The Journals of Gerontology, Series B: Psychological Sciences and Social Sciences, 2025, **80(9)**, gbaf107
https://doi.org/10.1093/geronb/gbaf107
Advance access publication 10 June 2025
Special Issue: Palliative and End-of-Life Care in Aging: Research Article

GSA
GERONTOLOGICAL SOCIETY OF AMERICA®
OXFORD

Communicating palliative hope in late-stage dementia: thematic analysis of hope work in care plan meetings with nursing home residents' families

Jenny Paananen, PhD[1,2,*] and **Aija Logren, DSocSci[3,4]**

[1]Faculty of Social Sciences, University of Helsinki, Helsinki, Finland
[2]Department of Nursing Science, University of Turku, Turku, Finland
[3]Faculty of Social Sciences, University of Helsinki, Helsinki, Finland
[4]Department of Social Sciences, Faculty of Social Sciences and Business Studies, University of Eastern Finland, Kuopio, Finland

*Address correspondence to: Jenny Paananen, PhD. Email: jenny.paananen@utu.fi

Decision Editor: Kate de Medeiros, PhD, FGSA (Social Sciences Section)

Abstract

Objectives: The study analyzes how nursing home professionals communicate palliative hope in care plan meetings with family members of residents with late-stage dementia.

Methods: Eleven care plan meetings between nursing home professionals and residents' family members at Finnish nursing homes were video- or audio-recorded and analyzed with inductive thematic analysis. Data were collected in 2020–2021 using convenience sampling: All nursing homes within one region in Finland were contacted with the help of the local Memory Association, and all volunteers were accepted as study participants.

Results: We identified three main themes of palliative hope in late-stage dementia: 1) Life is good and there is still time, 2) Agency and identity are not lost, and 3) Death will be good and professional support is available.

Discussion: As overarching goals of hope work, we identified acceptance and appreciation. Nursing home professionals have an important role in constructing and maintaining hope and thus supporting families. They can remind families that residents are not lost as people, they are in good care, and that there are still time and opportunities for a good life, meaningful moments, and connection, which families can appreciate despite the progressive illness. By highlighting the possibility of a peaceful death for the resident and willingness to support families in the end-of-life phase, nursing home professionals can help families accept the inevitable. Combined with good-quality palliative care, palliative hope work can support families' social relationships and foster meaningful experiences at the end-of-life stage.

Keywords: end-of-life, interaction, long-term care, memory disorder, palliative care

Fostering hope is essential in health care, as having hope is known to reduce stress, increase resilience and quality of life, as well as nurture personal relationships (Guedes et al., 2021; Velić et al., 2023). However, while hope can be broadly defined as "expectation for a positive future," it is important to acknowledge that the concept of a *positive future* is highly individual and situational. Non-terminally ill patients relate hope to getting better, being cured, and surviving, whereas terminally ill patients find hope in living day to day, feeling better, and in relief of pain (Duggleby, 2001). For patients whose terminal illness has approached the stage where they need palliative care, hope gives meaning to the remaining lifetime and strength to endure suffering. Near the end of life, hope can be recalibrated again: Patients close to dying can find hope in acceptance and inner peace as well as in achieving a good death and in ideas of eternal rest or afterlife (Duggleby, 2001; Hall, 1990; Kirby et al., 2021). Similarly, the hope of patients' family members can—and perhaps should—change focus along with the illness. It could therefore be argued that the core task of palliative care teams in terms of hope is to facilitate the recalibration process for patients and their families so that their expectations for the future remain positive yet realistic. This work is done in talk, so in order to understand how the task can be accomplished, it is necessary to study hope in social interaction, not just people's experiences or perceptions about it. We analyze how professionals talk about patients' future and what kind of resources they utilize in order to invoke or maintain hopefulness. Descriptions of how hope is fostered provide evidence, which can be utilized in the development of care practices and support measures for families, and in training health care professionals.

This study illustrates how hope is understood and communicated with family members in the context of late-stage dementia. Dying of dementia is, in many ways, different from dying of other causes, such as cancer, which has been the focus of studies on end-of-life interaction. First, dementia is a

---

Received: December 27 2024; Editorial Decision Date: April 7 2025.

terminal illness with no known cure, which means that patients do not transition to palliative care after there is no more response to curative treatment but rather as the need for symptom control increases (Merel et al., 2014). Second, life expectancy with dementia varies considerably: Depending on the diagnosis and individual factors, on average, patients survive 2–10 years with the disease, but some people survive more than 20 years (Alzheimer's Society, 2024; Rait et al., 2010). As the deterioration process in dementia is slow and fluctuating, prognosticating death is difficult (van Riet Paap et al., 2015). Third, dementia causes deterioration in cognitive and functional abilities, which in later stages of the disease can pose significant limitations to communication (Kim & Bayles, 2007). Limitations of capacity have an effect on the social relationships of the person as well as decision-making on care measures (Miller et al., 2016). Family members of people with dementia are also known to experience anticipatory grief due to the changes that dementia causes to their loved one's personality, behavior, and functional abilities (Cheung et al., 2018). Hence, we argue, the sources of hope—and despair—are also connected to the particularities of dementia: Its unpredictability, longevity, and debilitating nature may remarkably limit the expectations of a positive future for the patients and their family members.

From a broad perspective, it is known that factors contributing to the hope of patients and those close to them in palliative care settings include getting honest information about the illness, being able to talk about the process of dying, focusing on the present instead of the future, setting attainable goals, and focusing on positive thoughts, memories, and the presence of loved ones (Herth, 1990; Kylmä et al., 2009). Factors that threaten hope include loss of health care personnel's interest, devaluation of personhood, and negative messages (bad news, the use of negatively perceived words) from the health care system (Flemming, 1997; Herth, 1990; Holtslander et al., 2005; Kylmä et al., 2009).

Managing hopes and expectations can be a delicate activity and requires considerate interactional work. However, relatively little is known about how hope is constructed and maintained through *social interaction* (Beach, 2014; Beach & Dozier, 2015; Velić et al., 2023). Beach (2014) argues that hope is an interactional resource to manage uncertainty, and patients might display hope indirectly. In response, professionals manage a patient's hopeful expectations while also maintaining their relationship with the patient. In a study of how practitioners addressed problems with patients' advance care plans, Land et al. (2019) recognized a specific interactional practice: Instead of proposing an alternative plan, the practitioners raised a hypothetical scenario and encouraged the patients themselves to propose a solution they would prefer. Similarly, reviewing how practitioners approach talking about death and other distressing topics, Parry (2024) concluded that they are framed as hypothetical and referred to indirectly, building on what patients themselves have already brought up in the discussion.

Health care practitioners' efforts to manage hopes and expectations through interaction can be viewed as *hope work* (Peräkylä, 1991). In an ethnographic study on leukemia and emergency wards, Peräkylä identified three variants: 1) curative hope work, in which a patient is defined as "getting better," 2) palliative hope work, in which the patient is defined as "feeling better," and 3) work to dismantle hope, in which the patient is seen as being "past recovery" and professionals guide the patient or their family members to let go of curative hope. As our study focuses on nursing home residents with late-stage dementia who are in long-term care, the hope work in our data revolves around the latter two.

Previously, Kirby et al. (2021) studied discursive patterns of hope work by analyzing video-recorded family meetings between palliative care physicians and patients with cancer or motor neuron disease. They found that hope was communicated by highlighting perseverance: Patients were complimented for their coping in relation to equivalent cases, and hope was connected to not giving up. In addition, the uncertainty of the future functioned as a resource of hope. The discourse around the limitations of medical knowledge and avoidance of taboo conversations allowed room for optimism.

Since previous studies have focused on other types of diseases, there is no research on hope work in dementia care. In this study, we address this gap by examining how nursing home professionals communicate palliative hope in care plan meetings with family members of residents with late-stage dementia. We explore what kind of hope work is characteristic in dementia care and how professionals use hope work to support family members. Hence, our goal is to identify the goals of palliative hope work in the context of dementia.

Methods

Data

The data analyzed in this study are confidential and consist of 11 video- or audio-recorded care plan meetings (approximately 10 h) at four Finnish nursing homes in 2020–2021. This kind of data of real encounters enables the analysis of hope work as it unfolds in situ, and thus makes it possible to examine it in its original context, compared to interviews and questionnaires, which would reveal perceptions and experiences of hope work. The data were originally collected for the project Alongside Dementia, which was approved by the Ethics Committee of the University of Turku (decision 47/2019). The goals of the original study were to analyze family members' access to information and participation in decision-making concerning the resident with advanced dementia. This study uses the part of the data (11/16 meetings) for which the participants gave permission to be archived for other studies. The ethical guidelines of the Finnish National Board on Research Integrity (2019) were followed accurately.

The project Alongside Dementia utilized convenience sampling by contacting all nursing homes within a selected region in Finland with the help of the local Memory Association. All units that volunteered were accepted. All nursing home professionals and family members received oral and written information about the study and signed a written consent form. The participation of residents depended on their condition and willingness (as well as the meeting protocol of the nursing home) and required the agreement of their families. All volunteers were accepted as participants, and according to a recommendation of the Ethics Committee, no additional personal information was collected about the participants. All participants were adults; based on the data, some of the family members were in working life (under 65 years of age), while others were retired (65–85 years of age). In the data extracts, the nursing home professionals are referred to by their title and number (for example, Nurse 1), while the residents and family members have been given pseudonyms.

Care plan meetings concern the resident's condition and care, practical matters, and the nursing home's operating principles. The focus of the meetings is to inform family members about the current situation and the near future, but usually, there is also space for the family to share their thoughts and wishes. However, the concept of care plan meetings varies across Finnish nursing homes, and there are no uniform guidelines on how care should be discussed and how different topics should be handled. Some nursing homes arrange care plan meetings yearly, some meet the families only once after the transition, and some do not arrange meetings at all. In these data, 6/11 are first meetings with the family.

Each meeting in our data concerned a different resident with a memory disorder diagnosis and advanced dementia. Only one resident participated in the care plan meeting, whereas the rest of the meetings involved only professionals and family. There were one to two family members and one to three nursing home professionals (e.g., practical nurse, head nurse, manager) at each meeting. The family either had medical power of attorney as accorded in the resident's care will or had agreed to act as contact persons for the resident.

Due to the convenience sampling, an equal representation of different population groups could not be achieved in the study. Based on the data, however, some of the participants spoke Finnish as a second language and can therefore be regarded as representing linguistic minorities. Nevertheless, our dataset is too small in order to analyze whether the family members' age, gender, culture, or ethnic background had an effect on how nursing home professionals communicated hope with them.

Thematic analysis

The data were analyzed using inductive thematic analysis (Braun & Clarke, 2006, 2019). First, we familiarized ourselves with the data. JP read the transcriptions closely and selected passages that seemed to depict hope work for a closer analysis, i.e., all passages where the professionals conveyed positive or optimistic evaluations about the resident's current or future situation or managed family members' expectations about the resident's illness progression and end of life in some way. In the next phase, the video-recorded material was watched and analyzed together in data sessions. In the data sessions, analytical observations were made freely. These observations formed the base for the coding scheme. Then, JP coded all the data systematically using NVivo 14 software. In the first coding phase, JP coded all passages in which some kind of hope work could be identified (N = 48). The passages could consist of one or more turns of talk that formed a continuous narrative, and several codes could be assigned to one passage. Then, JP arranged the coded passages into preliminary themes. In the final phase, JP and AL refined and grouped the codes together and identified the main themes and sub-themes in terms of hope.

Results

We identified three main themes of palliative hope that were communicated in care plan meetings between nursing home staff and family members of residents with late-stage dementia: 1) Life is good and there is still time, 2) agency and identity are not lost, and 3) death will be good and professional support is available (see Figure 1). We analyze the themes in detail in the next three sections and illustrate the interactional hope work through authentic data excerpts.

Life is good and there is still time

In the care plan meetings, nursing home professionals often had to inform families about deterioration in the resident's condition. Some residents had lost the ability to communicate, some had stopped walking, and some had started to have problems swallowing. Yet, however devastating the news was, we found that the professionals found ways to balance it with positive descriptions of the resident's life and situation.

First, the professionals often conveyed that the resident was doing relatively well or better than expected, which in effect invited the family members to appreciate the situation. For example, they could describe the resident's condition as *astonishing* or their medication list as *surprisingly short*. They could also explicitly compare the resident's situation to that of others,

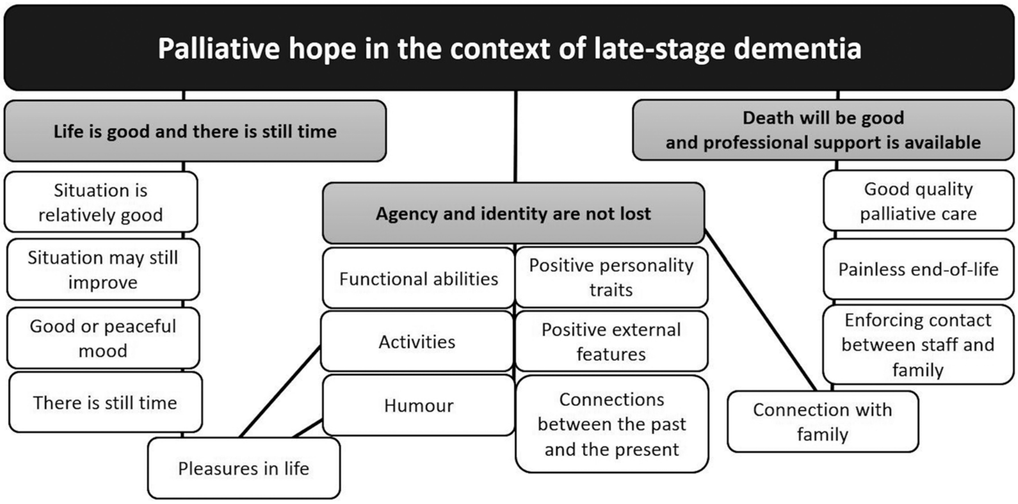

Figure 1. Thematic map on palliative hope work in the context of late-stage dementia.

as in extract 1. Before the extract, the staff told Ada that her spouse Rauno had improved after a recent collapse and could now walk short distances and eat without assistance again. However, despite regaining some functional abilities, Rauno had lost a lot of weight. In the extract, the manager shifts the topic from the alarming news to a positive aspect:

> Extract 1
> Manager: So that's the case, but it's true, Rauno doesn't have a heavy medication load. The kind that many people have when they have all kinds of problems. Sometimes we have people with a really long list of medications, and when we go through the list with the doctor and try to figure out what might not be necessary, there's nothing that we can drop. They have so many medications but with illnesses and other problems that we really can't omit anything (laughs).
> Nurse 1: Yeah.
> Manager: That's really so… I mean Rauno here is really lucky, in my opinion, in not needing so much medication.
> Ada: Yeah. What a life he would have had without Alzheimer's.
> Manager: You can say that again. He would be doing excellently.
> Ada: But it's no use thinking about it, no.
> Manager: No, this is how it is now. You shouldn't think about it too much.
> Participants: Resident Rauno's spouse Ada, nursing home manager, nurses 1 and 2.
> Sub-themes: Situation is relatively good.

In extract 1, the nursing home manager topicalizes Rauno's relatively minor medication needs and tells Ada about other people who have *so many medications* and *all kinds of problems*. After the anecdote, the manager describes Rauno as *really lucky*, which is a notably positive assessment considering that Rauno is in around-the-clock care, approaching his end of life. Ada's response indeed challenges the notion of being lucky: She wonders how life would have been without dementia. After the comment, the manager and Ada work to abandon the line of thought in agreement (*it's no use thinking about it; you shouldn't think about it too much*). Hence, hope is constructed upon being content about how things are *in the given circumstances*, which demand that the circumstances be accepted as they are.

Second, the professionals highlighted a resident's positive feelings and experiences. For example, a resident was often described as being in a good mood, and the professionals told the family about activities that the resident had recently enjoyed, such as listening to music, eating sweets, or sitting outdoors in the sun. These notions conveyed that the resident still had pleasures in life: Life with late-stage dementia could be good.

In extract 2, the staff reminisces on how happy resident Antti was to hear about plans for his birthday and how he had started to *glow with happiness*:

> Extract 2
> Nurse 1: You see, last week, when he had the birthday party. When I told him what was coming, you should have seen his face! His eyes just sparkled when I told him that you're coming on Saturday.
> (…)
> Manager: It clearly meant a lot to him, I mean, he just…
> Lea: Yeah.
> Manager: He's glowing with happiness. He sits around and…
> Nurse 1: Yeah. Yeah, and his smile is so enchanting!
> Manager: It is! He sits and he smiles and he jokes about things, and sure, sometimes he walks around looking more serious, but like, he's so different now.
> Nurse 3: Mm, yeah. We've also umm seen the other side of reality.
> Manager 1: Yes, of course.
> Nurse 3: But then we just keep on holding onto these umm…
> Lea: Agreed plans.
> Nurse 3: Yeah, and the good sides, as there are those, we try to…
> Manager 1: We focus on them.
> Participants: resident Antti's spouse Lea, nursing home manager, nurses 1 and 3.
> Sub-themes: Good or peaceful mood, Pleasures in life.

Alongside sharing their observations of Antti's good mood, nurse 3 and the nursing home manager mentioned that they had also seen *the other side of reality*, presumably referring to problematic dementia-related behavior Antti exhibited during his transition to the nursing home. What is noteworthy in terms of hope work is that, while acknowledging the hardships of living with dementia, the staff explicitly guided Antti's spouse Lea to focus on the existing *good sides* and to hold on to them.

Third, the professionals could convey that the resident was in good shape and had a lot of energy. In some meetings, they also topicalized prognosis and communicated that the resident probably had years of life ahead. However, the possibility of sudden changes could also be embedded in these discussions, like in the following extract, in order to avoid promising too much:

> Extract 3
> Manager: But it's true, it has, umm, I mean, life expectancy has grown during the past decades. And since Leenu is still in such a good condition, she may well have several years left still.
> Nurse 4: Yeah. Yeah.
> Olivia: Mm-m.
> Manager: So let's see. We never…we never know, do we.
> Nurse 1: Yeah, we don't.
> Manager: Something surprising can always happen. Like we've had in the past. Sometimes, people have a heart that's a bit weak, so they pass away due to that. But if there's nothing like that, then the prognosis of Alzheimer's disease is very long. I mean, it can take a really, really…I think around 20 years, and even more.
> Participants: Resident Leenu's sister Olivia, nursing home manager, nurses 1 and 4.
> Sub-themes: There is still time, Situation is relatively good.

In extract 3, referring to the impossibility of knowing constructs ambivalence of hope amid vulnerability and uncertainty (cf. Kirby et al., 2021): The staff informs Olivia that people can survive decades with Alzheimer's disease, but they also convey the possibility of unexpected events. Here, we argue, the family member is guided to appreciate the positive aspects of the situation while accepting its realities.

Agency and identity as sources of palliative hope

While updating a family about a resident's current health and care, nursing home professionals routinely produced positive assessments about the resident's abilities, activities, and personal features. This kind of positive notion conveyed palliative hope in the sense that the resident could still be seen as an agentic individual capable of achieving things. Moreover, the professionals highlighted aspects that facilitated recognizing the residents as the same person as they were before the illness. For example, they could follow family member narratives about the resident's history with present-day compliments, creating a "positive continuum" between the past and the current situation. In extract 4, family members had been reminiscing about Oiva's past hobbies. When Kirsi, Oiva's adult daughter, shares that the whole family used to do sports, nurse 6 praises Oiva's skill in throwing and catching a ball in an enthusiastic manner:

> Extract 4
> Kirsi: We all did competitive sports in the family when we were younger. And we used to ski and do track and field sports and…
> Nurse 5: (reads from paper) Volleyball and…
> Nurse 6: How nice! And he still throws a ball—that's why I asked you on the phone a while ago whether he played ball games in the past, because he throws extremely well! Like this, from above (gestures throwing), and he also catches the ball really well! So that skill is still there.
> Kirsi: The last time he played ball with the dog! (laughs) With my daughters' dog.
> Nurse 6: Oh. (laughs)
> Esa: Yeah, he likes that.
> Nurse 6: Yeah, and you could immediately see that it's his skill!
> Participants: Resident Oiva's adult children Kirsi and Esa, nurses 5 and 6.
> Sub-themes: Connections between the past and the present, Functional abilities, Activities, Pleasures in life, Connection with family.

By addressing a skill that is *still there*, nurse 6 pinpointed a personal feature that dementia had not affected. This was probably motivated by earlier talk about Oiva's incapability to manage at home. After the nurse's comment, however, the mood of the discussion changed, and the whole group ended up smiling and laughing. There were several comparable cases in the data where professionals' positive assessments lightened the atmosphere. Among other things, they addressed residents' remaining sense of humor, taste for sweets, and ability to sing familiar songs.

It is noteworthy that no accomplishment seemed to be too small to notice. For example, residents whose dementia had progressed to later stages were complimented on using utensils when eating, lifting their limbs when getting dressed, and participating in washing their faces. Although this type of notion did not necessarily create the same kind of moments of good mood in the meetings as did the more personal assessments described above, they seemed to construct palliative hope in terms of having agency: Even if the resident needed care and assistance, they were in meaningful contact with others and participated in daily tasks.

In the case of Irja, whose condition was the most severe of all those in our data, having problems with swallowing and being unable to move, the staff produced positive assessments about her external features. In extract 5, the nursing home manager praises Irja for her looks:

> Extract 5
> Manager: Irja is still a beautiful woman. I think she has aged beautifully.
> Beautiful, bright gaze and fine skin.
> Jaakko: Yeah.
> Ari: Mother was quite good looking when she was young.
> Manager: I believe you!
> Participants: Resident Irja's spouse Jaakko and adult son Ari, manager, nurses 1 and 7.
> Sub-themes: Positive external features, Connections between the past and the present.

In our data, the nursing home staff had something comforting to say about the resident in every meeting. In response, family members expressed agreement and shared their own positive perceptions and memories about the resident (extract 4: father playing with the family's dog; extract 5: mother's good looks when she was young). In these instances, we argue, the focus of interaction was shifted from the resident's deterioration toward hopeful aspects. The family members' responses give reason to believe that professionals' hope work can indeed increase hopefulness in family members' own talk.

The promise of a good death and professional support

One of the core messages that the nursing home professionals conveyed to families in terms of palliative hope was that being beyond cure did not mean being beyond care. They highlighted that residents were kept comfortable and that their end of life would be peaceful. In meetings where future death was addressed, it was described as *beautiful*, *painless*, *peaceful*, and *quiet*, aligning with the concept of good death (see e.g., Meier et al., 2016). Alongside discussing end of life, professionals also conveyed that support was available for family members, like in extract 7:

> Extract 7
> Manager: So, you just have to sort of live with the situation. And then the good thing about being part of this kind of a care community is that there are many of us here.
> Nurse 1: Yeah.
> Manager: We can share this with you, and you can discuss things with us and share your thoughts about them and of course with those close to you, too. And we can give you our perspective on how things are going. And shed light on what's happening.
> (…)
> Manager: And then of course we all know that at some point, the illness will take him to the end. Of life. But even that usually goes quite beautifully. I mean, this isn't the kind of illness that causes unbearable pain or other things like for example cancers do.
> Participants: Resident Rauno's spouse Ada, manager, nurses 1 and 2.

Sub-themes: Enforcing contact between staff and family, Painless end-of-life.

In extract 7, the nursing home manager stresses that Ada is part of a care community and will be kept informed about Rauno's situation. A moment later, the manager addresses future death explicitly but minimizes the emotional impact by describing the process as painless and peaceful. She also contrasts dementia with cancer, communicating that the end of life with dementia is less devastating.

In extract 8, palliative hope at the end of life is constructed after a family member refers to the situation as something they *would not hope for anyone*, and something that *nothing can be done about*. The staff responds to this hopelessness by pursuing a more compassionate viewpoint on the resident's situation:

Extract 8
Manager: Do you have any thoughts or wishes you'd like to share?
Ari: Well, I don't know.
Manager: And how have you felt about this situation in general? Her condition will…of course it will little by little…
Ari: Well, of course, if one could choose, one would never umm hope for this for anyone but (laughter).
Manager: No.
Ari: But umm, there's nothing we can do about it, and this is it now, and…
Nurse 7: But on the other hand, it gives me comfort to think that she is alright here.
Ari: Yeah yeah, yeah.
Nurse 7: It gives families comfort as well, even though we can't do anything about the illness.
Ari: No no, no no.
Nurse 7: There's not much we can do about that anymore.
Ari: I mean, it's good that she is here. It's great. But we all know how it will end…
Manager: Yes.
Nurse 7: True.
Ari: But the remaining time will be, umm, let's say comfortable, or easy or…
Manager: Yeah, painless at least.
Ari: Painless, yes.
Manager: That's the thing, I suppose, when we're at the finishing line, it's the time when we treat the pain and hope that all goes well. And monitor carefully.
Ari: Yeah. Yeah.
Nurse 7: True. True.
Manager: That's how it is, that's how one can think. And of course we'll monitor the situation with you, together. And then you can come visit and stay as long as you like, and be with her.
Ari: I see.
Participants: Resident Irja's spouse Jaakko and adult son Ari, manager, nurses 1 and 7.
Sub-themes: Good quality palliative care, Painless end-of-life, Connection with family, Enforcing contact between staff and family.

In extract 8, the professionals index positive aspects of Irja's situation: Irja is in good care and has both nursing home staff and her family looking after her. In response, Ari displays appreciation toward Irja's nursing home care, especially the palliative aspects of it (*it's good that she is here*; *the remaining time will be comfortable, or easy*). This notion corrects the earlier remark about *not wishing this for anyone*, so that it does not refer to Irja's situation as a whole but only to the illness. Hence, again, the professionals' hope work seems to actually affect how family members verbalize the situation.

The manager also conveys a willingness to increase collaboration with Irja's family in the end-of-life phase and promises that they can stay by Irja's side for as long as they like. It is noteworthy that the data were collected during the Covid-19 pandemic when visiting nursing homes was in many ways heavily restricted. Thus, the manager communicates that the ongoing restrictions will not be applied to Irja's family in the last phase of the illness, so their opportunities to be close to her will improve. As social distancing during the pandemic caused distress and anxiety among the families of nursing home residents (Paananen et al., 2021), this information was particularly meaningful and constructed a significantly more hopeful perception of what was ahead.

Discussion

In this study, we analyzed authentic, video-recorded care plan meetings between nursing home professionals and the families of residents in order to shed light on how palliative hope is constructed in the context of late-stage dementia. The results show how hope work is a part of palliative care, constructing meaningfulness for the remaining yet limited lifetime. Hope work contributes to supporting the well-being and quality of life of the residents and their families by drawing their attention to the positive aspects that still remain, maintaining a hopeful attitude toward life, and supporting personal relationships. Using thematic analysis, we identified three main themes of palliative hope work: 1) Life is good and there is still time, 2) agency and identity are not lost, and 3) death will be good and professional support is available.

In the context of terminal illness, hope is contradictory: Because the expectation for the patient's future is death, the concept of hope as a positive future must be calibrated so that it can include, and make the best of, end of life (Duggleby, 2001; Herth, 1990). As we have shown, hope work indeed aims to help families accept the inevitable future and cherish the remaining life. Hence, *acceptance* and *appreciation* seem to be the overarching goals of hope work. Despite advanced illness and the need for around-the-clock care, the situation was often depicted as being relatively good or, in some way, better than expected. This kind of notion signals that things *could be worse*, which invites both appreciation and acceptance. Hope work focused on residents' remaining possibilities, capabilities, and positive features, thus guiding the families to find meaning and joy in the moments that were still attainable. At the same time, hope work managed family members' expectations so that they remain optimistic but also realistic (see also Paananen and Pino, 2025). These practices work toward appreciation and acceptance. It is also noteworthy that positive and hopeful notions typically followed, or were followed by, negative news or predictions about the resident's illness progression and deterioration. Hence, palliative hope was communicated to make negative information more bearable and easier to accept.

Based on the analysis, nursing home professionals have an important role in actively working to construct and maintain hope and thus support families: Even when a resident has extremely limited functional capacity, professionals remind the family that they are not lost as persons, they are in good care, and that there are still time and opportunities for a good life, meaningful moments, and connection (cf Flemming, 1997). Hope work highlights positive aspects and opportunities and guides families to appreciate them. Therefore, we believe that hope work can, at best, relieve anticipatory grief experienced by families (see Cheung et al., 2018).

Our qualitative analysis is limited to describing the interactional hope work detectable in video-recorded material. A mixed methods approach, including questionnaires or interviews (such as Beach & Dozier, 2015), might show whether hope work results in positive external outcomes, such as increased hopefulness or decreased feelings of loss and despair. Nevertheless, we have described the efforts of professionals to construct hope regardless of how hopeful family members' perceptions were. In describing our data excerpts, we also touched on some of the interactional features, such as how hope work seems to be often located with talk about negative aspects and how professionals connect their talk to what family members have said. A particularly interesting feature is that family members often responded to professionals' hope work by sharing some good memories about the residents and thus connecting the past and the present in a positive way or by displaying appreciation toward the nursing home care. This notion suggests that it is possible that hope work could result in immediate, observable changes in the flow of interaction, potentially indicative of achieved relief and support. Nevertheless, a more detailed analysis of the sequentiality of hope work in the talk is needed. A micro-analytic approach (such as conversation analysis) would be useful to examine the family members' responses and initiatives and to define the kinds of interactional practices and patterns in hope work in more detail.

Since dementia is often seen as a devastating and stigmatizing illness (e.g., Low & Purwaningrum, 2020; Sweeting & Gilhooly, 1997) and nursing home care is currently facing criticism due to a lack of resources, the general perceptions of living and dying with dementia can be unnecessarily negative. It is therefore important that research on dementia not focus only on issues but also on positive experiences and successful practices. Our study on hope work illustrates how nursing home professionals pursue hope and human dignity in late-stage dementia in conversations with residents' families. Combined with good-quality palliative care, palliative hope work can foster the social relationships of residents and help families focus on the meaningful experiences that are still possible.

Our study has illuminated how hope work is constructed in Finnish dementia care, and thus the findings help to recognize and distinguish hope work in other contexts as well. Because of the scarce previous literature on hope work across illnesses and different cultures, it is yet difficult to say to what extent the particular kinds of hope work described in our study are limited to the examined context. Because dementia severely threatens physical and cognitive capacity and personality (likely more than many other types of illnesses), the theme of agency and identity may be particularly characteristic of hope work in late-stage dementia. Even though the exact ways in which hope is constructed may not be identical across cultures and contexts, we argue that hope work, in general, is a beneficial practice, which could be integrated into care protocols, support measures, and training.

Data availability

The data are confidential.

Funding

This work was supported by the Research Council of Finland (grant number 331555) and the Kone Foundation (grant number 202007262).

Conflict of interest

The authors declare no conflicts of interest.

Ethical approval

The Ethical Committee of the University of Turku approved the study (decision 47/2019). All nursing home staff members and family members received oral and written information about the study and signed a written consent form. The ethical guidelines of the Finnish National Board on Research Integrity were followed accurately.

AI tool usage

Language was checked by Scribendi online service.

References

Alzheimer's Society. (2024). The progression, signs and stages of dementia. https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/how-dementia-progresses/progression-stages-dementia

Beach, W. A. (2014). Managing hopeful moments: Initiating and responding to delicate concerns about illness and health. In Hamilton H. E. & Chou W. S. (Eds.), *The Routledge handbook of language and health communication* (pp. 459–476). Routledge. https://doi.org/10.1017/S0047404516000737

Beach, W. A., & Dozier, D. M. (2015). Fears, uncertainties, and hopes: Patient-initiated actions and doctors' responses during oncology interviews. *Journal of Health Communication: International Perspectives*, *20*, 1243–1254. https://doi.org/10.1080/10810730.2015.1018644

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*, 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*, 589–597. https://doi.org/10.1080/2159676X.2019.1628806

Cheung, D. S. K., Ho, K. H. M., Cheung, T. F., Lam, S. C., & Tse, M. M. Y. (2018). Anticipatory grief of spousal and adult children caregivers of people with dementia. *BMC Palliative Care*, *17*, 124. https://doi.org/10.1186/s12904-018-0376-3

Duggleby, W. 2001. Hope at the end of life. *Journal of Hospice and Palliative Nursing*, *3*, 51–64. https://journals.lww.com/jhpn/toc/2001/03020

Finnish National Board on Research Integrity. (2019). The ethical principles of research with human participants and ethical review in the human sciences in Finland. TENK Publ 3/2019. https://tenk.fi/en/advice-andmaterials

Flemming, K. (1997). The meaning of hope to palliative care cancer patients. *International Journal of Palliative Nursing*, *3*, 14–18. https://doi.org/10.12968/ijpn.1997.3.1.14

Guedes, A. F., Carvalho, M., Laranjeira, C., Querido, A., & Charepe, Z. (2021). Hope in palliative care nursing: Concept analysis.

International Journal of Palliative Nursing, *27*, 176–187. https://doi.org/10.12968/ijpn.2021.27.4.176

Hall, B. A. (1990). The struggle of the diagnosed terminally ill person to maintain hope. *Nursing Science Quarterly*, *3*, 177–184. https://doi.org/10.1177/089431849000300410

Herth, K. (1990). Fostering hope in terminally ill people. *Journal of Advanced Nursing*, *15*, 1250–1259. https://doi.org/10.1111/j.1365-2648.1990.tb01740.x

Holtslander, L. F., Duggleby, W., Williams, A. M. & Wright, K. (2005). The Experience of hope for informal caregivers of palliative patients. *Journal of Palliative Care*, *21*, 285–291. https://doi.org/10.1177/082585970502100408

Kim, E. S., & Bayles, K. A. (2007). Communication in late-stage Alzheimer's disease: Relation to functional markers of disease severity. *Alzheimer's Care Quarterly*, *8*, 43–52. https://journals.lww.com/actjournalonline/abstract/2007/01000/communication_in_late_stage_alzheimer_s_disease_.8.aspx

Kirby, E., Broom, A., MacArtney, J., Lewis, S., & Good, P. (2021). Hopeful dying? The meanings and practice of hope in palliative care family meetings. *Social Science & Medicine*, *291*. https://doi.org/10.1016/j.socscimed.2021.114471

Kylmä, J., Duggleby, W., Cooper, D., & Molander, G. (2009). Hope in palliative care: An integrative review. *Palliative and Supportive Care*, *7*, 365–377. https://doi.org/10.1017/s1478951509990307

Land, V., Parry, R., Pino, M., Jenkins, L., Feathers, L. & Faull, C. (2019). Addressing possible problems with patients' expectations, plans and decisions for the future: One strategy used by experienced clinicians in advance care planning conversations. *Patient Education & Counseling*, *102*, 670–679. https://doi.org/10.1016/j.pec.2018.11.008

Low, L. F., & Purwaningrum F. (2020). Negative stereotypes, fear and social distance: A systematic review of depictions of dementia in popular culture in the context of stigma. *BMC Geriatrics*, *20*, 477. https://doi.org/10.1186/s12877-020-01754-x

Meier, E. A., Gallegos, J. V., Thomas, L. P., Depp, C. A., Irwin, S. A., & Jeste, D. V. (2016). Defining a good death (successful dying): Literature review and a call for research and public dialogue. *The American Journal of Geriatric Psychiatry*, *24*, 261–271. https://doi.org/10.1016/j.jagp.2016.01.135

Merel, S. E., DeMers, S., & Vig, E. (2014). Palliative care in advanced dementia. *Clinics in Geriatric Medicine*, *30*, 469–492. https://doi.org/10.1016/j.cger.2014.04.004

Miller, L. M., Whitlatch, C. J., & Lyons, K. S. (2016). Shared decision-making in dementia: A review of patient and family carer involvement. *Dementia*, *15*, 1141–1157. https://doi.org/10.1177/1471301214555542

Paananen, J., & Pino, M. (2025). Turning Toward the Inevitable: How Nursing Home Staff Manage Relatives' Expectations of Dementia Progression. *Research on Language and Social Interaction*, *58*, 165–187. https://doi.org/10.1080/08351813.2025.2484994.

Paananen, J., Rannikko, J., Harju, M. & Pirhonen, J. (2021). The impact of Covid-19-related distancing on the well-being of nursing home residents and their family members: a qualitative study. *International Journal of Nursing Studies Advances*, *3*, 100031. https://doi.org/10.1016/j.ijnsa.2021.100031

Parry, R. (2024). Communication in palliative care and about end of life: A state-of-the-art literature review of conversation-analytic research in healthcare. *Research on Language and Social Interaction*, *57*, 127–148. https://doi.org/10.1080/08351813.2024.2305048

Peräkylä, A. (1991). Hope work in the care of seriously ill patients. *Qualitative Health Research*, *1*, 407–433. https://doi.org/10.1177/104973239100100402

Rait, G., Walters, K., Bottomley, C., Petersen, I., Iliffe, S., & Nazareth, I. (2010). Survival of people with clinical diagnosis of dementia in primary care: Cohort study. *BMJ*, *341*, c3584. https://doi.org/10.1136/bmj.c3584

Sweeting, H., & Gilhooly, M. (1997). Dementia and the phenomenon of social death. *Sociology of Health & Illness*, *19*, 93–117. https://doi.org/10.1111/j.1467-9566.1997.tb00017.x

van Riet Paap, J., Mariani, E., Chattat, R., Koopmans, R., Kerhervé, H., Leppert, W., Forycka, M., Radbruch, L., Jaspers, B., Vissers, K., Vernooij-Dassen, M., & Engels, Y. (2015). Identification of the palliative phase in people with dementia: a variety of opinions between healthcare professionals. *BMC Palliative Care*, *14*, *56*. https://doi.org/10.1186/s12904-015-0053-8

Velić, S., Qama, E., Diviani, N., & Rubinelli, S. (2023). Patients' perception of hope in palliative care: A systematic review and narrative synthesis. *Patient Education and Counseling*, *115*, 107879. https://doi.org/10.1016/j.pec.2023.107879