Hope in palliative care: A longitudinal qualitative study

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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.
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>Metaphor</th>
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*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 the 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.
References


12. Southall D. The patient’s use of metaphor within a palliative care setting:


37. Duggleby W, Hicks D, Nekolaichuk C, et al. Hope, older adults, and chronic...


