Hope in palliative care: A longitudinal qualitative study

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Chapter 7: General Discussion

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

Toward a Relational Approach

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

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

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

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

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

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

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

Figure 1. The Ethics of Hope

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

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

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

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

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

The lung physician could also ask Ms Johnson: “Your husband says that he hopes to visit your son abroad. How do you see that?” Or: “Is that also your hope or do you hope for something else?” These questions may be helpful in stimulating dialogue between patients and their family members and they provide insight into differences and similarities between (hope of) patients and family members. It requires from healthcare professionals that
they are able to communicate with palliative care patients and patients’ family members (24).

Reflection on Research Methodology

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

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

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

Interviewer: “It also sounds as if you’re saying: ‘I know that it is not possible [to have a lung transplantation]. (...) And at the same time: ‘In some way I do hope that’...'”

Patient: “Yes. Exactly. Because then I sometimes think to myself: how would be something like that [possibilities for lung transplantation] in
the AMC hospital *[hospital where interviewer works]*, how do they deal with people over there?"

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

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

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

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

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

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

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