Hope in palliative care: A longitudinal qualitative study
Olsman, Erik

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 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>
<thead>
<tr>
<th>Table 1. Characteristics of Participants (n=29)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>N</td>
</tr>
<tr>
<td>Age</td>
</tr>
<tr>
<td>Gender</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Disease</td>
</tr>
<tr>
<td>Incurable cancer</td>
</tr>
<tr>
<td>COPD, GOLD 3 or 4</td>
</tr>
<tr>
<td>HF, NYHA III or IV</td>
</tr>
<tr>
<td>Education</td>
</tr>
<tr>
<td>High</td>
</tr>
<tr>
<td>Middle</td>
</tr>
<tr>
<td>Low</td>
</tr>
<tr>
<td>Spirituality</td>
</tr>
<tr>
<td>Not spiritual</td>
</tr>
<tr>
<td>Monotheistic</td>
</tr>
<tr>
<td>Spiritual / other</td>
</tr>
</tbody>
</table>

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).

<table>
<thead>
<tr>
<th>Table 2. Characteristics of Hope, Hopelessness and Despair</th>
</tr>
</thead>
<tbody>
<tr>
<td>DESPAIR</td>
</tr>
<tr>
<td>HOPE</td>
</tr>
</tbody>
</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
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?
<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 in good way</td>
<td>after loss of wife</td>
<td>hope for future gain</td>
<td>hope for future gain</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></td>
<td></td>
<td>hopeless: past loss</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></td>
<td></td>
<td>despair: possible future – loss</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>despair: possible future loss</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></td>
<td>future loss</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>future loss</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>Time</th>
<th>Female, 51, cancer</th>
<th>Female, 91, COPD</th>
<th>Male, 76, HF</th>
<th>Female, 60, COPD</th>
<th>Male, 42, cancer</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<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>
<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>
</tr>
<tr>
<td>0.5 year</td>
<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>
<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>
</tr>
<tr>
<td>1 year</td>
<td>HOPE: for better quality of life, even when it means that I will die earlier</td>
<td>HOPE: that I may last for a while, like it is now</td>
<td>HOPE: You improve and then you start to get hope; Hope that my present life will continue</td>
<td>[only two interviews]</td>
<td>(only two interviews)</td>
</tr>
</tbody>
</table>

The most dominant voice (hope, hopelessness or despair) was described as first one.