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Health professionals' dealing with hope in palliative patients with cancer, an explorative qualitative research

Corine Nierop-van Baalen[1,2] | Mieke Grypdonck[2] | Ann van Hecke[2] | Sofie Verhaeghe[2]

[1]Haaglanden Medical Centre, The Hague, The Netherlands

[2]Department of Public Health, University Hospital, Ghent University, Ghent, Belgium

Correspondence
Corine Nierop-van Baalen, Department of Public Health, University Hospital, Ghent University, De Pintelaan 185, 5K3, B-9000 Ghent, Belgium.
Email: corine.nierop@casema.nl

Abstract

Hope is important for individuals with cancer in palliative care. Health professionals' perspective on hope affects the communication with palliative patients. The aim of this study was to explore how Dutch health professionals deal with palliative patients with cancer who hope for prolongation of life. Focus group discussions (FGD) were conducted. An interpretive description approach was used to understand the interpretation of and reaction to hopefulness in palliative patients with cancer by health professionals. Three FGDs were held, each consisting of five to ten health professionals working with palliative patients recruited in a general Dutch hospital and homecare organisation. The ways in which the participating health professionals interpret hope in palliative individuals with cancer and their behaviour towards these hopeful palliative patients are shaped by their reliance on their own normative ideas. Patients' hopefulness generally violates these norms and is, therefore, considered a problem that requires intervention. Hope that does not correspond with the medical facts is experienced as problematic by Dutch health professionals who therefore believe they should intervene and do something about it. Health professionals are challenged to face and address patients' and families' perceptions of hope, especially when those perceptions might differ from their own as professionals.

KEYWORDS
cancer, health professionals, hope, oncology, palliative care, qualitative research

1 | INTRODUCTION

Hope is important for individuals with cancer in all illness phases, also or perhaps especially for individuals in a palliative phase. Several studies (Acquaye, Lin, Vera-Bolanos, Gilbert, & Armstrong, 2016; Davis et al., 2017; Eliott & Olver, 2002, 2009; Kylmä, Duggleby, Cooper, & Molander, 2009; Loneus, Widdershove, & Proot, 2003; Seibaek, Delmar, & Hounsgaard, 2016; Seibaek, Petersen, Blaakaer, & Hounsgaard, 2012) describe the importance and sometimes the need of hope for palliative patients. The meaning of hope was addressed in the study of Benzein, Norberg, and Saveman (2001) and Nierop-van Baalen, Grypdonck, Van Hecke, and Verhaeghe (2016). Nierop-van Baalen et al. (2016) conclude that there are three reasons why patients hope: because they cannot forsake it, because they greatly benefit from it in terms of reduced anxiety and depression, and because it helps them to cope with the situation.

Quantitative research describes the positive effects of hope, for instance on patients' mood (Benzein & Berg, 2005; Duggal, Sacks-Zimmerman, & Liberta, 2016; Kavradim, Ozer, & Bozcuk, 2013; Rustoen, Cooper, & Miaskowski, 2011; Vellone, Rega, Galetti, & Cohen, 2006). It has long been established that hope is an important factor that improves the quality of life of patients with a short life expectancy (<3 months) (Conrad, 1985; Macleod & Carter, 1999; Owen, 1989; Stoner & Keampfer, 1985). In a systematic review of

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hope and cancer covering studies from 2005 to 2009, Olver (2012) found that hope and optimism negatively correlate with depression and anxiety. Davis et al. (2017) also described in their empirical study that hope inversely correlated with anxiety and depression.

Although hope has been studied extensively, it is still not clear what exactly is meant by hope given that many definitions and concepts of the term exist (Eliott & Olver, 2009). Eliott and Olver (2002) searched for a generally accepted definition of hope, which they did not find. They were searching for a definition of hope within an empirical/realistic paradigm, which presupposes that reality exists independently from the observer, to be discovered by an objective researcher, unfettered by culturally or historically situated subjectivity. One frequently used definition in the literature is given by Dufault and Martocchio (1985), who describe hope as "a multi-dimensional dynamic life force characterised by a confident yet uncertain expectation of achieving a future good, which, to the hoping person, is realistically possible and personally significant." Among the many definitions of hope, two concepts of hope in palliative care can be distinguished, as described in an integrative review by Kylmä et al. (2009): living with hope as a mental state, originating in the feeling that life can take a more favourable turn, without it being linked to a specific object; and hoping for something as the wish to see something happening that is uncertain, but still can be achieved or that at least is not impossible. However, in daily speech and even in scientific literature the two concepts are not always distinguished and not easily distinguishable. Both of them are often covered by the same term: hope.

The way in which hope is treated in the professional oncology literature differs from country to country. In the North American and Asian oncology literature, hope is seen as a positive force (Herth, 1990; Herth & Cutcliff, 2002; Itzhaky & Lipschitz-Elhawi, 2004; Mok, Lau, Lam, Chan, & Chan, 2010). In these countries, health professionals are taught to encourage hope (Buckley & Herth, 2004; Duggleby, Degner, et al., 2007; Herth, 1990, 1995). Much of the West European oncology literature, however, describes hope, which transcends medical expectations as a problem, and doctors are urged to help patients come to a more realistic assessment of their situation (Dupuis, 1998; Kersten, Cameron, & Oldenburg, 2012; The, Hak, Koëter, & Van der Wal, 2000; Van Laarhoven, Leget, & Van der Graaf, 2011).

Health professionals' perspective on hope in palliative care affects the communication with these patients (Olsman, Leget, Onwuteaka-Philipsen, & Willems, 2014; Werner & Steihaug, 2017). Health professionals are able to enhance, maintain or destroy hope in patients through their attitudes, behaviour and ways of communicating (Mok et al., 2010). At present, there is a discrepancy between the need for support of individuals with advanced cancer and the ways in which Dutch health professionals often deal with the hope of these patients.

Research has brought to light that health professionals experience difficulties in dealing with hope in palliative patients (Clayton, Butow, Arnold, & Tattersall, 2005; De Haes & Teunissen, 2005; Eliott & Olver, 2009; Hancock et al., 2007; Shinall, Stahl, & Bibler, 2018). However, little is known about the origin and nature of these difficulties. Such information is essential for improving both patients' and professionals' experiences and professionals' behaviour.

The aim of the study, therefore, was to explore how Dutch health professionals deal with palliative patients with cancer who hope for prolongation of life.

2 | METHODS

For this study, an interpretive description approach was used. Data were collected by focus group discussions. Interpretive description (Hunt, 2009) is a qualitative research methodology aligned with a constructivist and naturalistic orientation to inquiry. This approach was chosen because it generates knowledge in a form that is clinically relevant and applicable, by theoretically orienting the data collection, analysis and interpretation process towards the inductive articulation of thematic patterns that reflect commonalities and diversities within populations (Thorne, Gregory Hislop, Kuo, & Armstrong, 2006; Thorne, Reimer Kirkham, & MacDonald-Emes, 1997) .

Focus group discussions were chosen because they yield data through the interaction of individuals and have a synergistic nature (Cyr, 2016). This means firstly that the data collected by the group are greater than the sum of its parts and secondly that rich experiential information is generated. This gives focus groups a comparative advantage over other data collection methods. In addition, the participants were used to discuss their feelings and difficulties regarding these patients with colleagues. Focus group discussions offer insight into how moral discourses become visible within this interactional setting, and how participants position themselves in relation to those discourses (Murdoch, Poland, & Salter, 2010). When the themes include moral practices, interactive focus group discussions can reduce socially desirable bias more than is the case in one-to-one interviews, because participants know each other and each other's way of working, and they are discussing themes among themselves instead of with the researcher.

2.1 | Recruitment and data collection

Health professionals who daily work with palliative patients were asked, by mail, to participate in focus group discussions about the ways in which they deal with hopeful palliative patients, what they experience as going well and what they experience as difficult. The palliative phase of the illness was understood to have the following characteristics: health professionals knew that no curative options were left and this fact was clearly discussed with the patients. The recruitment procedure was designed to collect experiences from different disciplines. Therefore, we conducted three focus groups, a multidisciplinary group, a nursing group and a group of community nurses, each consisting of five to ten health professionals. These professionals were recruited at a general Dutch hospital with a specialised oncology department and in a large home care organisation. The choice of the organisations was made by convenience.

TABLE 1 Participants' characteristics

Focus group	*N*	Profession	Sex	Age	Number of years of work experience
Multidisciplinary	8	Internist, chaplains (2), psychologist, nurses (2), clinical nurse specialist, ward doctor in training	Four men and four women	Average 40 years Range 26–56 years	Average 13 years Range 1–26 years
Hospital nurses	5	Nurses from different wards, oncology, pulmonary disease, outpatient clinic and clinical nurse specialist (2)	Five women	Average 48 years Range 40–57 years	Average 17 years Range 9–30 years
Community nurses	9	Community nurses	Nine women	Average 40 years Range 21–53 years	Average 14 years Range 1–34 years

Participants had to meet two criteria: they were Dutch-speaking, and they were daily working with palliative cancer patients. The participants from the general hospital received an open invitation by mail and could register for an arranged day/time (self-selecting sample). They had 2 weeks to respond to the invitation. The mail explained that the data were collected for research purposes and how the data would be handled. Health professionals involved with the hospital multidisciplinary palliative care consultation group were invited and the team leaders of three wards were asked to send the email to the nursing team. In total, 76 hospital health professionals received the invitation. Of these, 25 health professionals replied to the open invitation. Two health professionals were unable to come on the arranged day, and one nurse was ill on the day of the focus group discussion. Twenty-two health professionals finally took part in one of the three focus group discussions. Their characteristics are given in Table 1. Nurses could choose to enrol in either a multidisciplinary group or a group of nurses. The community nurses (*n* = 9) were also invited by mail; they preferred to have their focus group discussion as part of a regular knowledge exchange meeting. They all agreed to participate knowing that the focus group discussions were held for research purposes and informed about how the data would be analysed. The three focus groups discussions took place in January 2012.

According to Dutch law, this study did not require approval from the Medical Ethics Committee. The participants were free to register and participate in the study. Their willingness to participate in the focus group discussions was considered to constitute informed consent.

All focus group discussions were conducted by the same researcher (the first author); a clinical nurse specialist in oncology acted as a second moderator in the multidisciplinary and hospital nurses groups. Each focus group discussion lasted 90 min. The focus group discussions were not structured. A topic guide, see Table 2, was used to check whether all relevant topics were discussed; if a topic was not discussed, the moderator introduced the topic. All focus group discussions started with the same question: What are difficult situations for you in dealing with hopeful palliative care patients? The primary role of the moderator was to ask further questions if necessary. We did not explain beforehand what we meant with the concept hope or the meaning of hope as we wanted to uncover what the health professional themselves understood by hopeful patients.

TABLE 2 Topic guide

Areas to explore within the context of dealing with hopeful palliative patients
1. Perceptions and beliefs about hope For example, what are their opinions about hope in palliative care?
2. Situations that healthcare professionals experience as difficult For example, what are the difficult situations and how they experience and deal with these?
3. Situations in dealing with hopeful patients which go well For example, why they experience these situations as good and how do they feel about this?
4. Hope interventions For example, which interventions do health professionals use en when do they use them
5. Factors that influence or might influence their hope intervention For example, what are the underlying processes or thought about this?

All the interviews were audio-recorded, fully transcribed and anonymised to guarantee the privacy of the participants. To the second researcher, only the pseudonyms and their professions were known. Each participant's contribution was highlighted in a separate colour (Blomberg, Widmark, Temestedt, Törnberg, & Tishelman, 2011). In this way, it was easy to follow the different opinions of each participant in the interview.

2.2 | Data analysis

After each interview, the whole interview was read to see whether adaptations were needed to the topic guide. It was not necessary to make adjustments to the topic guide. Every focus group interview was first read in full to acquire an overall picture of what had been discussed, and subsequently read through again to grasp in more detail what had been said about hope and hopeful patients. The meaning participants give to the word hope was derived from their discourse. In the analysis process, we have carefully checked and analysed what meaning the participants had in mind each time they used the term hope. The interviews were analysed employing constant comparative analysis as adapted by Boeije (2002, 2010). Each passage in the interviews was assigned a code which represents its content and the initial coding was fully inductive. After this open coding, we integrated the codes around themes through axial coding. Emerging themes were identified and developed by studying the transcripts and the codes and by considering possible meanings and the way they are connected and distinguished. Finally, by selective coding, the themes were verified, further refined and developed.

2.3 | Rigour

Although this is an explorative study, several measures were taken to increase rigour. To address trustworthiness, we used Guba's and Lincoln's (1989) criteria: credibility, dependability, confirmability, transferability and authenticity, which was added later (Guba & Lincoln, 1994 in: Cope 2014). Concerning credibility, the analyses were facilitated by the first author's familiarity with the field. However, as this large involvement can also lead to distortions, it was corrected by triangulation to enhance dependability and confirmability. Two researchers [MG, CN] read all the focus group interviews and analysed the interviews separately. After they had read each other's analysis notes, they commented on them, and discussed each other's interpretations. The findings from the analysis were critically examined regarding their consistency and congruencies. The first researcher subsequently consulted the data again to verify the interpretations against the data. Authenticity also was enhanced by researcher triangulation and by taking into account the social context in which the participants work. The participants knew and respected each other and each other's work and felt safe to speak freely.

The resulting themes are presented below and are illustrated through quotes from the participants, using only the focus group in which they participated, to ensure anonymity and confidentiality.

3 | RESULTS

Health professionals' experiences, attitudes and behaviours are shaped by normative ideas about how the final phase of life should proceed. Patients' hopefulness generally violates these norms and is, therefore, considered a problem that requires intervention. The framework that follows consists of eight normative concepts that health professionals tend to ascribe to regarding palliative patients. They have been derived from the focus group data; that is, they were not mentioned explicitly but come to light when interpretatively reading the discourse. The health professionals cherish one or more of the following interrelated ideas. Each of these is entertained by a majority of the participants.

3.1 | The truth must be told

Participants are of the opinion that the truth needs to be told, because they do not wish to tell their patients any lies. They also want to counter the hope for unachievable goals in order to save their patients from having to face the consequences of decisions taken on the basis of patients' wrong assessment of their situation (e.g. the decision to buy a house).

> I would like a bit more openness, or honesty [about themselves]. I don't want to give them any false hope.
> (focus group of nurses)

Participants also insist that the prognosis be clear to the patients because they want to enable their patients and the latter's loved ones to prepare for the unavoidable end and take leave properly. Participants see patients' hope for unachievable goals as an information problem (the patient in question has not understood the information properly). Telling the truth about the prognosis once more will counter false hope in patients or so the participants believe. Participants do not distinguish between hope and denial. Denial is seen as something negative, as something that needs to be corrected, and participants assume that denial is based on a lack of understanding of the information. Therefore, they believe that what they interpret as denial can be corrected by informing the patient properly.

> Hope is also very useful, certainly when they're still being treated. On the other hand, however, if it becomes an ongoing denial of reality, you need to do something about it as a caregiver.
> (multidisciplinary focus group)

3.2 | Death must be faced

As described above, participants and especially nurses, including community nurses, want patients and their loved ones to face approaching death, so that they will be able to take leave of each other properly. If they are able to do so, this means they have accepted that the end is near, and this is what they feel should happen.

> [...] you wish they would accept the fact. It's no use, and instead of wasting time on denying the fact, they would do better to spend the time they still have on taking proper leave (multidisciplinary focus group)

According to the participants, ideally patients should give up hope for prolongation of life and instead hope for a good death. Hope for prolongation of life begs for intervention or for asking others to intervene, for example by arranging an appointment with the physician to discuss the prognosis once again. Participants consider it important that patients face the unavoidable fact that death is near.

3.3 | Needless suffering should be avoided

By preparing patients for their approaching death, participants also want to avoid a situation in which patients make choices that would prevent this resignation, such as opting for experimental treatment, causing them to suffer needlessly, that is without any medical benefit.

> These people travel to Germany for useless treatment while they're critically ill and spend the time they still have on driving back and forth to Germany, vomiting. It's terrible. (multidisciplinary focus group)

3.4 | To die fighting should be prevented

Health professionals try to prevent patients from "going down fighting" because they are aware that friends and family of the patient may feel discomfort about this after the death of the patient. This is not in line with the values of the health professionals themselves (especially in the case of two participants, both of them physicians). Health professionals sometimes find themselves in a situation in which their "professional values" (i.e. when there are available treatments, you need to offer them) clash with their personal values (i.e. patients and family members should be able to accept death and take proper leave).

> Well, the main value I adhere to is, of course, that I want to give someone the opportunity to take proper leave and, yes, to spend time on this. Perhaps they'll be able to accept the fact that they're dying and their friends and family may then come to terms with it. Yes, that's the value I adhere to. But that doesn't happen if such patients continually want new chemotherapy, or another scan. (multidisciplinary focus group)

These physicians say that patients often want to negotiate about further treatment, especially when the physician has already advised them to refrain from undergoing it. They feel that patients want to stay in the game as it were and grasp every opportunity for further treatment. These physicians, however, know that treatment can also actually reduce patients' quality of life and sometimes even shorten the period of time they have left. They sometimes feel in a bind of the patient's making as some patients leave their attending physician to be treated somewhere else.

> There are always doctors who go on at all cost. If you can't find them here, you can find them in Belgium or Germany, or wherever. (multidisciplinary focus group)

A few participants – a psychologist and chaplains – feel less need to distance themselves from their patients' thoughts. They do not have to take decisions regarding treatment, of course. However, they also set clear boundaries.

> In that sense we, as psychologists or chaplains, have a freer role. I think it's essential that, in that capacity, we stay close to the patients' inner life. That is to say up to a certain point, because this should not turn into an unhealthy situation. (multidisciplinary focus group)

3.5 | Significant others must be able to go on with their lives

Health professionals are of the opinion that when the dying process goes well, the mourning process of the surviving friends and family will also go better. Therefore, it is better for everybody concerned that the patient accepts death. In their opinion, keeping up hope implies a greater risk of problematic mourning. For all health professionals, a good death implies that no avoidable problems are being created for the survivors. They are the ones being left behind; how they will get on with their lives is a matter of primary concern.

> Yes, that's a difficult situation, for the friends and family, for the patients themselves, and also for the caregiver, when people continue to fight and keep denying that they are dying. That's… years later, the survivors may still have problems to come to terms with that. (multidisciplinary focus group)

Health professionals, and especially nurses and community nurses, want to play a more active role in guiding patients and their family and friends towards the end. They like the idea of having contributed to a good death. Nurses take the initiative to talk with the patient about his or her approaching death based on their own assumptions about what is good for patients in general; that is, the actions of the health professionals are driven by their own assumptions about what a good death consists of, and consequently, they do not engage in an open dialogue with the patient.

3.6 | The family and the patient must be united until the end

Health professionals attach great importance to the patient's relationship with family and friends. To the participating health professionals, a good relationship with family and friends means that all the people concerned think and feel the same about important matters, such as whether or not treatment should be continued. When patients and family and friends think differently about the latter, health professionals experience this as a problem that requires intervention. Furthermore, health professionals place family and friends in a strong position; the focus of guidance is on family and friends. As they are, after all, the ones who need to get on with their lives.

> It's also such a pity to see that they can't complete the process in a good way together. That's such a pity. You see it happening and you can't do anything about it. (nurses focus group)

Although several health professionals did point to the positive effects of hope – hope can be seen as a positive force, and can give energy – they emphasise the negative effects, such as loneliness, which especially occurs in situations in which the patients and their family and friends think differently about the continuation of treatment.

3.7 | Unrealistic goals must be exchanged for achievable goals

If patients' behaviour does not correspond with the normative ideas of professionals about a good death, the latter feel the need to intervene. They try to exchange unrealistic hope for what they regard as more realistic hope. In doing so, health professionals tend to focus on the object of the hope of patients, and much less on hope itself. First of all, they weigh the object of this hope to see whether it is realistic, and if in their view it is not, they intervene, for example, by asking family and friends to move up family weekends or parties. Another intervention consists of providing the patient once more with prognostic information. The citation below shows the shared opinion of the different health professions and the way they interact with each other.

> They [the patients] live in such a different world. Say, for example, a holiday. You might say, all right, let them pay for a trip they will never make. Or buy a new house. But that has all kinds of consequences. Such a holiday is relatively harmless, so why not just let them book it? (participant 1). But that goes against your own values. If you know better, I think it goes too far (participant 2). If they ask me, I tell them to book it a bit earlier (participant 3). Yes, why wait when you're still in a relatively good condition? (participant 4). Yes, in that way you don't discourage them, you just ask them to be more realistic (participant 5). (multidisciplinary focus group)

3.8 | Unrealistic hope requires intervention, unless…

Sometimes health professionals do not contradict the hope of patients, mainly to maintain a good care relationship or limit negative reactions of patients. They often do so after having experienced negative reactions from patients indicating serious damage to the relationship. However, health professionals are only inclined to do so if it does not jeopardise their own norms. Nurses and community nurses for instance are willing to go along with the hope of their patients as long as they do not need to belie their own nature and when their responses do not create too much ambivalence.

> I don't want to have to entirely fool myself. That's where I draw the line. If I don't feel good about it, something will have to be done about it. In such a case I let them know that I don't go along with their hope, because I don't want to come into conflict with myself. (focus group of community nurses)

Some health professionals know from experience that trying to influence patients' hope does not help.

> Hope seems to be some sort of strategy, and you usually have little influence over it. (multidisciplinary focus group)

Although they indicate that it is no use trying to adjust this hope, they do not intend this to mean that this hope *should* not be adjusted, demonstrating that they have no positive appreciation of hope.

> And when you have seen this frequently, you eventually begin to think it's no use going against it, and to take away this hope and make them face reality […] So I sometimes go along with it although not always. (focus group of community nurses)

One participant, however, saw the hope of patients also as a way of coping, as a wish that does not need to be corrected. According to this participant, hope enables a patient to deal with a difficult situation, and everyone goes through this hope process at their own pace.

> What I do often see is that this hope takes other forms. Initially, they hope to make it until next year, and then they hope they will at least survive until their grandchild gets born, and then they hope to make it until spring. People do adjust their hope, but perhaps not always as fast as we would like them to. But eventually many people do (multidisciplinary focus group)

The same participant also pointed to the function of hope.

> It's often very ambivalent. They want to accept the situation, but they're not yet ready to accept everything. They still need a reason to get up in the morning, to enjoy the visits of family and friends. I think everyone goes through the process of acceptance at their own pace. (multidisciplinary focus group)

4 | DISCUSSION

4.1 | Main results

This study has attempted to explore and understand the difficulties experienced by health professionals in dealing with hope in palliative patients. The results show that the health professionals' conduct is based on normative ideas. These normative ideas seem to be judged as valid for all patients and have the following in common: the concept of a good death: a death that takes leave-taking from beloved ones into account, so they can go on with their lives. This requires acceptation of and resignation to the truth on the part of the patient, expressed in stopping treatment when the doctor proposes it. Consequently, when a patient does not want to stop the treatment a problematic discrepancy arises between what is and what ought to be. This discrepancy requires interventions by health professionals, even when there are circumstances that make it unlikely for the intervention to be successful. Health professionals believe that it is their professional role to guide patients to a good death. As a result, their care is not attuned to the needs of the patients as much as it could be.

The study gives insight into the perspectives from which different health professionals deal with hopeful palliative care patients in their daily practice. The focus group discussions were led by the same researcher, who was well acquainted with the practice of palliative care. The health professionals felt sufficiently comfortable to speak freely about dealing with these vulnerable patients and what it meant to them. The themes were, therefore, discussed in ample detail, which enhances the validity of the study. This study also has several limitations. First, it is a small-scale study, and therefore, each professional group was represented by only a small number of participants. Second, the sample was self-selecting and only a small percentage of those invited participated. We do not know to what extent the ideas represented in the study are shared by those who did not participate. However, we have noticed that the degree to which the ideas were similar among the participating professionals – a single exception notwithstanding – indicates that the findings are not exceptional.

Despite the small scale of the study, the themes were clearly expressed. Six of the seven themes were cogently presented in all three focus group interviews. Only the theme: “To die fighting should be prevented” was not given much attention in the focus group of community nurses. An explanation for this could be that community nurses work in a different setting, in which most of the patients were not being treated anymore.

As described before, the study is based on a small self-selected convenience sample and its members are not representative of all the different organisations, and not all the opinions and practices were represented. However, this study reveals that the participating health professionals show strong consensus in their normative ideas, and they present these ideas as rooted in their professional norms. Therefore, we believe it is likely that our findings can be transferred to a broad segment of health professionals, at least in the Netherlands.

That health professionals think differently about the meaning of hope than individuals with cancer do has also been discussed in the literature (Nierop-van Baalen et al., 2016; Skevington, Macarthur, & Somerset, 1997). Macleod and Carter (1999) also have shown that health professionals relate hope mainly to a cure or a stable illness, while the literature also describes other dimensions such as social, spiritual and existential dimensions of hope. We carefully examined in the interviews what the professionals referred to when talking about hope. The professionals focused on the (false) hope of their patients and their hope to live longer than medically possible. The professionals did not mention any existential and spiritual dimensions of hope. Other studies (Leung, Silvius, Pimlott, Dalziel, & Drummond, 2009; Nierop-van Baalen et al., 2016; Verhaeghe, van Zuuren, Defloor, Duijstee, & Grypdonck, 2006; Wiles, Cott, & Gibson, 2008) have described that hope and expectations are different constructs. The differentiation between them may help health professionals in communicating about illness-related expectations while maintaining the integrity of patients’ hope. The health professionals, in our study, do not distinguish between hope and expectations.

The participating health professionals give precedence to family and friends’ needs rather than to the patients’ needs, and consequently, the participants give little or no attention to the meaning of the patient’s existential suffering in dealing with a short life expectancy. This may be related to a tendency to avoid difficult conversations with dying patients. It may also be the case that the precedence given to family and friends is caused by the phenomenon of self-comfort in health professionals (Baart, 1996). They badly want to consider the care they give as good and useful and when their care for the individual with cancer does not allow this, they displace this wish on to their care for the patient’s family and friends. Especially when family members share the same values as the health professionals, this form of care is probably easier and a more obvious choice. As a result, health professionals are able to avoid feeling powerless.

The findings of the study show that professionals in the Netherlands deal with hope quite differently from what has been reported in the literature about North American professionals and similarly to what has been reported about West European countries. In West European countries, many professionals feel uneasy when a patient expresses hope that goes (far) beyond the communicated prognosis. In other professional cultures, hope is seen as an asset that should be fostered or sustained (Nierop-van Baalen et al., 2016). The present results also differ from the (North American) study of Herth (2001) about cherishing hope and hope interventions, and from the results of the Canadian study of Duggleby and Wright (2007); they studied, with a mixed method design and thematic analysis, the perceptions of 113 professional palliative caregivers attending a palliative care conference. These caregivers valued hope as a positive power and described hope in palliative patients as hope for peace, for a better future, spirituality (finding meaning and purpose), and making a difference. Hope helped them to foster positive relationships and communication with palliative patients and families, to provide comfort, and to offer hope.

The health professionals who participated in this study want to see the hope for a cure evolve into hope for a proper death. The resistance to “unrealistic” hope has been part of the palliative discourse for a long time (Kübler-Ross, 1969). However, in the countries under discussion understanding among health professionals is changing (Cannaerts, Dierckx de Casterlé, & Grypdonck, 2004; Loneus et al., 2003; Van Laarhoven et al., 2011). At the same time, a recent study (Oosterhuis-Vlug, Francke, Pasman, & Onwuteaka-philipsen, 2017) shows that health professionals still think that physicians could support patients’ transition from “hope for a cure” to “hope for a good death.” A qualitative Australian study (Johnson, Butow, Kerridge, & Tattersall, 2018) about autonomy and advanced care planning found that medical norms and professional boundaries surrounding “good deaths” have a greater influence on care than patient preferences. To the participants (consultant oncologists and palliative medicine doctors), there was a broad consensus that helping patients to achieve a "good death" was a critical part of duty of care. Consequently, patients whose preferences were seen to go against these norms, were often perceived as being "difficult," or even "irrational." However, in their study on the meaning of hope for people with cancer in the palliative phase, Nierop-van Baalen et al., 2016) found that physicians who constantly repeat the "truth" hinder the coping of individuals with cancer.

In the literature, little is known about the differences between health professionals when it comes to interpreting the expression of hope of palliative individuals with cancer as a sign of not knowing, not understanding or not accepting the situation. Whether the differences in practices situated in different countries are due to cultural differences has never been investigated. Anthropologic research is needed to fill these gaps.

An explanation as to why the Dutch health professionals persist in repeating and enforcing the truth to hopeful palliative individuals with cancer has been provided by The et al. (2000). This observational ethnographic study has attracted extraordinary attention and has been incorporated into education programmes. Profound regret features large in their description of the factors that result in "false optimism about recovery" in individuals with small cell lung cancer. The et al. suggested that this false optimism can be attributed to the unclear prognostic information given by the doctors which hindered individuals with cancer in making well-informed treatment decisions. Relatives expressed regret about this. It should be noted, however, that the bereaved relatives were interviewed within 3 months after the death of their loved ones. Moreover, the reproachful manner in which some social scientists (Dupuis, 1998; The et al. 2000) speak about physicians who are not clear enough about the truth enforce these ideas and this behaviour. However, those studies that attempt to really understand the patients' perspective (Benzein et al., 2001; Loneus et al., 2003; Nierop-van Baalen et al., 2016) suggest that the most helpful approach would be not to explain once more what the medical problem is, but to confirm the patient in his hope, as hope, and distinguish it from rendering expectations, that is I hope with you.

4.2 | Implications

4.2.1 | Implications for practice and policy

It is important for health professionals to realise that hope can be looked at from different perspectives and that the patients' perspective may be different from their own. They should be aware of the risk of imposing their own norms onto the individuals with cancer. Currently, scant attention is given to hope as such and the meaning of this hope for the individual with cancer. If health professionals are able to see that a patient's hope may be connected to his or her deepest desire, instead of an actual expectation that the object of hope will be achieved, they may feel less need to intervene to correct the hope. It might help to enter into a dialogue on hope with the individual with cancer rather than give advice to the patient. More insight into the meaning of hope from the patients' perspective may contribute to this. A better understanding of the process of hope and more nuanced ideas about denial will help health professionals to attune their care. Professional education could also prepare professionals to deal with hope in a more nuanced way. Nurses can learn to work contextually rather than base their work on principles as such.

4.2.2 | Implications for further research

More research is necessary to examine to what extent these findings can be completed or refined. Our analysis has shown that some health professionals have opinions about dealing with hopeful palliative patients that differ from those of their peers within the same team. Therefore, a study of the differences among health professionals, within their practice setting, may throw light on the processes and factors underlying these differences. It is also important to explore the positive and negative effects of hope on patients to better distinguish when the negative effects overshadow the positive effects. This study has demonstrated that there are differences between countries in dealing with hopeful palliative individuals with cancer. These differences within can be further investigated. It is also interesting to study why and how these differences persist. The respondents' framework was that of Western patients, that is in part explicable by the location of the participating healthcare agencies, which are in an area with a relatively low concentration of people from a non-Western background. Studying perceptions of health professionals who regularly give care to patients with a non-Western origin of health professionals which such an origin may complete the picture.

5 | CONCLUSION

Our analysis of three focus group discussions reveals the use of normative concepts by health professionals in dealing with hopeful palliative cancer patients. Health professionals mainly focus on the object of hope and feel the need to intervene when they think that this object is unrealistic. This study shows that in those cases they would rather repeat the true prognostic information to enable the individual with cancer to face and prepare for death than think about and proceed from the meaning that hope has for these individuals. Health professionals could be more aware of the possibility that facing impending death, and hoping for better times can go hand in hand.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

ORCID

Corine Nierop-van Baalen http://orcid.org/0000-0002-9454-3844

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