Hope in palliative care: A longitudinal qualitative study

Olsman, Erik

Citation for published version (APA):
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 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>
</tr>
</thead>
<tbody>
<tr>
<td>What are your first ideas when you hear the word &quot;hope&quot;?</td>
</tr>
<tr>
<td>Do you hope for something? Do you look forward to something? If so, for / to what?</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>
</tr>
</tbody>
</table>

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

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

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

If you used more than one question, please answer the following questions for each separate question.
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).