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Witnesses of hope in times of despair: chaplains in palliative care. A qualitative study

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ABSTRACT



Hope is an important topic in spiritual care in palliative care but the experiences of chaplains with hope have hardly been explored. The objective of this study was to explore Dutch chaplains' experiences with hope in palliative care. Semi-structured interviews were conducted, which were thematically analyzed. The 10 chaplains had a variety of ordinations: Muslim, Protestant, Roman Catholic, Humanistic, or otherwise. Participants spoke about changes in patients' hope, often implying despair and surrender, in which patients' self-reflection was pivotal. Participants felt witnesses of hope, not by offering hope, but by acknowledging patients' hope and despair while being with their patients. They criticized other professionals who, not bearing witness to these experiences, tried to offer hope to patients. We conclude that chaplains may become witnesses of hope in times of despair, which includes the (ideological) critical function of spiritual care.


KEYWORDS

Chaplaincy; despair; hope; palliative; spiritual

Introduction

Palliative care aims at improving the quality of life of patients with a life-threatening illness and their families and consists of physical, psychosocial and spiritual care (WHO, 2019). However, spiritual care is the least developed dimension of palliative care and univocal understanding of spiritual care in palliative care, including its central concepts, is lacking (Selman, Young, Vermandere, Stirling, & Leget, 2014; Steinhauser et al., 2017). Therefore, it is helpful to clarify one concept: hope. It is important to study hope because it has been described as an important topic in spirituality in the last phase of life (Alidina & Tettero, 2010; Kylmä, Duggleby, Cooper, & Molander, 2009; Sinclair, Pereira, & Raffin, 2006). Hope is also significant within this context because it helps patients with a life-threatening disease to cope with their situation and motivates their caregivers to provide good palliative care (Duggleby & Wright, 2007; Kylmä et al., 2009; Lin & Bauer-Wu, 2003; National Coalition for Hospice & Palliative Care, 2018, p. 89). A review study on hope in palliative care found a distinction between “living with hope”

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and “hoping for something” and this study concluded that research on hope in palliative care from perspectives of others than patients was scant (Kylmä et al., 2009).

A review study, providing insight into healthcare professionals’ perspectives on the hope of palliative care patients, found a realistic, functional and narrative perspective on hope (Olsman, Leget, Onwuteaka-Philipsen, & Willems, 2014). Only one of the included studies in this review study had exclusively focused on chaplains, who, all but one, were Christian. This study found four organic moments in the relationship with the patient—evocative, accompanying, comforting and hopeful presence—concluding that being with the other could foster hope (Nolan, 2011). A more recent study on metaphors of hope suggested that, compared to other included healthcare professionals, chaplains most often approached hope as part of their relationship with patients (Olsman, Duggleby, et al., 2014). Still, these relational dimensions of hope have hardly been scrutinized from the perspective of chaplains.

In the researchers’ country, and in several other so-called Western countries, spiritual care is characterized by spiritual diversity. Not only the number of chaplains with another ordination than a Christian one is increasing (Ganzevoort, Ajouaou, van der Braak, de Jongh, & Minnema, 2014; Gilliat-Ray, Ali, & Pattison, 2013), but also patients and family members may draw from a variety of spiritual sources (Heelas & Woodhead, 2005). In addition, the interactions between chaplains and care receivers are frequently characterized by spiritual diversity (Liefbroer, Olsman, Ganzevoort, & van Etten-Jamaludin, 2017). In the present study, this diversity will be acknowledged by approaching chaplains with a variety of ordinations. The objective of this study was to explore Dutch chaplains’ experiences with hope in palliative care.

Method

Semi-structured interviews were conducted with chaplains working in palliative care, which were part of a larger research project (Olsman, Willems, & Leget, 2016; Olsman, Duggleby, et al., 2014). The interviews with the chaplains had not yet been reported as a group. The researchers worked from a hermeneutic perspective (Ricoeur, 1994), which includes several perspectives: they were interested in the *lived experiences* of hope of participants (phenomenology), how participants gave *meaning* to these experiences (language philosophies), and how *power* interfered with these experiences and meanings (critical theories) (Liamputtong & Ezzy, 2005).

Participants

Eligible participants were recruited via networks of chaplains, such as e-mail list servers and newsletters. Purposive and snowball sampling were used, aiming at variation in ordination, age and gender. In accordance with Dutch law on research involving human subjects, this study did not have to be reviewed by an ethics committee, which was confirmed by the Medical Review Ethics Committee of the Academic Medical Center, University of Amsterdam. Interested participants received information by e-mail, including information about their rights. When they gave consent to participate, an appointment for an interview was made. In the Netherlands, health care professionals only have to give oral consent. Two eligible participants did not participate because of a lack of time.

Procedure

Interviews started with the open question to tell about hope in palliative care. The interviewer did not define hope and related themes prior to the interviews because he was interested in participants' experiences and definitions. Participants' stories were explored. The researcher had developed and pilot tested an interview guide (see [Supplementary File 1](#)), which was, however, hardly used because most of the time of the interview was used to explore the themes participants addressed during the interview.

The interviews took place at participants' homes or workplace, they were audio-recorded and lasted approximately one hour each. Nobody else was present during the interviews. Differences in intonation, like emphases or silences, were also transcribed. The researcher wrote field notes, for example on first thoughts, interview setting, and non-verbal communication, which contributed to reflexivity during the research process (Fossey, Harvey, McDermott, & Davidson, 2002; Malterud, 2001). When participants preferred it, they received the transcribed interviews. Apart from comments such as "Nice to read it," no comments were made.

Analysis

The main researcher thematically analyzed all interviews by hand and by making use of MAXqda software (Tong, Sainsbury, & Craig, 2007). One other researcher thematically analyzed two interviews, and a third researcher thematically analyzed two other interviews. They wrote down in the margins of the transcript these themes and gave a description of the themes. They discussed the results of their thematic analyses. This led to two major themes and three minor themes. For examples of the minor themes, see [Supplementary File 2](#). Saturation on the two major themes was reached when the interviews with eight participants had been analyzed. This meant that the analysis of these themes led to conceptually similar findings. After that, two more chaplains were interviewed. For an example of the code tree in relation to the major themes, see [Supplementary File 3](#).

The researchers did member checking by email, with seven of the ten interviewees, by sending them the findings (Popay, Rogers, & Williams, 1998). Of the ten interviewees, two did not respond to our emails and one was no longer working in palliative care. This confirmed the two major findings. Then, we approached the Dutch national network of chaplains in palliative care, of whom seven responded. These seven had a variety of ordinations and, apart from some minor suggestions, the results presented in this paper were confirmed during this member checking.

Results

Participants

The 10 chaplains (mean age: 50.4; range: 29–64; mean years of experience: 17; range: 5–36) were interviewed once. They had the following ordinations: two Muslims, two Protestants, three Roman Catholics, two Humanistic, and one with no ordination. Five worked in hospitals and five in other settings, including hospice, nursing home and

community settings. They had experience in working with various patients, like patients with incurable cancer, severe heart failure, severe chronic obstructive pulmonary disease, a life-threatening neurological disease, or vulnerable, geriatric patients.

Findings

The analyses of the interviews led to two major themes: (1) changes in patients' hope: despair and surrender, and (2) chaplains as witnesses of hope.

Changes in patients' hope: despair and surrender

Participants spoke about changes in patients' hope, especially the changing content or object of hope, which related to changes in patients' situations. A hospital chaplain stated that over time, the content of hope changed, "What always strikes me, when you guide someone for a longer period, in palliative care, that hope comes back after a while. The content of hope changes" (2, Roman Catholic) [numbers refer to participant numbers]. Another chaplain worked in geriatric and hospice care and used the metaphor of hope as a road. She illustrated that when patients moved on, their road (and hope) changed, "It's like you're moving on a road of hope because the situation changes. At a certain moment, you can also talk about the funeral or how someone hopes to be remembered. These are of course all kind of aspects of hope" (4, Humanistic).

Participants often referred to despair as an element of these changes, and hope and despair were both characterized by uncertainty about the future. A hospital chaplain, for example, explained that the uncertainty of hope may refer to something positive, "The word 'hope' is like, 'Actually, I don't expect it, but you never know, and when I'm lucky, I'll get it'" (6, Roman Catholic). The negative side of uncertainty was addressed as well, which related to despair, "They [very old patients] hope it won't take too long and when they are about to die, that they won't suffer (...). There are quite a few of them desperately, really desperately waiting for death. But death keeps them waiting and waiting. That can be horrible" (10, Protestant).

Participants not only spoke about despair as an element of changes but often referred to surrender as an element of these changes in hope as well. A chaplain who worked in various health care settings, for example, related surrender and hope to (trust) in God. Having explained how patients hoped for things, like improvement of their physical condition, he suggested that hope could also change into a hope that reflected surrender, "Surrender is the ultimate word. When you've reached total surrender, then there is some hope in that too (...). It's the hope that things will turn out well, related to God. (...) So, hope doesn't always mean that you need to reach something" (8, Muslim). A chaplain who worked in nursing homes referred to the relationship between hope and trust in the following way, "Hope and trust relate to each other (...). I think trust is a bit stronger term. Let's put it this way, the hope has something to do with 'not being sure' like, 'Let's hope it turns out this or that way.' With trust, it's already a bit more surrender" (10, Protestant).

In these changes in hope, patients' self-reflection often was pivotal. A hospital chaplain, for example, explained how one of her patients with cancer was very desperate but

started reflecting, “She was very desperate and for that very reason she was reflecting on things that were essential for her. Because of that, she was able to find hope again” (9, Muslim). Another chaplain, who worked in various health care settings, used the metaphor of a new life area that was dawning, which could be one of the results of self-reflection, “People start to think in a new way about themselves and their situation, then a sort of new hope arises because people learn to deal with themselves in a new way (...). This hope implies that a new life area is dawning” (5, Humanistic).

Witnesses of hope

Participants were hesitant to “give” or “offer” hope to patients. One reason was that chaplains did not want to create dependency by offering hope, “When you want to offer hope, you create a dependency. [The risk is:] when you’re no longer there, then the hope will disappear or not come true. (...) This is dangerous, in my view. I am not a hope giver” (8, Muslim). Participants rather bore witness to patients’ experiences of hope and despair, which in itself could be hopeful as well. One chaplain expressed how she wanted to be with her patients and acknowledge their experiences, “Sometimes they need to let go of many things. But then they’re so autonomous again, in seeing new chances and new hopes. That’s really special to witness” (1, Protestant). This “being with” patients was mentioned by others as well, “The hope, for me, it was in being with him and supporting him, that’s also what he told me because I’ve been able to mean a lot for him” (4, Humanistic).

In order to be witnesses of hope, they had to bear witness to their own hope, and in particular their own despair, mortality, and powerlessness. A male chaplain who worked in nursing homes addressed his own experiences of despair and fear and added, “I experience powerlessness. It’s so hard to get people out of that (...). I would love to say, ‘Well, you don’t need to worry.’ But I don’t do that because I want to acknowledge their fear as well and not deny that” (10, Protestant). Something similar was addressed by a chaplain who suggested that chaplains can transform themselves when they bear witness to these experiences, “I think it’s paramount, to bear witness to those experiences [own experiences of despair] (...). I think these are experiences through which you [as chaplain] can transform yourself and develop further” (4, Humanistic).

Participants criticized colleagues with other professional backgrounds than spiritual care, when they, instead of bearing witness to these experiences, tried to offer hope and solutions to patients. One female chaplain, who mainly worked in community settings, argued that hospital physicians may offer hope to avoid thoughts about death and dying, “I think that medical specialists need to deal with their own death. That’s difficult for them (...). That relates to the issue of hope, you know. What I just talked about, that many doctors may offer hope ‘Then I don’t have to think about death’” (7, no ordination). A male hospital chaplain stated that chaplains could not “offer” anything, like addressed in the following way, “Chaplains are the least as possible focused on finding solutions. (...) They rather ask ‘What does this mean to you?’ and ‘How do you deal with that?’ and ‘What’s your path in this?’ So, bearing witness to the difficult situation. (...) Doctors offer many solutions, ‘Well, we’re gonna do this and that. It’s terrible, but we’re gonna try it.’ But someone [like a chaplain] who can only say, ‘This

must be a disaster!’ I don’t think that’s often said to patients, but then patients feel recognized tremendously” (6, Roman Catholic).

Discussion

This study explored Dutch chaplains’ experiences with hope in palliative care. The findings suggest that working with hope in palliative care from the perspective of spiritual care includes working with hope-related themes, such as despair and surrender. The findings also indicate that hope, from this perspective, is not something that can be given or offered to patients, but something that may arise in the relationship between chaplain and patient. This can only happen when caregivers recognize their own experiences of despair and other tough experiences, which helps them to recognize those experiences in their patients as well.

The findings offer a conceptual clarification of hope in palliative care. The partial overlap between hope and related concepts, such as despair and surrender, was found in other studies as well (Kylmä, 2005; Nunn, 2005; Olsman, Leget, Duggleby, & Willems, 2015; Sachs, Kolva, Pessin, Rosenfeld, & Breitbart, 2013). Furthermore, the findings add to the understanding of hope, described in an integrative review (Kylmä et al., 2009). The findings presented here highlight that the being of hope, which implies the presence of confirmative relationships (Kylmä et al., 2009), is characterized by trust, and relates to surrendering. The findings also suggest that “hoping for something,” referring to the action of hope including its future orientedness (Kylmä et al., 2009), is characterized by uncertainty about the future, in which despair may (start to) play a role as well. The clinical relevance of this finding is that it helps health care professionals to concentrate not only on the positive dimensions of hope but also on its unfavorable dimensions, associated with uncertainty and/or despair.

From the perspective of the interviewees, changes in hope occurred when patients’ situation changed. This is in line with a longitudinal qualitative study, in which patients with different life-threatening diseases were interviewed. This study found that the nature of included patients’ hope, despair and hopelessness changed when their physical condition changed (Olsman, Leget, Duggleby, et al., 2015). Interestingly, the chaplains in the current study described these changes in hope in cyclical terms, indicating that hope, despair, and surrender may pop up and disappear and pop up again, etc. Stated differently, participants did not describe, for example, surrender as an end-stage of patients’ processes of coping with dying. This finding is in line with the critique of stage models, expressed in, for example, theory on coping with loss (Corr, 1993), but also in practical theology (Day, 2002; Luther, 1992). This finding and these theories suggest that chaplains should not direct their patients toward an end-stage of a spiritual process, like surrender. They should rather try to facilitate dialogue on what is of ultimate meaning for the patient at this particular moment. This includes the facilitation of the patient’s internal dialogue (Hermans & Hermans-Konopka, 2012) while bearing witness to patients’ experiences of hope and despair.

One may ask how the findings presented in this paper relate to hope in other health care contexts. In a synthesis of review studies on hope in health care settings, hope was conceptualized in three ways: (1) an expectation, which was an appraisal of a future

outcome, (2) resilience, which refers to the endurance of adversity, and (3) a desire, which was the expression of meaning (Olsman, 2020). Chaplains in the study presented here rather seemed to emphasize the experiential dimensions of hope (and despair), which reflect hope as desire. One may subsequently hypothesize that hope as desire is more common in palliative care than other health care settings. The synthesis of review studies suggests otherwise though. Based on the 71 included review studies, this synthesis study found that hope in palliative care was conceptualized in all three ways, whereas, for example, hope in mental healthcare was often conceptualized as resilience. More importantly, this study found that the ethics of hope was often described within the context of palliative care, in which especially physicians struggled with wanting to be honest and truthful on the one hand, while wanting to maintain patients' hope, because of its positive functions, on the other. The former reflects hope as (un)realistic expectation and the latter hope as resilience (Olsman, 2020). Interviewed chaplains in this paper rather emphasized the experiential dimensions of hope, which reflects the third conceptualization of hope: hope as desire. If indeed chaplains, more than other professionals, like physicians, tend to conceptualize hope as desire, this concept deserves scrutiny in clinical practice and future studies because it may elucidate the role and work of chaplains.

This study sheds light on the perspectives of chaplains on their relationship with patients in the last phase of life. The findings, in addition, are in line with the finding of Nolan (2011) that being with the other could, in itself, be hopeful. They are also in line with the study of Olsman, Duggleby, et al. (2014), who found that especially chaplains may approach hope as part of their relationship with patients. The innovation of the current study is that it brings to the fore the concept of witness. A witness is someone who is not a distanced observer but rather someone who is involved in the situation (Olsman, Nieuwenhuijse, & Willems, 2019). This involvement means that chaplains try to be open for patients' stories of hope and despair (Lester, 1995), and it requires their compassion to acknowledge the suffering, including despair, hopelessness, and powerlessness. In addition, compassion and hope have been related to each other in several studies (Coulehan, 2013; Halifax, 2012; Sinclair et al., 2016; Taylor & Walker, 2012). Hence, describing the chaplain as a witness connects several central concepts in spiritual care in palliative care. Such a witness may become a witness of hope, as our study suggests, when (s)he is compassionate and open to stories of hope and despair.

The role of the witness also serves as a heuristic concept because a witness has the courage to offer critique. Chaplains in this study criticized other health care providers who did not bear witness to their own despair, powerlessness and mortality, hindering them to become—to phrase it in the words of Nouwen (1979)—a source of healing for others. This calls attention not only to the significance of self-care for chaplains, and their wounds (Nouwen, 1979) but also to the ideological-critical function of the witness. This function entails that the witness is willing to tell about what she witnessed, even when this opposes the dominant ideas, for instance during a team discussion in a hospital. Pre-eminently, chaplains have the tools to raise these critical questions because most of them were educated in the humanities, where the critique of inequality and power differences has been raised frequently. This critique has also been associated with hope, like the (neo) Marxist hope, which was the utopic hope for a just and equal

society (Bloch, 1968). Freire's (1994) hope, in addition, was the hope for social justice and education in underdeveloped countries, and in the work of Moltmann (2005), the socialist and Christian hope are combined.

At the same time, chaplains can only be critical, when they are seen not only as outsiders but also as members of a team, who commit themselves to an organization. This is underlined by a recent systematic review of spiritual care in palliative care in Europe, which suggested that the visibility of spirituality and spiritual care in healthcare was reinforced when chaplains participated in existing organizational structures (Gijsberts, Liefbroer, Otten, & Olsman, 2019). Again, reference can be made to the concept of witness, being someone who is involved in the scene and cannot (only) be a critical observer at a safe distance. Rather, the witness is sensitive for whose voice is marginalized within a given context, which may be the voice of a desperate sufferer. A theory of hope and/or theology of hope, in that case, means that the chaplain witnesses the suffering of this person and is willing to critique others, who inadvertently or purposively deny the existence of despair, mortality or powerlessness of their patients. The witness becomes a witness of hope when she, through her compassionate being and doing, recognizes the suffering of others and shows that this world could be otherwise, like the theories of hope suggest.

The chaplains in this study did not emphasize their ordination in relation to hope (and despair). For example, the religious chaplains did not describe themselves as witnesses of God or Allah, though they may perceive themselves in that way. The chaplains, who had different ordinations, rather shared an emphasis on the experiences of their patients, including their patients' experiences of hope and despair. This finding could be interpreted against the background of Western-Europe, where institutionalized religion increasingly gave way to (subjective) spirituality (Heelas & Woodhead, 2005; Luther, 1992; Sengers, 2006). This change is also reflected in the fact that chaplains in several Western healthcare settings often work with patients with a variety of spiritual backgrounds (Liefbroer et al., 2017), requiring that their first focus is not on providing spiritual care that is faith specific, but rather on spiritual care that is generic in order to include the experiences of patients with different spiritual backgrounds. In addition, a recent survey of 208 spiritual caregivers suggested that their authorization by an institution seldom relates to how they perceive spiritual and religious diversity in their work (Liefbroer & Berghuijs, 2019). Based on these studies and the findings presented here, it seems that only after having paid attention to the experiences of hope and despair of their patients, chaplains may (sometimes) bring up their own ideas and experiences of hope and despair, which may relate to their ordination and spiritual tradition. In so doing, their own spirituality has become an option among other spiritualities, like those of their patients. It reflects what the philosopher Charles Taylor referred to as one definition of secularity, "a move from a society where belief in one God is unchallenged and indeed, unproblematic, to one in which it is understood to be one option among others" (Taylor, 2007, p. 3).

A strength of this study is that chaplains with different ordinations were included, offering possibilities to define spiritual care in a spiritually diverse landscape (Ganzevoort et al., 2014; Gilliat-Ray et al., 2013; Heelas & Woodhead, 2005; Liefbroer et al., 2017). However, future studies should include the experiences of spiritual

caregivers with Jewish, Buddhist or Hinduist ordinations, who are hardly present in this country. Another limitation of this study was that the multidisciplinary nature of palliative care (WHO, 2019) has hardly been highlighted. Consequently, future studies are necessary to explore how spiritual care, including working with hope, is provided by other caregivers or interprofessionally (Lennon-Dearing, Florence, Halvorson, & Pollard, 2012; Puchalski, Kheirbek, Doucette, Martin, & Yang, 2013). Also, the sample size may be a limitation of this study. Though saturation was reached on the themes presented in this paper, and though they were confirmed during member checking, further research is required to confirm or critique the findings. Last but not least, future studies should scrutinize how patients and patients' family members see the role of the chaplain.

In conclusion, this study provided insight into hope and related concepts, helping to understand how chaplains work with hope in palliative care. Hope belongs to the heart of their work, not as an object that could be offered or given to patients, but rather as something that may arise when they acknowledge patients' despair and other tough experiences. It requires from them that they bear witness to their own hope, despair, powerlessness, and mortality and that they support colleagues to do the same. How caregivers may do so, deserves a study by itself. The role of witness serves as a heuristic concept that helps to understand what chaplains do when providing spiritual care in the last phase of life. The witness is compassionately involved in the situation, which may lead to the witness becoming a witness of hope. The concept of "witness of hope" not only embodies several concepts of spiritual care in palliative care, like hope, despair and compassion but also helps to recognize the (ideological) critical function of spiritual care. The latter implies that chaplains stand up against persons or systems that exclude the tough experiences of patients, testifying that this world could be otherwise. The hope of the author is that the results of this study will support readers to be or to become witnesses of hope when caring for patients with a life-threatening disease and patients' family members.

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