to the last.’ (...) Patients sometimes tell me: ‘Yes, well, the doctor expects me to do it. The doctors are willing to do so much for me’” (physician 5). Another physician told about a patient’s hope for an experimental treatment: “His hope is that it will help. Well, that absolutely is false hope. Because he gets an...
experimental chemotherapy and in my view the effect is zero.” This physician explained how hope was nourished by the bonding with the patient’s oncologist: “If you [as oncologist] deal with patients for such a long time, it is very difficult to take some distance and say: ‘Well, now it’s really finished.’ They are not capable of doing that, or they don’t want to do that” (physician 4).

Hope and the power of hope were limited when hope was reduced to hope for cure. One patient told about the inborn nature of his heart failure and added: “Hope is not possible for me. There is no hope” (patient 3). According to several participating healthcare professionals hope for cure was dominant. One participating physician told how she searched for ‘second best’ hopes, like hope to see the daffodils grow or to experience the birth of your grandchild: “So these kinds of new little hopes arise when the big hope for definitive cure, when that door has been closed. Then, a circuit of second-rate little hopes arises” (physician 12).

Loss of Hope and Suffering. When discussing hope, many participants spoke about suffering and loss of hope. Participants also gave clues about good ways of dealing with loss of hope and suffering. A chaplain in our study stated: “To be able to deal with that suffering, that hopelessness of life (...) [you should realize] that there is never one appropriate answer” (chaplain 9). A specialist physician asserted that the suffering of losing hope often involved sadness: “With patients with cancer you very often deal with sadness as a response to the situation. That has something to do with the loss of hope” (physician 7).

A patient participant expressed that he had lost hope and everything that had been important in his life: his wife and his health. He told that he suffered from hopelessness. However, he felt supported by his psychologist: “She is open for that, you know. She immediately takes that seriously” (patient 1). A participating specialist nurse took seriously the loss of hope as well, by not downplaying emotions: “You reckon with the fact that sorrow or emotions come up while losing hope, and I’ve learned to allow that, not to immediately downplay that” (nurse 11).
Hope and Suffering within Relationships

Participants had different experiences with hope and suffering. Whereas some participants emphasized suffering, others emphasized hope, and yet others tried to pay attention to both suffering and hope.

Patients – Family Members. Patients and family members sometimes emphasized different sides: either hope or suffering. A patient participant was interviewed together with his wife. He asserted: “I hope that it will continue this way, as long as possible (...). But she said: ‘Maybe you could have better died.’ But please not! This period is worth living it” (patient 17). His wife responded: “Well, I thought: then he doesn’t have to dread it, then he won’t suffer.” She no longer emphasized his suffering: “He says: this is better with respect to his experience. Well, that’s true. And I’m better prepared now” (family 19).

Another patient participant told how her parents “kept saying” to her: “You’ll make it!” She explained it as: “They maintain hope and want their daughter to continue her life. But well, that won’t happen. That’s heavy.” She herself mainly experienced suffering: “I won’t make it. My heart says: this is the end. I’ve fought so much, every time again! Every time again” (patient 21).

Patients and Family Members – Healthcare Professionals. Differences were also found between healthcare professionals one the one hand and patients and their family members on the other. In one case a patient was interviewed together with her husband. She (patient 10) always hoped for a “better tomorrow”. Her husband explained that she could talk “in a very hopeful way” (family 12). They explained how their cardiologist, in their view, thought that they had “false hope” and how the cardiologist, as a consequence, focused too much on her suffering. They made clear to their cardiologist that she focused too much on the suffering and since then, the cardiologist took a different approach. The husband concluded: “The relationship is very good now” (family 12).

In another case a physician told about her hospice patient who hoped for a miracle cure. She tried to discuss what the patient “expected of her
future”. However, this evoked anger because the patient felt approached only as sufferer: “She said: ‘Everybody only tells me bad news. I don’t need to hear that because I will continue praying that a miracle will happen’.” The physician continued: “So then I told her: ‘I would like to talk about it at least once and after that I will stop nagging.’ So after that I haven’t talked about the future for a very long time” (physician 3).

Reflections of Healthcare Professionals. Several healthcare professionals tried to pay attention both to hope and to suffering. One participating nurse spoke about one of her patients: “The degree you appeal to her power has to do with hope (…) but if you ask too much of her, then you would deny her suffering” (nurse 9). Another healthcare professional asserted: “Disease and hope don’t go along very well. So it is the person and hope. It is the art of not focusing too much on the disease.” He added: “You need to pay attention to that [symptoms], of course. But also take into account: what else is playing a role here?” (physician 15). Some healthcare professionals expressed how they needed hope while facing suffering of patients. One of them stated: “Nurses don’t find it easy to give chemotherapies because you make your patients ill and you decrease their quality of life, because you hope that they will have quality of life after their treatments” (nurse 13).

Discussion
The results of our study suggest that palliative care patients, their family members and their healthcare professionals associate hope with power, and with suffering and the loss of hope. The results also suggest that within relationships both hope and suffering may play a role and that healthcare professionals try to balance both sides.

Strengths and Limitations
One of the strengths of this study is that it empirically examined hope from several perspectives: patients, family members, and healthcare professionals. Another strength is that – because of the study’s longitudinal character – interpretations of hope during previous interviews
were checked during subsequent interviews. In addition, the fact that one interviewer interviewed all participants reinforced trust between interviewer and participants, which is significant in longitudinal qualitative approaches (26).

However, our study only examined the micro level of individual stories and future studies should scrutinize hope at social levels, like others have done in hospitals (30), and hope at political levels, which includes issues such as justice and allocation of (financial) resources. In addition, future research is necessary in other healthcare settings than palliative care, in order to sharpen or revise the findings presented in this paper, which may reinforce the external validity of the results found in our study. In the last place, the concept of suffering should be empirically scrutinized in future research.

_Moral Theories_

The empirical findings presented above will be further articulated from a moral point of view.

_Hope: Empowerment._ The findings on hope and power reflect social-psychological and critical-sociological perceptions of empowerment. Social-psychological theories have described empowerment as a process of personal growth (31), and self-efficacy of palliative care professionals may indeed increase their hope (32). From a critical-sociological theory perspective, empowerment means the liberation from ties of oppression and inequality (21,33), which is a useful concept in order to critically approach the oppression of dominant hopes, like the hope for cure. The critical-sociological theory perspective on empowerment may furthermore help to critically approach the powerful bonding of hope between specialist physicians and patients, which was also addressed by others (4,5). Empowerment and hope in these cases entail deconstructing dominant or taken for granted hopes and reconstructing new hopes, like one of the physicians in our study did (see above).

_Suffering: Compassion._ The findings of suffering and the loss of hope,
and taking seriously the suffering of another person, are reflected in the ethical concept of compassion. Martha Nussbaum (34) defined compassion as “a painful emotion occasioned by the awareness of another person’s undeserved misfortune.” It includes three cognitive beliefs: 1) the suffering is serious, 2) the person does not deserve it, 3) similar possibilities of sufferer and compassionate person – the suffering could happen to both of them. Compared to empathy, compassion is not morally neutral: a torturer may be empathetic but is not compassionate (34). However, a critical comment should also be made: “If reason is used to justify the validity of compassion then compassion becomes a slave to reason. Subsequently, compassion becomes a slave to an abstraction, an idea of the good life like Nussbaum’s eudaimonistic conception” (35). This remark should remind healthcare professionals that their own eudaimonistic evaluations and those of their patients may be different, which requires exploration in clinical practice.

**Empowerment and Compassion: Solicitude.** The data suggested that hope and suffering are related themes and others have also addressed these themes (36,37). Several healthcare professionals in our study tried to balance both, which did not mean that they always ended up in the middle but rather expressed their capacity to weigh both sides. Empowerment and compassion can be balanced in solicitude.

Erik Erikson’s reference to solicitude helps us to understand how solicitude includes the care for others, from which hope, power and empowerment may arise. According to Erikson, hope is the most basic and earliest human power that is rooted within caring relationships (38). Animals also care for their young, “only man, however, can and must extend his solicitude over the long, parallel and overlapping childhoods of numerous offspring united in households and communities.” He concludes: “Care is the widening concern from what has been generated by love, necessity, or accident; it overcomes the ambivalence adhering to irreversible obligation” (38). For Erikson, hope remains a central factor in developing ego identity and autonomy (39), which relates to empowerment.
Solicitude also includes compassion. Paul Ricoeur wrote that solicitude resembles friendship and aims at the good life (40). Friendship is characterized by “a fragile balance in which giving and receiving are equal, hypothetically.” Solicitude, however, is first dissymmetrical: the suffering of the other evokes my “benevolent spontaneity” and compassion. Although compassion may lead to dissemetry, “this is perhaps the supreme test of solicitude, when unequal power finds compensation in an authentic reciprocity in exchange, which in the hour of agony, finds refuge in the shared whisper of voices or the feeble embrace of clasped hands.” According to Ricoeur the re-establishment of equality requires the recognition of the superiority of the other's authority, and a shared recognition of fragility and mortality. “A self reminded of the vulnerability of the condition of mortality can receive from the friend's weakness more than he or she can give in return by drawing from his or her own reserves of strength” (40).

In summary, solicitude includes the power of hope and empowerment, which are supported by mutually dependent relationships. On the other hand solicitude includes compassion, which is the shared recognition of fragility and suffering, in which the difference between giving and receiving is transcended.

**Conclusion**

In conclusion, an ethics of hope requires solicitude, in which empowerment and compassion are balanced. The results presented in this study may help healthcare professionals to develop relationships characterized by solicitude, in which healthcare professionals have the sensitivity to weigh compassion and empowerment within particular relationships. The results may also help them to reflect on their normative arguments and considerations, ultimately leading to reciprocal caring relationships between palliative care patients, their family members and their healthcare professionals.
References


18. Olsman E, Leget C, Duggleby W and Willems D. A singing choir: understanding the dynamics of hope, hopelessness and despair in palliative care patients. A longitudinal qualitative study. Accepted for publication by *Palliat Support Care*.


Supplementary File 1. Interview Guides

Interview Guide Patient and Family Participants

1. Opening
   a) Could you tell me what your first ideas were when you heard about the topic of this research: hope?
   b) Answers (and stories) were further explored by explorative questions: ‘What do you mean by …?’ ‘Could you tell something more about…?’ et cetera.

2. Concept of hope
   a) What does hope mean for you and what is its relation to hopelessness or despair?
   b) Are there other themes related to hope?

3. Dynamics of hope
   a) Have there been changes in your hope? Prompts: If yes, in what way? Did your hope, for example, increase, decrease, or remain the same? Could you tell me more about that?
   b) Have there been changes in your hopelessness? Prompts: If yes, in what way?
   c) Have there been changes in your despair? Prompts: If yes, in what way?
   d) Did other themes play a role in these changes? Prompts: If yes, which themes?

4. Social dimensions of hope
   a) What is the role of other persons in your hope? Prompts: which actions, responses or relationships help you to keep hope? Who threatens your hope? How did other respond to (changes in) your hope?
   b) Is hope the same for you, your family and healthcare professionals? If not, in what way is it different and how do you deal with that difference? If yes, how do you notice that it is the same?

5. Ethics of hope
   a) What do you see as a good way of dealing with (changes in) hope?
   b) What do you see as a good way of dealing with hopelessness?
   c) What do you see as a good way of dealing with despair?
      Prompts: Could you give an example? Could you tell me more about that?
Interview Guide Healthcare Professional Participants

1. Opening
   a. 'What were your first ideas when you heard about the topic of this study, which is: hope in the lives of people who suffer from a disease from which they will sooner or later die?'
   b. Answers will be further explored by explorative questions: 'What do you mean by ...?' ‘Could you tell something more about...?’ et cetera.

2. Concept of hope
   a. What is hope and what is its relation to hopelessness or despair?
   b. (How) does hope relate to emotions like fear, joy, sorrow, etc
   c. (How) does hope relate to religiosity or spirituality?

3. Dynamics of hope
   a. Do you see changes in hope in palliative care patients and their friends/families? If yes, in what way? Prompts: in what way does hope change? What are factors that influence changes in hope?
   b. Do you see changes in hopelessness in palliative care patients and their families/friends? If yes, in what way? Prompts: in what way does hopelessness change? What are factors that influence change in hopelessness?
   c. Do you see changes in despair in palliative care patients and their friends/families? If yes, in what way? Prompts: in what way does despair change? What are factors that influence changes in despair?

4. Social dimensions of hope
   a. Could you give an example of a situation in which hope of patients and family members was different? How did you deal with that difference?
   b. Could you give an example of a situation in which hope of palliative care patients and/or their friends/families was different from your own hope? How did you deal with that difference?

5. Ethics of hope
   a. What is a good way of dealing with hope?
   b. What is a good way of dealing with hopelessness?
   c. What is a good way of dealing with despair?

5. Ethics of hope
   a. What is a good way of dealing with hope?
   b. What is a good way of dealing with hopelessness?
   c. What is a good way of dealing with despair?

Prompts: Could you give an example? Which values are important for you in this example?

6. Hope and disease
a. Do you see similarities and/or differences between (changes in) hope among different palliative care patient groups? (e.g. between severe COPD/other chronic diseases and cancer) **Prompt:** If yes, in what way?

7. Hope of professionals

a. Could you give an example of things you hope for yourself? **Prompt:** think about hope in your own life and/or in your contact with palliative care patients or patients’ families or friends.

b. What are situations in which you experience hopelessness or despair in relation to palliative care patients? **Prompt:** could you tell something more about that?
## Supplementary File 2. An Example of the Code Tree: Hope and Power

<table>
<thead>
<tr>
<th>Quotations</th>
<th>Themes</th>
<th>Hope associated with</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;Well, that [church] was like: keep hoping, allow yourself time, be strong and powerful, things like that&quot; (patient 21)</td>
<td>keep hoping: allow time, be strong, powerful</td>
<td>power</td>
</tr>
<tr>
<td>&quot;She was so powerful because of her hope that she didn't leave any space for saying goodbyes.&quot; (nurse 15)</td>
<td>powerful because of hope, no space for goodbyes</td>
<td>power</td>
</tr>
<tr>
<td>Let's say: that hope, which people have had, I also think it is a sort of motivator, a sort of power, like: I will go on.&quot; (physician 10)</td>
<td>hope is motivator, power</td>
<td>power</td>
</tr>
<tr>
<td>&quot;Hope is: I wanna stay alive. That will to survive is very strong in human beings, no matter how ill they are. They cling to that&quot; (patient 6)</td>
<td>Hope: strong will to survive</td>
<td>strong will → power</td>
</tr>
<tr>
<td>&quot;Hope also includes a desire and courage as well, you make an inventory of power, and hope also gives power&quot; (physician 12)</td>
<td>hope includes desire, courage and gives power</td>
<td>power</td>
</tr>
<tr>
<td>&quot;Some people [with hope] try to keep themselves on their feet with thoughts like: it's not as bad as it seems. And: I want to do many things. I also think that we as healthcare professionals sometimes are more negative than patients&quot; (chaplain 10)</td>
<td>hope keeps people on their feet, keeping yourself on your feet → power</td>
<td>power</td>
</tr>
</tbody>
</table>
**Supplementary File 3. An Example of the Code Tree: Loss of Hope and Suffering**

<table>
<thead>
<tr>
<th>Quotations</th>
<th>Themes</th>
<th>Loss of hope / no hope associated with</th>
</tr>
</thead>
<tbody>
<tr>
<td>Then they've lost hope (...) at the point that they say: 'It's ready now. I'm done with struggling.'&quot; (nurse 6)</td>
<td>lost hope: done with struggling</td>
<td>struggling → suffering?</td>
</tr>
<tr>
<td>[During desperate moments I think about:] losing control. That I won't be any longer who I used to be. I think that's the word. That I won't have any control over my body. That you're pissing, shitting and stinking&quot; (patient 12)</td>
<td>desperate moments: losing control over body</td>
<td>no control over body and losing yourself → suffering</td>
</tr>
<tr>
<td>&quot;First they hope for cure. Then you've lost the hope for cure and then you hope to live for another year (...). You may deny it to a certain degree but the disease's nature is that that won't work anymore at a certain moment&quot; (physician 7)</td>
<td>lose hope because of physical suffering</td>
<td>suffering</td>
</tr>
<tr>
<td>About her hope, our puzzle is: how do you simultaneously acknowledge her suffering and take things over from her? (nurse 9)</td>
<td>hope versus suffering</td>
<td>suffering</td>
</tr>
<tr>
<td>&quot;We [man with COPD and I] saw each other during coffee, tea (...). He had always played [a wind instrument] in orchestras (...) so that man misses that a lot [pause]. Well, he had fun at that moment [with me]. No hope, but now again he had hope&quot; (patient 29)</td>
<td>no hope because he missed his favorite hobby → hope again</td>
<td>missing favorite things, no fun → suffering?</td>
</tr>
<tr>
<td></td>
<td></td>
<td>because he had fun</td>
</tr>
</tbody>
</table>
Chapter 6: A Hope Communication Tool

A modified version of this chapter was accepted for publication as: Olsman E, Leget C and Willems D. Palliative care professionals’ evaluations of the feasibility of a hope communication tool: a pilot study. Prog Palliat Care 2015. DOI: http://dx.doi.org/10.1179/1743291X15Y.0000000003

Abstract

Background: Palliative care professionals have recognized the importance of hope for their patients. However, they sometimes experience hope as a barrier for end-of-life communication. A hope communication tool may help them to address hope during clinical encounters but has not been developed yet. The objective of this study was to examine the feasibility of a hope communication tool for palliative care professionals.

Method: Based on synthesis studies of hope, a hope communication tool (HCT) was developed. Palliative care professionals were asked to use and evaluate the tool by making use of a written evaluation scheme, mainly consisting of open-ended questions. Similarities and differences between participants and suggestions for revisions were thematically analyzed and discussed within the research team.

Results: Fourteen healthcare professionals (nine females; mean age 50.9 years) participated in the study: nine nurses, three physicians and two chaplains. The HCT helped participants to reach depth and address end-of-life issues. Most participants used it for other reasons than described in the tool. They used it when they faced difficulties that related to patients' hope or hope-related themes, such as unrealistic hope or fear. Participants also gave feedback on the open or abstract character of questions, the assumptions of questions, and the distinctions between categories.

Discussion: The HCT is feasible and helps to reach depth and address end-of-life issues. The findings lead to a revised HCT, which should be evaluated in future research.
**Introduction**

Hope is important for palliative care patients and contributes to their psycho–spiritual well–being (1), whereas hopelessness has been associated with negative health outcomes (2–4). Palliative care professionals have recognized the importance of hope for their patients (5), however, they sometimes experience hope as a barrier for end–of–life discussions (6–10). In addition, patients' hopelessness may cause feelings of powerlessness in their professionals (11). Strategies to foster patients' hope have been described (12,13), and a living with hope program was developed, which increased patients' hope and quality of life (14).

However, a tool that supports healthcare professionals during clinical encounters with palliative care patients to address hope and related themes has not been developed yet. The objective of this study was to develop a hope communication tool (HCT) and examine palliative care professionals' evaluations of the feasibility of this tool. The central question was as follows: How do palliative care professionals evaluate the feasibility of the HCT? The findings of our study may support palliative care professionals to address hope in relation to end–of–life issues, and attune to patients' psychosocial and spiritual needs.

**Method**

The pilot study consisted of a qualitative evaluation of the HCT.

**Development of the Hope Communication Tool**

A hope communication tool was developed on the basis of synthesis studies on hope in palliative care. The HCT consisted of questions and it described reasons for using it, for example getting to know a patient during an intake, or attuning care after physical improvement or deterioration, or after bad news. For the HCT, see Figure 1.

One of the synthesis studies had found a difference between the being and the doing of hope (1), which we described as “hopefulness” and “hoping for”. Another synthesis study described differences between hope, hopelessness and despair (15), and a third one found three perspectives on palliative care patients' hope, referring to hope's realism, helpfulness and meaningfulness (5). The question ‘what does give you hope, grip or
strength?’ was based on a qualitative study on palliative care professionals’ metaphors of hope (16).

**Figure 1. The Hope Communication Tool for Palliative Care**

<table>
<thead>
<tr>
<th>Hoping for</th>
<th>Hopefulness</th>
</tr>
</thead>
<tbody>
<tr>
<td>What do you hope for your future?</td>
<td>What does give you hope, grip or</td>
</tr>
<tr>
<td></td>
<td>strength?</td>
</tr>
<tr>
<td>What does this hope mean to you?</td>
<td>How does this hope help or hinder you?</td>
</tr>
<tr>
<td><strong>Anticipating</strong></td>
<td><strong>Acceptance</strong></td>
</tr>
<tr>
<td>What do you reckon with concerning the future?</td>
<td>What does help or hinder you in dealing with your disease?</td>
</tr>
<tr>
<td>How can I accompany you in that?</td>
<td>How can I accompany you in that?</td>
</tr>
<tr>
<td><strong>Despairing</strong></td>
<td><strong>Hopelessness</strong></td>
</tr>
<tr>
<td>Which moments do you despair?</td>
<td>Which moments do you feel hopeless?</td>
</tr>
<tr>
<td>What can I mean for you during these moments?</td>
<td>What can I mean for you during these moments?</td>
</tr>
</tbody>
</table>

Reasons for using it: 1) getting to know a new patient (intake) or 2) attuning support around physical improvement /deterioration or after bad news

**Research Ethics**

In The Netherlands, healthcare professionals only have to give oral consent. The tool was an intervention on the level of caregivers, which, under Dutch law, did not need to be reviewed by an ethics committee (17). Furthermore, healthcare professionals were encouraged to use the tool as a part of their normal and daily communication with palliative care patients (see Supplementary File 1, pages 112–113). As a consequence, consent and safety of patients was guaranteed, like it is guaranteed in daily healthcare practice.

**Data Collection and Analysis**

Palliative care professionals were informed about the study via palliative care networks and email list servers. Sampling aimed to acquire variation in gender, age, and professional background, and snowball sampling was also used (18).
Eligible participants were asked to read the instructions. They were asked to use the tool in a situation in which their patient could benefit from it, and to evaluate the tool after the conversation, using a written evaluation scheme with open-ended questions. Questions included: How do you evaluate the effect of this question? How did the conversation continue after you had asked this question? For the instructions and questions, see Supplementary File 1 (pages 112–113).

Similarities and differences between participants’ answers and suggestions for revising the tool were thematically analyzed. The results were discussed within the research team (authors of this paper).

Results

Participants

Between June and September 2014, the HCT was evaluated by fourteen healthcare professionals, among whom nine nurses, three physicians and two chaplains (nine females; mean age 50.9, range 33–69; mean years of experience with palliative care patients 21.9, range 9–38). Seven defined themselves as non-believers, five as Christian, and two in other ways. Ten of them used the HCT during encounters with a total of twelve patients, most of whom suffered from incurable cancer. The other four participants evaluated the tool on the basis of their clinical experience.

Evaluations of the Hope Communication Tool

General Evaluation. Participants reported that the tool helped them to reach deeper levels during conversations: “It opens up a conversation about deeper feelings” (participant 04). Another participant wrote: “It brought up a conversation that otherwise would certainly not have taken place: with so much depth and openings for spirituality” (participant 02).

Reasons for Use. Although some participants used the tool in accordance with the described reasons for using it, most participating palliative care professionals used it for another reason: to deal with difficult issues that related to hope or related themes. One participant explained: “I will use the tool more often. Sometimes a conversation is difficult. The tool offers a
hold to discuss things.” It helped her to ask confronting questions: “It’s a confronting question [about anticipation and truth], which you want to ask with tact. The conversation tool supports you in that” (participant 07). Other participants used it because their patient had unrealistic hope: “Because with this man his inexhaustible hope is remarkable, despite his severe disease” (04). Patients with a lot of fear were also a reason for using the tool: “[She is] very vulnerable and often in panic, in which her mother played a central role. In that case the questions helped to talk about hope and despair” (participant 05). Another participant, describing his reason for using it, expressed something similar: “His fear and uncertainty were central” (participant 08). Participants did not use questions of the categories anticipating and acceptance, except questions about truth and realism.

**Advantages and Drawbacks of Open Questions.** Some participants critically commented that the questions were too open or abstract: “The meaning of hope is a difficult question for quite some people. Giving meaning is also determined by the patient’s mood and asks for a certain capability of abstraction” (participant 13). Another participant reported: “I want to keep the question open. But well, not everyone is able to deal with such abstract questions” (participant 09). However, others stated that open questions on hope were rather easy to answer, as was illustrated above. One participant also wrote: “Hope is an easy word that everyone can recognize and to which everybody can give a meaning” (participant 06).

The open character of the questions implied that the answer could not be predicted, which made some participants feel vulnerable or uncertain. One participant reported: “Asking ‘What may I mean for you?’ has added value. It’s difficult though because I present myself as vulnerable (imagine that someone replies: ‘Nothing’)” (participant 08). Another participant wrote: “It’s sometimes difficult to know what I can do with this information. You unlock something and don’t always know what to do with that” (participant 06).

**Suggestions for Improvement.** Suggestions for improvement mainly concerned the formulations and assumptions of questions and the
distinctions between categories. Several participants referred to the fact that the categories despair – hopelessness, and hoping for – hopefulness were not clearly distinguished in everyday life. One of them wrote: “Instinctively I see no differences” (participant 12).

Participants also wrote about the assumptions of some questions. For example, the questions on despair and hopelessness assumed that patients did have periods of hopelessness or despair. One participant suggested to ask: “Are there moments that you despair / feel hopeless, and if so, which moments?” (participant 04). Another participant suggested to revise one of the questions: “The question on support is formulated from the healthcare professional’s point of view, which assumes that support is necessary, assuming that the patient would not be able to deal with it independently. I would suggest (...) the question: can I mean something for you with respect to this?” (participant 13). This same participant preferred other words than despair and hopelessness: “For the patient it is much clearer to talk about: no longer seeing any perspective, getting stuck, worrying, not being able to figure out” (participant 13).

One of the participants reported that the questions may be difficult for some patients and we put the idea to her to start the conversation with the question “what are your first ideas when you hear the word hope?” (and not “what do you hope for?”), which she saw as a good start: “I think it definitely may help” (participant 11). She added: “I also think that patients do state things about hope to which you may attune, like hope for success of a treatment or being able to spend the holiday, etc” (participant 11).

**Discussion**

The findings suggest that healthcare professionals evaluate the HCT as feasible. The tool may offer ways to deal with the difficulties surrounding hope during end-of-life communication (6–11). The findings also suggest that the tool may bring depth during conversations, which relates to spirituality. Others have also related hope to spirituality (19,20), and the HCT may thus help to discuss spirituality with patients.

However, future research is necessary, for instance, to explore discussions on hope in non-Western healthcare settings. In addition, psychosocial work in Dutch palliative care is often done by nurses and
chaplains, who were included in this pilot study. However, future studies should explore the experiences of using the tool of psychosocial care providers in other countries, like social workers and psychologists in palliative care.

Furthermore, the findings lead to a revised HCT (see Figure 2).

**Figure 2. The Revised Hope Communication Tool for Palliative Care**

<table>
<thead>
<tr>
<th>Hope</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>What are your first ideas when you hear the word “hope”?</td>
<td></td>
</tr>
<tr>
<td>Do you hope for something? Do you look forward to something? If so, for / to what?</td>
<td></td>
</tr>
<tr>
<td>Is there something from which you draw hope or that offers you strength or grip in your life? If yes, what?</td>
<td></td>
</tr>
</tbody>
</table>

**Further Exploration of Hope**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>What does this hope mean to you?</td>
<td></td>
</tr>
<tr>
<td>How does this hope help or impede you?</td>
<td></td>
</tr>
<tr>
<td>To what degree do you think your hope for the future will come true?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Hopelessness / Despair</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Are there moments of hopelessness or despair in your life? If so, which moments?</td>
<td></td>
</tr>
<tr>
<td>Are there moments that you feel lost or stuck? If yes, which moments?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Support</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Can I support you concerning your hope, hopelessness or despair? If so, in what way?</td>
<td></td>
</tr>
</tbody>
</table>

Reasons for using it: 1) getting to know a new patient (intake), 2) attuning support around physical improvement/deterioration or after bad news, or 3) difficulties around hope (e.g. unrealistic hope) or difficulties around hope–related themes (e.g. fear)

In the first place, participants did not recognize the differences between the six concepts. For example, the included healthcare professionals often used despair and hopelessness interchangeably, which may reflect the variety of ways in which these concepts have been defined (15,21–23). In addition, participants stressed the similarities between hopefulness and hoping for something. The synthesis study on which the difference between these concepts was based had also found that these concepts
were related (1). Another finding was that, except questions about truthfulness and realism, participants did not use the categories of anticipating and acceptance.

These findings suggest a new classification of categories, in which hoping for something and hopefulness are placed in one box, and hopelessness and despair are placed in one box, and in which anticipating and acceptance can be left out (except from questions about truth). The questions that had been used as further exploration of the six categories, like “What does this hope mean to you?” and “How does this hope help or hinder you” are now placed in a separate box entitled “Further exploration of hope”. The question about truth is part of this further exploration as well. In addition, questions about support are placed in a separate box, which may help healthcare professionals to plan their care while attuning to (hope, hopelessness and despair of) their palliative care patients.

Secondly, participants did not agree on whether the questions were too abstract or too open for patients, and some participants suggested new ways of addressing hope and related themes. As a consequence, in the revised HCT new questions were added, such as “Do you look forward to something?” and “Are there moments that you feel lost or stuck?” Still, users may reformulate questions during clinical encounters in order to attune to (the hope of) their palliative care patients.

Furthermore, most participants used the HCT for other reasons than the ones described. Generally, they used it when they experienced difficulties in relation to patients’ hope or hope-related themes. As a consequence, a third reason for using the HCT has been added to the revised HCT: healthcare professionals could also use it when they experience “difficulties around hope (e.g. unrealistic hope) or hope-related themes (e.g. fear)”. Fourthly, participants reported that some questions had assumptions and suggested to revise these questions, for instance by asking “Are there moments of hopelessness or despair in your life, and if so, which moments?” instead of “Which moments do you despair/feel hopeless?” These questions were revised.

In conclusion, the HCT is feasible and can be used in clinical practice. The tool may support healthcare professionals to discuss spirituality and (difficult) end-of-life issues during clinical encounters with palliative care
patients. Future research should evaluate the revised HCT. Ultimately, the HCT should lead to good psychosocial and spiritual care for those living the last phase of their lives.

References


Supplementary File 1. Instructions and Evaluation Questions

Instructions
The tool can be used during a conversation that you would have had anyway because the objective of the instrument is to offer you language with which you may address hope (more easily) with patients. For that reason you may use the tool in a flexible way.

1) Take a look at the instrument (see attachment) and ask yourself: will there be a conversation during the following days during which the tool may support me? (the patient has to be in later stages of a progressive disease)
2) Prepare the conversation by focusing on some of the questions. For example, choose one question that you think is most important for this conversation and choose a question that you normally wouldn’t ask very easily.

After the conversation, answer the following questions and send your answers to me by e-mail.

1) With whom did you have the conversation (m / f), from which disease did (s)he suffer and what was her/his age?
2) What were your considerations to use the tool in relation to this patient?
3) What was the setting of the conversation? (everyday talk, intake, discuss treatments, etc.; in the house of the patient, in hospital room, etc)
4) Which question(s) did you use?
5) Why did you ask this question?
6) During which moment of the conversation did you ask this question?
7) How did the conversation continue after you had asked this question?
8) How do you evaluate the effect of this question? (for example, the effect on the patient, on the conversation, on yourself)
9) Do you have suggestions for revising and improving the tool? For example, with respect to the formulation of questions, or other suggestions? If yes, which suggestions?

Please fill out the following things about yourself:
Male / female:
Profession:
Age:
Years of experience with patients who suffer from progressive diseases:
Work setting (hospital, hospice, home care, etc):

Spirituality:

Did you like working with the tool? Of course you can answer the questions again after a conversation with another patient.

Your response will be treated confidentially, which means that your name will be deleted and disconnected from your e-mail. Your e-mail will be deleted after the study (Fall 2014).
Chapter 7: General Discussion

In this final chapter we will synthesize the findings from which we will draw ethical and clinical implications. In so doing, we outline how we achieved the objective of this study, which was to provide insight into hope in palliative care and to offer healthcare professionals clinical and moral guidance. We will also reflect on the research methodology and suggest possibilities for future research.

**Toward a Relational Approach**

As was described in the first chapter of this thesis, hope research is characterized by a multiplicity of definitions and approaches. Our synthesis of the literature, describing healthcare professionals' perspectives on hope of their palliative care patients, did not reduce this multiplicity but rather provided insight into relationships between definitions of hope on the one hand, and actions and values on the other, which helps to understand how different definitions of hope include different normativities that affect clinical practice.

In addition, the introductory chapter of this thesis referred to the ethics of hope, which has often been reduced to a physician's conflict of duties: do not lie versus do not destroy patients’ hope. This realistic perspective on hope opposes hope with truth and relates to Western disclosure practices (1–3). Our synthesis of the literature found that this realistic perspective was (only) one among other perspectives (functional and narrative). These findings help to widen our reflections on hope and put into perspective the dominance of the realistic perspective.

That is important because realistic perspectives on hope were not explicitly mentioned in synthesis studies on palliative care patients (4–8). Furthermore, the narrative perspective is the most relational perspective because it is based on intersubjectivity (9), and several philosophers addressed hope's social and relational dimensions (see first chapter). However, the narrative perspective was absent in the physician studies that had been included in our synthesis study. These findings suggest that particularly physicians run the risk of neglecting hope's relational
dimensions. There are, however, two important reasons for adopting a relational approach to hope, which includes individualistic approaches to hope rather than the other way around (individualistic approaches that include relational approaches).

Firstly, by (only) holding a realistic perspective, physicians tend to place themselves at the side of realism and truth. However, several studies suggested that healthcare professionals could not solely be seen as representatives of realism and truth. One prospective cohort study for example showed that doctors were systematically optimistic with respect to estimating the prognosis for terminally ill patients (10), and another study found that oncologists and their small cell lung cancer patients together construed a false optimism (11). A more recent study indicated that healthcare professionals and their oncology patients mutually reinforced the continuation of chemotherapies, in which hope was a central topic (12). Hence, an individualistic approach to hope denies the existence of relational processes that reinforce (implicitly) shared hope and it leaves unexamined healthcare professionals' own hope.

Secondly, the study on the dynamics of hope, hopelessness and despair in palliative care patients found that within their stories several patients held contradicting beliefs and experiences. Others have also shown how palliative care patients may hope for cure while being aware of approaching death (13). Hence, some patients with “false” hope may simultaneously take a realistic perspective on their situation. As a consequence, it is important that healthcare professionals explore how palliative care patients connect or disconnect these contradictions. In addition, healthcare professionals have to decide how they want to relate to both sides during clinical encounters.

In conclusion, a relational approach to hope acknowledges that hope can be a shared hope, that healthcare professionals hope things as well, and that palliative care patients in their stories may hold inconsistent beliefs and experiences, such as hope for cure and preparation for death. Obviously, individualistic approaches help to understand how the truth of bad news may distort patients' hope, and therefore relational approaches to hope should include individualistic ones.
**Ethical and Clinical Implications**

What are the ethical implications of this conclusion? In our view it should lead to an ethics of hope that is presented in Figure 1, which includes most of the ethical dimensions presented in the previous studies. The figure could be further extended, for instance by adding other relational values (14,15). A relational approach to hope should always start from within the dotted ellips, and others have also addressed the importance of compassion and empowerment in relation to hope (16,17). Healthcare professionals may regularly approach hope from an individualistic point of view by stepping out of the inner ellips and by taking an outer perspective. In that case they may emphasize how hope helps their (palliative care) patients or how hope is opposed to truth, leading to an emphasis on the reality of suffering.

![Figure 1. The Ethics of Hope](image)

Ideally, healthcare professionals are able to take into account all values described in this figure because our studies suggest that all these values are important in clinical settings. The figure for instance helps them to reflect on the absence of certain values in their own clinical practice or within their healthcare settings. The figure may also help them to reflect on which approach fits best with a particular patient’s needs and capacities. However, some hopes may be less dynamic than other hopes and for example the hope to be remembered after death may be less affected by bad medical news than the hope that a treatment will have effect. Future
studies should therefore validate or revise the values presented in Figure 1. They should also develop training programs that stimulate moral reflection on hope and evaluate the effectiveness of these programs.

Adopting a relational approach to hope also involves that healthcare professionals acknowledge their own hope, the loss of their own hope, and how their own hope relates to palliative care patients' hope. In this regard, the metaphor of hope as a tune, described in the chapter on metaphors of hope, may be helpful. Others have described nurses' capability of harmonizing hope: "Having a sense of balance would imply that they [nurses] would have to come to a consensus, or that both sides [patients and nurses] would have to understand each other equally. Instead this process [of harmonizing] resembled having a sense of harmony that allowed different perspectives to exist alongside one another" (18). Another author described how chaplains worked with dying patients and concluded that being presented with a patient can in itself foster hope (19,20). Development of these capabilities of harmonizing hope and being present in a hopeful way may be important for providing palliative care, which includes physical, psychosocial and spiritual care. Meanwhile, healthcare professionals also need compassionate colleagues or friends that support them when they face the reality of patients' suffering.

Furthermore, hope has often been understood as a factor that may obstruct end-of-life communication and delay end-of-life discussions (see chapter 1). In this regard, the last presented study may be helpful, which tested the feasibility of a hope communication tool and indicated that this tool facilitates end-of-life communication. The tool mainly consisted of open questions and it stimulated dialogue at deeper levels, which means, in our view, that both parties are willing and able to acknowledge the other's perspective in its own right (21). This requires from healthcare professionals that they ask their palliative care patients questions about hope, hopelessness and despair, which may offer starting points for conversations about future perspectives that include positive and negative scenarios, such as treatment restrictions and possibilities. Again, the figure is important because healthcare professionals may emphasize what can be done (empowerment; helpfulness) and what cannot or can no longer be done (compassion; truthfulness). In so doing, healthcare professionals also
need the ability to cope with feelings of hopelessness and despair in their patients: “To ‘know’ that in some situations the experience of deep hopelessness cannot be cured or talked away allows us to stay more connected to our clients’ experience” (22).

Another important finding in this thesis was that palliative care patients may hold (seemingly) inconsistent elements in their stories. They may for instance simultaneously experience hope and hopelessness, which has also been reported by others (23). The clinical importance of this finding is that healthcare professionals should not in advance take an “either-or” approach, as if, for instance, the presence of hope means the absence of hopelessness or despair. In addition, patients may hope for cure, while thinking about dying. As a consequence, healthcare professionals should be able and willing to address not only hope but also hope’s shadow sides or opposite themes.

Healthcare professionals may ask their patient for permission to explore these themes. The lung physician in the introductory chapter could for instance say to Mr Johnson: “You told me that you hope to visit your son abroad,” and then ask: “What does your son mean to you?” After that, the lung physician may bring up less optimistic scenarios, for instance by saying: “Would it be okay for you to discuss once or twice what we do in case you won’t be able to visit your son?” Furthermore, the findings in our study on the dynamics of hope in palliative care patients suggest that physical changes are associated with changes in hope, hopelessness and despair. As a consequence, the lung physician may refer to a recent exacerbation, like a severe pneumonia, and say for example: “You were in the hospital a couple of months ago because of a pneumonia. Let’s hope that it will take a very long time until you will have a next one. But I would like to talk about how I could support you when something serious like that happens more often. Is that okay?”

The lung physician could also ask Ms Johnson: “Your husband says that he hopes to visit your son abroad. How do you see that?” Or: “Is that also your hope or do you hope for something else?” These questions may be helpful in stimulating dialogue between patients and their family members and they provide insight into differences and similarities between (hope of) patients and family members. It requires from healthcare professionals that
Reflection on Research Methodology

One of the major strengths of the qualitative interviews conducted in this thesis was that they offered insight into participants' understandings of hope. The longitudinal character, in addition, helped to establish trust between researcher and participants, which was important for generating valid data. However, longitudinal qualitative approaches generate a lot of data and are time consuming (25,26). As a consequence, we often had to limit ourselves to analysis of data fragments in which participants used hope and the Dutch derivatives hopelessness and despair. Nevertheless, the data generated in our study can be used for other analyses in the years to come, and data provided by longitudinal qualitative interviews are open to secondary analysis (27).

Future studies are necessary to examine what palliative care patients, their family members and healthcare professionals do with hope, for instance by making use of qualitative (participatory) observations (28). That is important because an older study found that patients with small cell lung cancer and their oncologists together developed a false optimism about recovery (11). Future studies should examine whether this optimism is similar to or different from hope, and they should explore hope in other hospital settings, such as cardiology and lung diseases departments. In this regard, further development and validation of the hope communication tool may be useful in order to improve palliative care communication.

An ethical issue, other than the ones reported in the previous studies, was that one of the participants with severe COPD raised the following issue at the end of the second (and last) interview:

Interviewer: “It also sounds as if you’re saying: ‘I know that it is not possible [to have a lung transplantation]. (…) And at the same time: ‘In some way I do hope that’…”
Patient: “Yes. Exactly. Because then I sometimes think to myself: how would be something like that [possibilities for lung transplantation] in
the AMC hospital [hospital where interviewer works], how do they deal with people over there?"

She agreed to be interviewed a third time. However, when she was called after six weeks, and the weeks after that, she did not answer her phone and she did not respond to voicemails. It made us realize that she, being well informed about the study, nevertheless may have participated in our study because she had “false” hope.

Palliative care patients participate in scientific studies because it enhances their sense of value and because of altruism (29,30). We may add that palliative care patients may participate in a study because of “false” hope. One of the advantages of qualitative research, compared to for instance survey research, is the possibility of discussing hope and other reasons for participation. In the future, qualitative researchers may for example ask their participants questions such as: “What do you hope concerning your participation in this study?”

Furthermore, while exploring study participants’ hope, qualitative researchers also need an ethics of solicitude, in which they are truthful about the objectives of the study, the benefits and costs for patients, and in which they are compassionate when these benefits are different from what study participants had hoped for. Simultaneously, qualitative researchers need to emphasize how future patients and healthcare professionals may benefit from the results of the study. In addition, participants may feel empowered when they notice that their story is worth listening to. Solicitude then means that researchers care about their study participants by acknowledging that a good quality of their relationship with (potential) study participants is more important than generating data at any cost. Meanwhile, researchers need the ability to demarcate their own role from the role of healthcare professionals. For example, they can only address issues that relate to the study and study objectives and not provide medical information to patients.

Another methodological and theoretical issue in this thesis was time. Time is limited in every study but within palliative care death is knocking on patients’ door, and fatigue and death were the most common reasons for drop out. Furthermore, within quantitative longitudinal approaches time
is generally related to statistically significant trends in human actions and experiences, whereas within qualitative approaches time is reflected in, for instance, what participants experience as defining moments (31), which relates to differences between clock time, subjectively experienced time, and narrated time (32,33). For example, in their stories, patient participants in our study related hopelessness to the past and despair to the future, and they related hope to both past and future. Hence, future research should explore the relation between hope, hopelessness and despair on the one hand, and patients’ and healthcare professionals’ understanding of time on the other. These studies may also provide insight into similarities and differences between healthcare professionals' and palliative care patients' understanding of time and prognosis.

A last issue was the main researcher’s own contribution to the research process. I am a white Dutch male, younger than most study participants, and I have no life-threatening illness. Theoretically, I am nourished by, among other theories, ethics of care, social constructionism, narrative theories, and gender theories. The influence of these factors on the research process has been part of discussions with thesis supervisors, researchers, colleagues, friends and others. These discussions have contributed to an ongoing reflexivity, which is important for establishing validity within qualitative research (34). In addition, these conversations protected my own well-being, which was particularly important when I witnessed the suffering of study participants. These experiences and conversations made me realize that I needed relationships characterized by solicitude as well.

Finally, one of my personal goals has been to translate experiences of study participants into study results and education programs that ultimately lead to better care for palliative care patients, their family members and their healthcare professionals. My hope is that first of all they will draw the benefits from the results presented in this thesis.

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Summary

Chapter 1 provides the background and objectives of this thesis. Although hope is important for palliative care patients, their family members and their healthcare professionals, the concept is hard to define. In addition, the ethics of hope has often been limited to a physician's conflict of duties – tell the truth or maintain patients' hope – and hope has often been perceived as barrier during end-of-life communication. The objective of this thesis is to provide insight into hope in palliative care and to offer healthcare professionals clinical and moral guidance. A longitudinal qualitative approach will be used, mainly consisting of semi-structured interviews with palliative care patients, their family members and their healthcare professionals.

Chapter 2 presents an interpretative synthesis of the literature, which aims at describing healthcare professionals' perspectives on hope of palliative care patients. Electronic databases were used to search literature on hope in palliative care and thirty-one articles were found to be of sufficient quality. The results of these studies were thematically analyzed. Three perspectives on hope were found: 1) realistic perspective – hope as an expectation should be truthful, and healthcare professionals focus on adjusting hope to truth, 2) functional perspective – hope as coping mechanism should help patients, and professionals focus on fostering it, and 3) narrative perspective – hope as meaning should be valuable for patients, and healthcare professionals focus on interpreting hope. The findings indicate that healthcare professionals should be able to work with all three perspectives on hope in order to improve communication with their palliative care patients.

Chapter 3 aims to provide insight into palliative care professionals' implicit understandings of hope. Metaphors of hope were examined, which palliative care professionals in The Netherlands and Canada spontaneously used during interviews. The sixty-four palliative care professionals were physician, nurse, chaplain, or had another professional background. Four metaphors of hope were found: 1) grip, which implied safety, 2) source, which implied strength, 3) tune, which implied harmony, and 4) vision,
which implied a positive perspective. While included physicians used hope as a grip most often, chaplains used hope as a tune most often. The findings offer metaphoric language, which healthcare professionals may use to address hope in their clinical practice.

Chapter 4 explores the dynamics of hope, hopelessness and despair over time, as experienced by palliative care patients. Twenty-nine palliative care patients were interviewed a maximum of three times, with average intervals of six months. Interview fragments on hope, hopelessness and despair were thematically analyzed and these concepts were then analyzed over time in each case. Participants associated hope with gains in the future or past, hopelessness with losses in the past, and despair with future losses. The three concepts could be understood as voices in a singing choir that could sing their own melody, sing together, or alternate. Participants associated changes over time in hope, hopelessness and despair with changes in their physical condition. This last finding suggests that healthcare professionals may address (one of) the three concepts when patients' physical condition has changed.

In chapter 5 the ethics of hope is scrutinized. The objective is to sketch a relational ethics of hope, based on the perspectives of palliative care patients, their family members/friends, and healthcare professionals. All interviews with twenty-nine palliative care patients, fifty-two healthcare professionals and nineteen family members/friends were thematically analyzed on hope. Participants associated hope with power, and with the loss of hope and suffering. Several healthcare professionals tried to pay attention to hope and suffering. The empirical findings are related to the ethical concepts of empowerment (hope) and compassion (suffering). The chapter concludes that a relational ethics of hope consists of solicitude, in which empowerment and compassion are balanced.

Chapter 6 examines the feasibility of a hope communication tool. Based on synthesis studies on hope, a hope communication tool was developed and healthcare professionals were asked to use and evaluate it. Fourteen healthcare professionals evaluated the tool among whom two chaplains, three physicians and nine nurses. The tool was useable and it supported healthcare professionals to discuss end-of-life issues and spirituality with their palliative care patients. Participants' suggestions for revisions lead to
a revised hope communication tool, which should be evaluated in future research.

Chapter 7 argues that healthcare professionals should employ a relational–ethical approach to hope, which means that empowerment and compassion should be part of the relationship between healthcare professionals and patients. Healthcare professionals need to take into account their own (experiences of) hope, hopelessness and despair as well. Reflecting on the research methodology we conclude that qualitative researchers also need an ethics of solicitude.
Samenvatting

Hoofdstuk 1 beschrijft de achtergrond en de doelstellingen van dit proefschrift. Hoewel hoop belangrijk is voor palliatieve patiënten, hun naasten en zorgverleners, is het een moeilijk te definiëren concept. De ethiek van hoop is bovendien vaak beperkt tot een conflict van plichten van de arts – de waarheid vertellen of hoop in stand houden – en verder is hoop vaak als belemmering voor communicatie rond het levens einde beschreven. Het doel van dit proefschrift is om inzicht te geven in hoop in palliatieve zorg en om zorgverleners klinische en morele handvatten te bieden. We zullen een longitudinale, kwalitatieve benadering gebruiken, die hoofdzakelijk bestaat uit semi-gestructureerde interviews met palliatieve patiënten, hun naasten en zorgverleners.

Hoofdstuk 2 presenteert een interpretatieve synthese van de literatuur, met als doel om zorgverleners' perspectieven op hoop van palliatieve patiënten te beschrijven. Electronische databases werden doorzocht en eenendertig artikelen bleken van voldoende kwaliteit. De resultaten van deze studies werden thematisch geanalyseerd en drie perspectieven op hoop werden gevonden: 1) een realistisch perspectief – hoop als een verwachting die waarheidsgetrouw moet zijn, en zorgverleners richten zich op het aanpassen van hoop op de waarheid, 2) functioneel perspectief – hoop als coping mechanisme die patiënten moet helpen, en zorgverleners richten zich op het voeden van hoop, en 3) narratief perspectief – hoop als zingeving die waardevol voor patiënten moet zijn, en zorgverleners richten zich op het interpreteren van hoop. De bevindingen suggereren dat zorgverleners – om communicatie met patiënten te verbeteren – met alle drie perspectieven op hoop moeten kunnen werken.

Hoofdstuk 3 heeft als doel om inzicht te geven in palliatieve zorgverleners’ impliciete interpretaties van hoop. Metaforen van hoop werden geanalyseerd, welke Canadese en Nederlandse palliatieve zorgverleners spontaan gebruikten tijdens interviews. De vieren zestig zorgverleners waren arts, verpleegkundige, geestelijk verzorger, of iets anders. Vier metaforen van hoop werden gevonden: 1) houvast, dat veiligheid impliceerde, 2) bron, die kracht impliceerde, 3) melodie, die
harmonie impliceerde, en 4) visie, die een positief perspectief impliceerde. Geïncludeerde artsen gebruikten hoop als houvast, terwijl geestelijk verzorgers hoop als melodie het vaakst gebruikten. De resultaten bieden metaforische taal, die zorgverleners kunnen gebruiken om hoop te bespreken in hun klinische praktijk.


In hoofdstuk 5 wordt de ethiek van hoop nader onderzocht, met als doel om een relationele ethiek van hoop te beschrijven, die gebaseerd is op perspectieven van palliatieve patiënten, hun naasten en hun zorgverleners. Alle interviews met negenentwintig patiënten, negentien naasten en tweeënvijftig zorgverleners werden thematisch geanalyseerd op hoop. Respondenten relateerden hoop aan kracht, en aan het verlies van hoop en lijden. Verschillende zorgverleners probeerden aandacht te geven aan zowel hoop als lijden. De empirische bevindingen zijn aan de ethische concepten empowerment (hoop) en compassie (lijden) gerelateerd. Het hoofdstuk concludeert dat een relationele ethiek van hoop dient te bestaan uit toegewijde zorg, waarin empowerment en compassie hun evenwicht vinden.

Hoofdstuk 6 onderzoekt de bruikbaarheid van een hoop communicatie tool. Op basis van synthese studies over hoop werd een communicatie tool
ontwikkeld en zorgverleners werd gevraagd deze te gebruiken en te evalueren. Veertien zorgverleners evalueerden de tool, onder wie twee geestelijk verzorgers, drie artsen en negen verpleegkundigen. De tool was bruikbaar en hielp zorgverleners om levenseinde thema’s en spiritualiteit met hun palliatieve patiënten te bespreken. Respondenten stelden ook verbeteringen voor, wat leidt tot een herziene hoop communicatie tool, die in toekomstig onderzoek moet worden geëvalueerd.

In hoofdstuk 7 stellen we dat zorgverleners een relationeel-ethische benadering van hoop moeten gebruiken, wat inhoudt dat empowerment en compassie deel zijn van hun relatie met patiënten. Zorgverleners moeten ook hun eigen ervaringen van hoop, hopeloosheid en wanhoop aandacht geven. Een reflectie op de onderzoeksmethode leidt tot de conclusie dat kwalitatieve onderzoekers ook een ethiek van solicitude (toegewijde zorg) nodig hebben.
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For English speakers, see below (fifth paragraph). De volgende mensen wil ik bedanken. Dick Willems en Carlo Leget, jullie theoretische bagage, jullie gedegen en tegelijk pragmatische aanpak en – niet te vergeten – jullie humor heeft vaak het beste in mij naar boven gehaald. Jeannette Pols, wat geweldig om jou als kamergenoot te hebben. Antje Seeber en Sanne van Roosmalen, wat had ik veel aan jullie als collega’s en nu zijn jullie mijn paranimfen.


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PhD Portfolio

Supervisors: prof. dr. Dick Willems (AMC), prof. dr. Carlo Leget (UvH)

About the Author

Erik Olsman (1980) graduated cum laude in Theology. He worked as a junior researcher at a lectorate of religious studies, and as a free lance non-denominational chaplain in psychiatry. His area of interest is meaningful communication in tragic situations, which includes themes such as ethics, spirituality, suffering and tragedy.

PhD Training

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</tr>
<tr>
<td>Oral Presentation on Perspective of Healthcare Professionals on Hope of Palliative Care Patients, 2nd Dutch Conference on Practical Philosophy</td>
<td>2010</td>
<td>0.5</td>
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<tr>
<td>Oral Presentation Dynamiek van Hoop in Palliatieve Zorg, Nationaal Congres Palliatieve Zorg</td>
<td>2010</td>
<td>0.5</td>
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<td>(Inter)national conferences</td>
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<tr>
<td>European Association of Palliative Care, Lleida, Spain</td>
<td>2014</td>
<td>0.75</td>
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<td>Advances in Qualitative Methods, Edmonton, Alberta, Canada</td>
<td>2013</td>
<td>0.75</td>
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<td>Narrative Care, University Twente, Enschede, NL</td>
<td>2013</td>
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<tr>
<td>European Association of Palliative Care, Trondheim, Norway</td>
<td>2012</td>
<td>0.75</td>
</tr>
<tr>
<td>European Association of Palliative Care, Lisbon, Portugal</td>
<td>2011</td>
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<tr>
<td>Existential Issues in Cancer: Who Cares?, VU, Amsterdam, NL</td>
<td>2011</td>
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<tr>
<td>2nd Dutch Conference on Practical Philosophy, Groningen, NL</td>
<td>2010</td>
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<tr>
<td>Other</td>
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<tr>
<td>Journal Clubs: Philosophy of Care (AMC), Ethics of Care (UvH)</td>
<td>'10-'14</td>
<td>4.0</td>
</tr>
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</table>
### Teaching

| Tutoring, Practica Ethiek, 15 groepen, +/− 14 BA studenten geneeskunde per groep | Year | ECTS |
| Lecture and interactive learning, Differentiatie Palliatieve Zorg, +/− 12 MA studenten geneeskunde (AMC) | 2014 | 0.5 |
| Tutoring, Intervisie Ethiek, 4 groepen, +/− zes huisartsen in opleiding per groep (AMC) | 2014 | 0.5 |
| Lecture and interactive learning, Hoop in Palliatieve Zorg, Chirurgie, ongeveer 10 verpleegkundigen (AMC) | 2014 | 0.2 |
| Lecture, Werken met Hoop bij Ernstige Progressieve Aandoeningen, Congres Tijd v Palliatieve Zorg, +/− 100 artsen, verpleegkundigen | 2013 | 0.5 |
| Lecture, Religion and Sexuality, Openingslezing Uva Pride serie over religie en gender, +/− 30 studenten/wetenschappers | 2013 | 0.5 |
| Lecture and interactive learning, Cultuur en Gezondheid: ethische diversiteit, +/− 8 BA studenten geneeskunde (AMC) | 2012 | 0.5 |
| Tutoring, Keuzevak Ethiek en recht: paper begeleiding, zes BA studenten geneeskunde of rechten (AMC) | 2012 | 1.0 |
| Lecture, Medische Ethiek, +/− 40 AIOS huisartsgeneeskunde MD (AMC) | 2012 | 0.5 |
| Lecture, Ada & Eva, Bijspijkerdagen. Recente ontwikkelingen in theologie en religiestudies, +/− 15 geesteswetenschappers | 2012 | 0.5 |
| Lecture, Hoop in Palliatieve Fase, Symposium Ethiek en Kanker, IKC, +/− 60 artsen, verpleegkundigen, geestelijk verzorgers) | 2012 | 0.5 |
| Lecture and interactive learning, Is There Hope at the End of Life?, Universität Dortmund, BA students philosophy, social work | 2012 | 0.5 |
| Lecture and interactive learning, Hoop, Seminar Palliatieve Zorg voor Gevorderden, IKC, +/− 70 artsen, verpleegkundigen | 2011 | 0.5 |

### Parameters of Esteem

#### Grants
- Stichting Sormani Fonds (Sormani Foundation). Research Canada 2013
- ZonMw. Ethical Dilemmas in Mental Healthcare for Asylum Seekers (with others) 2013
- Expertisecentrum NCL, Bartimeus. Research on Stories around NCL 2013
Publications

Peer reviewed
- Olsman E, Willems D and Leget C. Solicitude: balancing compassion and empowerment in a relational ethics of hope. An empirical–ethical study in palliative care. Med Health Care Philos 2015 (this thesis; a modified version was accepted for publication).
- Olsman E, Leget C and Willems D. Healthcare professionals’ evaluations of the feasibility of a hope communication tool in palliative care: a pilot study. Accepted by Prog Palliat Care 2015 (this thesis; a modified version was accepted for publication).
- Olsman E, Leget C, Duggleby W and Willems D. A singing choir: understanding the dynamics of hope, hopelessness and despair in palliative care patients. A longitudinal qualitative study. Accepted by Palliat Support Care 2014 (this thesis).

Other