Hope in palliative care: A longitudinal qualitative study

Olsman, Erik

Link to publication

Citation for published version (APA):

General rights
It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations
If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: http://uba.uva.nl/en/contact, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.
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

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)
   \[ n = 3676 \text{ (total)} \]

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).
<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>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>
<td>+ Claims to study behavior, but does not; however does not affect part on hope</td>
</tr>
<tr>
<td>Baile et al (22) a</td>
<td>To examine the attitudes and practices of oncologists in disclosure of unfavorable medical information to cancer patients</td>
<td>Surv</td>
<td>Oncol, N=167</td>
<td>Hosp</td>
<td>Ca</td>
<td>Various</td>
<td>+ Questionnaire distributed on a congress; no despiration of response rate</td>
</tr>
<tr>
<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>
</tr>
<tr>
<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>
<td>Interv</td>
<td>Nurs, N=18</td>
<td>Hosp</td>
<td>Ca, Var</td>
<td>Iran</td>
<td>+ Poor description of characteristics sample</td>
</tr>
<tr>
<td>Boyd et al (10)</td>
<td>To assess the feasibility of implementing advance care planning in UK primary care</td>
<td>Interv</td>
<td>GP, Nurs, (N=28)</td>
<td>Commun</td>
<td>Ca</td>
<td>UK</td>
<td>+ Poor description of reflexivity and influence of research team on findings</td>
</tr>
<tr>
<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>
</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>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>
<td>Interv</td>
<td>Phys, Nurs, N=27</td>
<td>Hosp</td>
<td>Ca</td>
<td>Netherlands</td>
<td>+ X</td>
</tr>
<tr>
<td>Carter et al (26) a</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, N=317</td>
<td>Var</td>
<td>MND, MS</td>
<td>New Zealand</td>
<td>+ X</td>
</tr>
<tr>
<td>Clayton et al (27) b</td>
<td>To examine the views of palliative care patients, caregivers and palliative care professionals on hope, future and coping</td>
<td>Interv</td>
<td>Var, N=22</td>
<td>Var</td>
<td>Ca</td>
<td>Australia</td>
<td>+ Poor description of theoretical orientation researchers and data collection procedure</td>
</tr>
<tr>
<td>Cutcliffe (28)</td>
<td>To describe how nurses inspire and instil hope in terminally ill HIV patients</td>
<td>Interv</td>
<td>Nurs, N=?</td>
<td>Hosp</td>
<td>HIV</td>
<td>UK</td>
<td>- Poor/no description of participant selection, data collection, respondents, and data analysis</td>
</tr>
<tr>
<td>Delvecchio Good et al (29) a</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, N=51</td>
<td>Hosp</td>
<td>Ca</td>
<td>USA</td>
<td>- Poor/no description of reflexivity and influence of research tema on findings, participant selection, and data analysis</td>
</tr>
<tr>
<td>References</td>
<td>Objective</td>
<td>Methods</td>
<td>Participants</td>
<td>Work Setting</td>
<td>Patients</td>
<td>Country</td>
<td>Q Risk of Bias</td>
</tr>
<tr>
<td>------------</td>
<td>-----------</td>
<td>---------</td>
<td>--------------</td>
<td>--------------</td>
<td>----------</td>
<td>---------</td>
<td>---------------</td>
</tr>
<tr>
<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</td>
<td>Home Care</td>
<td>Ca</td>
<td>Canada</td>
</tr>
<tr>
<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>
<td>Surv</td>
<td>Var, N=140</td>
<td>Hospit</td>
<td>Ca</td>
<td>USA</td>
<td>+ X</td>
</tr>
<tr>
<td>Fenwick et al. (32)</td>
<td>To explore end-of-life experience perceptions and occurrences with care providers</td>
<td>Mixed</td>
<td>Var, N=38</td>
<td>Hospic, Nurs</td>
<td>PC</td>
<td>UK</td>
<td>– Aim and sample size suggest qualitative approach; presentation of results in discussion section</td>
</tr>
<tr>
<td>Gordon &amp; Daugherty (33) a</td>
<td>To get a better understanding of how oncologists perceive their role as communicators of prognosis</td>
<td>F Group, Interv</td>
<td>Oncol, fellows, N=20</td>
<td>Hospit</td>
<td>Ca</td>
<td>USA</td>
<td>+ Poor description of data collection procedure and 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>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>
</tr>
<tr>
<td>Hirai et al.</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, Ca</td>
<td>Japan</td>
<td>+ Aim may suggest quantitative approach</td>
<td></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>Kiener et al.</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, Ca</td>
<td>Austria</td>
<td>+ Low response rate (23%) but non-response analysis done</td>
<td></td>
</tr>
<tr>
<td>Mahlungulu &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, Group</td>
<td>Nurs, N=40</td>
<td>Hospic, 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 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</td>
<td>Med stud, N=49</td>
<td>Hospic PC</td>
<td>USA</td>
<td>+ X</td>
<td></td>
</tr>
<tr>
<td>McCahill et al. (40)</td>
<td>To evaluate current practices and attitudes regarding palliative surgery</td>
<td>Surv N=419</td>
<td>Surg, Hospit Ca, Var</td>
<td>USA, various</td>
<td>+ Low response rate (24%) and limited non-response rate done</td>
<td></td>
<td></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 N=32</td>
<td>Phys, Hospit Var</td>
<td>USA</td>
<td>+ Presentation results (table) suggests quantitative approach; poor description of data analysis</td>
<td></td>
<td></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 Hospit 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>
</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 Hospit Ca</td>
<td>Hong Kong</td>
<td>+ Poor description of data collection procedure</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 N=19</td>
<td>Chapl, Hospic PC</td>
<td>UK</td>
<td>+ Poor description of reflexivity and influence of research team on findings</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</td>
<td>USA</td>
<td>+ Poor description of reflexivity and influence of research team on findings</td>
<td></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 Risk of Bias</th>
</tr>
</thead>
<tbody>
<tr>
<td>Owen (46) a</td>
<td>To develop a beginning understanding of the meaning of hope for cancer patients by focusing on clinical nurses specialists' vivid descriptions of hopeful patients</td>
<td>Interv</td>
<td>Nurs, N=6</td>
<td>Hosp</td>
<td>Ca</td>
<td>USA c</td>
<td>+ Small sample</td>
</tr>
<tr>
<td>Panq (47)</td>
<td>To examine how nurses in mainland China perceive and carry out their responsibilities to do with safeguarding patients’ best interests when there is a question of disclosing information to vulnerable patients (aim of the article's empirical part)</td>
<td>Mixed</td>
<td>Nurs, N=105</td>
<td>Unspec</td>
<td>PC</td>
<td>China</td>
<td>– Poor description of quantitative methodology, results and qualitative data analysis</td>
</tr>
<tr>
<td>Perakyla (48) b</td>
<td>To study the social meanings of death in hospital</td>
<td>Ethno</td>
<td>Hosp wards</td>
<td>Hosp</td>
<td>PC</td>
<td>Finland</td>
<td>+ Poor description of data analysis</td>
</tr>
<tr>
<td>Pfeifer et al. (12) b</td>
<td>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</td>
<td>Interv</td>
<td>Phys, Med, N=43</td>
<td>Med Center</td>
<td>PC</td>
<td>USA</td>
<td>– Poor description of research team and reflexivity and study design</td>
</tr>
<tr>
<td>References</td>
<td>Objective</td>
<td>Methods</td>
<td>Participants</td>
<td>Work Setting</td>
<td>Patients</td>
<td>Country</td>
<td>Q Risk of Bias</td>
</tr>
<tr>
<td>------------------------------------</td>
<td>---------------------------------------------------------------------------</td>
<td>---------</td>
<td>--------------</td>
<td>--------------</td>
<td>-----------</td>
<td>------------</td>
<td>----------------</td>
</tr>
<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, Ca</td>
<td>COPD</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</td>
<td>Nurs, N=6</td>
<td>Hosp, Ca</td>
<td></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, Var</td>
<td></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, Ca</td>
<td></td>
<td>Netherlands</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</th>
<th>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, Ca</td>
<td>N= &gt;600</td>
<td>Sweden</td>
<td>+</td>
<td>No general research question; poor description of influence of researchers on findings</td>
<td></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 2. Healthcare Professionals' Perspectives on Hope of Palliative Care Patients

<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

34
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
The authors thank Wendy Duggleby, Sanne van Roosmalen, Antje Seeber, Marianne Snijdewind, Annemarie van Hout, Jeannette Pols, Ellen Smets and Kris Vissers for their helpful comments on earlier drafts of this article.

References


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


