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Clinicians' experiences, perspectives, barriers, and facilitators of integrating palliative care into hematological malignancy care: a qualitative interview study

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Abstract

Purpose Palliative care is integrated into hematological malignancy care less frequently than in the care for patients with solid tumors. Therefore, this study aimed to better understand the perspectives and experiences of clinicians regarding integrating palliative care for patients with hematological malignancies.

Methods Interviews were conducted with clinicians who care for hematological patients. The interviews were analyzed using thematic analysis.

Results Participants acknowledged the importance of integrating palliative care. However, they noted that patients with hematological malignancies often have a more unpredictable disease course than patients with solid tumors. Unpredictability and the potential for rapid deterioration were identified as main barriers to the integration of palliative care. In addition, participants indicated that the availability of multiple treatment options may result in a tendency to prioritize these treatments over integrating palliative care. The participants recommended that palliative care should have a prominent position in the hematology curriculum and suggested that including palliative care topics in conferences could enhance awareness.

Conclusions To integrate palliative care into hematological malignancy care, it is necessary to enhance the knowledge and awareness of palliative care among hematological clinicians. A two-track approach, where both curative and palliative pathways coexist, could facilitate the integration of palliative care.

Keywords Palliative care · Palliative supportive care · Hematological malignancies · Blood cancer · Clinicians · Qualitative research

Novelty statement

1. What is the new aspect of your work?

This study highlights the importance of a two-track approach to integrate palliative care into hematological malignancy care, addressing unique challenges such as the disease's unpredictable course and the tension between maintaining hope and initiating palliative care discussions, while also emphasizing the distinct roles of hematology teams and specialist palliative care teams in managing complexity.

2. What is the central finding of your work?

Clinicians in hematological malignancy care recognize the value of integrating palliative care but face barriers like the disease's unpredictable course and challenges in initiating discussions, highlighting the need for increased awareness, knowledge, and a two-track approach to enhance integration.

3. What is (or could be) the specific clinical relevance of your work?

This study offers valuable insight into the intricate aspects of care for patients with hematological malignancies and the difficulties encountered by their clinicians in integrating palliative care into hematological malignancy care.

Introduction

Worldwide, cancer is a leading cause of death and a significant impediment to life expectancy [1]. It is estimated that there will be approximately 28.4 million new cases of cancer worldwide in 2040, representing a 47% increase from the 19.3 million cases recorded in 2020 [2]. Consequently, there will be an increased demand for palliative care services and a need to improve the integration of such care into standard oncology care [2, 3]. The World Health Organization (WHO) defines palliative care as “an approach that improves the quality of life of patients and their families facing challenges whether physical, psychological, social or spiritual associated with life-threatening illness” [4]. The importance of integrating palliative care services into oncology care is widely acknowledged [5–7]. A body of evidence suggests that palliative care can benefit cancer patients and their loved ones in several ways, including improving their quality of life, reducing symptom burden, preventing inappropriate end-of-life care, increasing satisfaction with care, and improving caregiver outcomes [5, 7, 8].

In 2022, hematological malignancies constituted the fifth most frequently diagnosed type of cancer in the Netherlands. The incidence has doubled in the last 25 years, and the mortality rate in the Netherlands was 3.956 in 2021 [9]. Hematological malignancies are characterized by a heterogeneous disease course and potential for curability, with disease progression being unpredictable and potentially deteriorating rapidly at the end of life [10]. These factors may contribute to the complexity of providing timely palliative care for patients with hematological malignancies [11].

Patients diagnosed with hematological malignancies receive palliative care less frequently and at a later stage of their disease than patients with solid tumors [14]. Nonetheless, these patients experience a physical and psychological symptom burden that is comparable to that of patients with advanced solid tumors [15]. Patients with hematological malignancies had less advance care planning conversations, were less likely to be referred to a specialist palliative care team (SPCT), and were more likely to receive care in the intensive care unit in the last 30 days of life [16] [17].

Clearly, the integration of palliative care into hematological oncology is still lagging behind [12, 13]. Therefore, this study aimed to gain a deeper understanding of the perspectives and experiences of hospital clinicians regarding the provision of palliative care to patients with hematological malignancies and to identify the barriers and facilitators they perceive in integrating timely palliative care into standard hematological malignancy care.

Methods

Study design and setting

Semi-structured interviews were conducted to gain insight into the experiences, perspectives, barriers, and facilitators of clinicians regarding the integration of palliative care into hematological malignancy care in the Netherlands. In the Netherlands, an integrated generalist and specialist palliative care model is used, in which all health professionals should be prepared and adequately trained to provide generalist palliative care to their patients and to manage patients with complex palliative care needs in close collaboration with dedicated palliative care specialists. Every Dutch hospital that provides oncology care has a specialist palliative care team, which offers both inpatient and outpatient palliative care and supports other healthcare professionals in delivering generalist palliative care [18]. The Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist was used for reporting [19].

Study population

Convenience sampling was used to recruit clinicians experienced in treating patients with hematological malignancies. The participants were recruited primarily through the network of the Netherlands Comprehensive Cancer Organization (IKNL) and via social media. Individuals were invited to contact the researcher (B.M.B.) via email to request further information regarding the content and purpose of the study. Clinicians were eligible to participate if they worked in a hospital in the Netherlands, cared for hematological patients, and were older than 18 years. To obtain a broad range of perspectives and experiences, clinicians working at different types of hospitals, including academic medical centers, tertiary care hospitals, and general hospitals, were included.

Data collection

In-person interviews were conducted in March and April 2024 in private rooms within the hospitals where the participants were employed, until data saturation was reached. The mean duration of these interviews was 45 min. A summary of topics and questions was used as an interview guide, which was developed by the researchers L.B., N.R., C.K., and B.M.B. The guide was based on existing literature and the expertise of researchers and clinicians. The guide consisted of the following topics: descriptive information, perspectives and experiences of integrating palliative care into hematological malignancy care, added value of integrating palliative care into hematological malignancy care, and

Table 1 Sociodemographic characteristics of the participant

	<i>n</i> = 16
Profession, <i>n</i>	
Hematologist	7
Hospital physician hematology	1
Physician assistant hematology	1
Hematology nurse specialist	4
Hemato-oncology nurse	2
Palliative care nurse specialist	1
Gender, <i>n</i>	
Female	11
Age, mean (range)	49 (34–75)
Type of hospital, <i>n</i>	
Academic medical center	7
Tertiary care hospital	7
General hospital	2
Training in palliative care, <i>n</i> ^a	
Yes	10
Years of work experience in current position, mean (range)	15 (3–40)
Years of work experience in healthcare, mean (range)	21 (10–42)

^aTraining included for physicians: a basic palliative care training, an 8-day course in palliative care, or a 2-year continuing medical education in palliative care. Training included for nurses: 8-day course in palliative care, continuing nursing education in oncology or a 1-year continuing nursing education in palliative care

barriers and facilitators in the integration of palliative care. Furthermore, participants were asked to complete a short questionnaire in order to collect socio-demographic data, including age, gender, current occupational role, type of hospital where the participant was employed, years of work experience in healthcare, years employed in the current position, and training in palliative care (Table 1). All interviews were conducted, audio recorded, transcribed verbatim, and supplemented with field notes during and after the interview by one researcher (B.M.B.). The process of data collection and analysis was cyclical, with constant comparison. The final version of the interview guide is presented in Supplement 1.

Data analysis

The interview transcripts were analyzed using thematic analysis, based on the six phases described by Braun and Clarke [20]. Data familiarization involved reading and rereading the transcripts in preparation for coding. The data were then coded systematically and inductively by two independent researchers (B.M.B. and L.B.) to establish interobserver

reliability and discussed with a third researcher (H.P.). The use of a constant comparative method within and across interviews enabled the identification of recurrent patterns or themes. Subsequently, these were interpreted through the exploration of meaning and connections. Multiple rounds of coding and an active search for deviant cases refined the themes, resulting in a comprehensive understanding of clinicians' perspectives, experiences, barriers, and facilitators. Quotes were used to illustrate the emerging themes. ATLAS.ti software version 24.1.1, a qualitative analysis package, was used for thematic analysis of the data [21].

Results

A total of 16 clinicians from 14 different hospitals across the Netherlands were interviewed. The participants had a mean age of 49 years (range: 34–75), with a mean working experience of 15 years in their current position (range: 3–40). The study included 13 treating hematology clinicians (seven hematologists, one hospital physician hematology, four nurse specialists, and one physician assistant) and two hemato-oncology nurses. Additionally, one nurse specialist from the palliative care consultation team was interviewed. The hospital physician hematology provides general care on the hematology ward. Due to their broad training, hospital physicians are able to maintain an overview of multiple conditions that patients may have. The training to become a hospital physician is a recognized postgraduate medical specialization that lasts three years. The palliative care nurse specialist and the two hemato-oncology nurses were included based on their experience with hemato-oncology teams and providing palliative care to these patients, rather than their involvement in direct treatment of the malignancy itself. In the present study, 10 out of a total of 16 respondents reported having undergone some form of training in palliative care. For the physicians, this included one of the following programs: a basic palliative care training, an 8-day course in palliative care, or a 2-year continuing medical education in palliative care. The training programs for nurses comprised the following options: an 8-day course in palliative care, continuing nursing education in oncology, or a 1-year continuing nursing education in palliative care. (Table 1).

Four themes were identified: perspectives on integrating palliative care in hematological malignancy care, barriers due to characteristics of hematological malignancy, barriers due to attitudes and beliefs, and facilitators to enhance the integration of palliative care (Table 2).

Table 2 Subthemes and quotes per theme

Perspectives on integrating palliative care in hematological malignancy care	
Subthemes	Quotes
The added value of palliative care into hematological care	<i>“For me, palliative care, is about ensuring quality of life until death. Very often this last phase is somewhat overlooked or not discussed enough, but you can still provide a lot of quality even if you can’t cure. You start to talk about other things that can bring someone comfort or happiness, rather than focusing on treatments that aim to cure. That’s what I find beautiful about palliative care. How do you say it? It’s about looking at quality in a different way.”—Hospital Physician hematology</i>
The pivotal role of specialist palliative care teams in the care of patients with hematological malignancies	<i>“They (SPCT) ask about what matters most in the last moments, family relationships, faith and spiritual care. They look at a much bigger picture than just the diagnosis. I know the patient and what is important to them, but they look at much more than that.”—Hematology nurse specialist</i> <i>“Collaboration with the specialist palliative care team becomes problematic when there is overlap and interference with medical management. For example, if they start saying that a certain therapy has a low chance of success and advise against, or if we’ve already made a pain management plan and the palliative care team gives the patient different advice.”—Hematologist</i> <i>“I find the palliative care team here at the hospital very supportive and approachable, and we have been able to reach out to them more and more. But sometimes it is still at the very end.”—Hospital physician hematology</i>
Barriers due to characteristics of hematological malignancy	
Subthemes	Quotes
The unpredictable course of disease and rapid deterioration	<i>“The unpredictability of the disease further complicates the situation. For example, if the disease recurs and is no longer treatable, it often progresses rapidly. In contrast to some solid malignancies, where you can weigh up treatment options and consider palliative care that might prolong the patient’s life for another year and a half, in our case it’s just a matter of weeks. Some patients die within a week of the discussion.”—Hematologist</i> <i>“One of the challenges in hematology is that the prognosis is difficult to predict and there are many complications. Patients can also suddenly develop an infection that is hard to treat and can lead to unexpected deaths. It’s always uncertain whether someone will survive such an infection. Unexpected events can always happen in hematology.”—Hematology nurse specialist</i>
The lack of a clear starting point for palliative care in hematological malignancy care	<i>“Timely initiation of palliative care is a challenge because it is difficult to determine within hematology. When I first came to the hospital, I was told that palliative care didn’t exist in hematology. Everyone can be treated with curative intent initially, which creates a difficult tension. In solid oncology, many patients are diagnosed with metastatic disease, and you know, even if it’s ten years, they’re going to die of it eventually. So, the whole treatment plan is already focused on palliation and prolonging life. In contrast, almost everyone in hematology can be treated with curative intent, although not everyone will be cured. This makes it very difficult to determine when to introduce palliative care.”—Hospital physician hematology</i> <i>“I find it difficult to create a specific care pathway for hematological cancers. For example, first, you receive the diagnosis, then you start treatment, and in week seven week you should have a conversation about palliative care. And, something always happens with hematology patients. They often end up here (hospital) because of a complication, which makes it impractical to have such conversations calmly at that time.”—Hematologist</i>

Table 2 (continued)

Perspectives on integrating palliative care in hematological malignancy care	
Subthemes	Quotes
The multitude of treatment options discourages consideration of palliative care	<i>“In oncology, you often have a longer trajectory where you can already see it coming. So, you start with palliative chemotherapy, which works for a while and then it doesn’t. So, it should be similar in that sense. However, in hematology we are often still on a curative path. For example, with AML, if you’re in remission and you follow up with a DLI, you still have a 30 to 40 percent chance of a cure. And a cure is a cure. It means living longer. Oncology can’t offer that.”—Hematologist</i> <i>“Patients often receive a diagnosis out of the blue and start their treatment right away. There’s a lot of information to process and sometimes there’s no time to discuss what to do if things don’t go well. It’s hard to find the space for that, although it’s important. Because the train of hematology treatments keeps moving, there’s rarely a pause to consider palliative care or to accept that things might take a different turn.”—Hematology nurse specialist</i>
Barriers due to attitudes and beliefs	
Subthemes	Quotes
Holding on to hope and its necessity for enduring the intensive treatments	<i>“It’s also about hope that you don’t want to take away from them (patients). This makes it difficult because a patient might feel that you (healthcare professional) are already being negative by discussing what could go wrong. You don’t want to take away their hope.”—Hematology nurse specialist</i>
The difficulty of discussing palliative care for clinicians	<i>“Sometimes, it’s easier to offer another treatment rather than to have the difficult conversation about where the patient wants to die or how they envision the final phase. Sometimes, there isn’t enough time for these discussions, or people find them difficult. In these cases, it can be more convenient to offer to try another treatment instead.”—Hematologist</i>
Facilitators to enhance the integration of palliative care	
Subthemes	Quotes
Increasing awareness and knowledge of palliative care in hematology	<i>“I think it’s all about explaining. That applies to a lot of things. I explain to many patients that I use the term palliative care, and then I clarify that it doesn’t mean terminal, but that people often live for many years. So, it’s just a matter of explaining to the individual patient what you mean.”—Hematologist</i> <i>“Attention to palliative care is growing, but when I attend my oncology conferences, palliative care and the option not to treat are very prominent. At hematology conferences, however, it remains a neglected topic, with the focus primarily on treatment options.”—Hematologist</i>
Implementation of a two-track approach can support palliative care integration	<i>“A two-track approach will help. I think it’s particularly beneficial for hematology. It allows hope to be maintained, which we know is crucial and is supported by research. So, with this two-track approach hope can be sustained. But at the same time, it’s important to prepare for the possibility that things may not go as planned and to think about what is essential, including the quality of life in the present moment.”—Palliative care nurse specialist</i>

Perspectives on integrating palliative care in hematological malignancy care

The added value of palliative care into hematological care

The participants identified improvement of quality of life as the primary added value of palliative care for patients with hematological malignancies. Participants emphasized that

palliative care provides a peaceful space that allows patients to focus their energy on intensive medical treatments. The importance of preparing patients for potential complications at the end of life and of discussing the wishes of patients and their loved ones as an integral aspect of hematological care was also underlined.

“For me, palliative care, is about ensuring quality of life until death. Very often this last phase is somewhat

overlooked or not discussed enough, but you can still provide a lot of quality even if you can't cure."—Hospital Physician hematology.

The pivotal role of specialist palliative care teams

Participants reported that they involved the SPCT when dealing with complex cases, such as instances of uncontrollable pain. They stated that the SPCT was seen as an additional component to the general palliative care they provided. Participants indicated that they found it valuable that the SPCT looked at the patient from a different perspective, thereby providing a broader understanding of the patient and offering insights that may not be apparent to the hematologist. Such insights included, for instance, spiritual wishes related to the end of life. Additionally, it was noted that patients may disclose more information to an external healthcare professional from the SPCT than to their hematologist.

Participants also reflected on the difficulties and challenges with involving the SPCT. A clear delineation of roles was essential, according to the participants, and they preferred the SPCT in a more supportive role and not being (too) involved in medical decisions. Some of the nurse specialists working in the hematology outpatient clinic indicated that they were less likely to involve the SPCT, citing that they were managing the palliative care themselves and often had a long-standing care relationship with the patient. In addition, participants indicated that patients did not always appreciate the involvement of another healthcare professional at this stage.

"Collaboration with the specialist palliative care team becomes problematic when there is overlap and interference with medical management."- Hematologist.

Barriers related to characteristics of hematological malignancy

The unpredictable course of disease and rapid deterioration

Participants noted that patients with hematological malignancies often have a more unpredictable disease course than patients with solid tumors. The disease course can vary from long periods of stability to a sudden decline and sometimes leading to death within days of diagnosis. Therefore, the goal of treatment can suddenly and unexpectedly shift from a primary focus on cure to discussions about impending end of life.

These were identified as important barriers to the integration of palliative care for patients with hematological malignancies.

The lack of a clear starting point for palliative care

Given the inherently unpredictable nature of hematological malignancies, participants expressed they found it difficult to identify the optimal time to initiate palliative care discussions. This difficulty is further compounded by the initial curative intent for many patients with hematological malignancies.

Participants noted that there is no clear, universally accepted point at which palliative care should be initiated. Furthermore, due to the variable course of hematological malignancy, the moment at which clinicians integrate palliative care differed considerably, varying from the moment of diagnosis to the point where no further treatment options are available. The unexpected and rapid deterioration was mentioned as a reason for having insufficient time to initiate palliative care discussions or to involve the SPCT.

The multitude of treatment options discourages consideration of palliative care

Participants acknowledged that many patients with hematological malignancies have access to a wide range of treatment options with a high potential for cure. Most participants expressed that the availability of multiple treatment options and the high potential for cure may result in a tendency to prioritize these treatments over integrating palliative care. The clinicians' primary focus on the treatments hinders their ability to engage in palliative care conversations.

Participants also noted that, in their experience, patients with hematological malignancies are often not receptive to palliative care. This may be due to the numerous intensive treatments they undergo and the focus placed on these treatments. Moreover, during the course of these treatments, according to the participants, both the patient and the clinician find themselves lacking sufficient opportunity to discuss palliative care.

Barriers due to attitudes and beliefs

Holding on to hope

Participants expressed their concern that initiating a discussion about palliative care may diminish patients' hope. The participants noted that patients have the desire to maintain hope, as this is essential for them to endure the rigors of intensive treatments for hematological malignancy. Furthermore, since most patients with hematological malignancies have access to potentially curative treatments, each new treatment offers a new opportunity for hope.

However, participants acknowledged that the need to maintain the patient's hope creates a conflict with the need

to discuss palliative care, which needs to be addressed in order to ensure the best possible care for the patient.

“It’s also about hope that you don’t want to take away from them (patients). This makes it difficult because a patient might feel that you (healthcare professional) are already being negative by discussing what could go wrong.”—Hematology nurse specialist.

The difficulty of discussing palliative care for clinicians

Clinicians indicated that it is easier for them to discuss potential treatment options and the likelihood of a cure than to discuss palliative care, resulting in a predominant focus on the prospect of a cure. Conversations about palliative care were sometimes described as a source of tension and discomfort for clinicians. An underlying reason for this discomfort is that palliative care discussions tend to raise difficult questions, particularly those related to prognosis. Due to the unpredictable nature of hematological prognosis, clinicians may be reluctant to provide definitive responses. The discomfort is further compounded by the fact that the curriculum for hematology fellows does not adequately equip them with the required skills to provide palliative care.

“Sometimes, it’s easier to offer another treatment rather than to have the difficult conversation about where the patient wants to die or how they envision the final phase.”—Hematologist.

Facilitators to enhance the integration of palliative care

Increasing awareness and knowledge of palliative care in hematology

Participants suggested that palliative care should become a prominent part of the hematology curriculum to increase knowledge about palliative care. Participants acknowledged the importance of giving patients a clear and accurate explanation of palliative care. This will help to avoid the misconception that palliative care is only for the terminally ill and to ensure that patients’ hopes and optimism are not inadvertently undermined.

“I think it’s all about explaining. That applies to a lot of things. I explain to many patients that I use the term palliative care, and then I clarify that it doesn’t mean terminal, but that people often live for many years.”—Hematologist.

It was acknowledged by participants that there is a necessity for greater awareness of palliative care in the treatment of hematological malignancies. It is recommended that awareness and knowledge of palliative care can be enhanced by facilitating discussions at conferences for hematologists.

Implementation of a two-track approach can support palliative care integration

Some participants indicated that a two-track approach could help to integrate palliative care into hematological malignancy care. This two-track approach means that the curative and palliative care pathways coexist, allowing for the possibility of a cure while simultaneously integrating palliative care. In a two-track approach, hope is maintained and disease-oriented treatment continued. At the same time, patients with hematological malignancies are prepared for the potential complications or an acute, unexpected course of the disease.

Discussion

We found that clinicians working in hematological oncology recognized the added value of integrating palliative care into hematological malignancy care. Several barriers were also identified. These barriers included specific characteristics of hematological malignancy, such as the unpredictable course of the disease, and attitudinal and belief barriers, such as the perceived difficulty of initiating discussions about palliative care. Increased awareness and more knowledge of palliative care in hematological malignancy care and a two-track approach were seen as important facilitators and strategies to integrate palliative care into hematological malignancy care.

First, our study shows that clinicians recognize the added value of palliative care. These findings are consistent with previous studies on the integration of palliative care into usual hematological care [8, 22, 23]. For example, Giusti et al. [24] found that patients diagnosed with multiple myeloma who received early palliative care experienced numerous benefits, including improved pain management. However, it is notable that the perceived value of palliative care is comparable to that in solid oncology. Therefore, the rationale for implementing palliative care is not fundamentally different between solid oncology and hematology [25]. Our results showed that participants perceive SPCTs as a valuable addition to their general palliative care provision and acknowledge that collaboration with SPCTs has increased in recent years. However, a clear delineation of roles is crucial, with a preference for the SPCT not to be overly involved in medical decisions and to act in a more supportive role. According to McCaughen et al. [26], palliative care specialists described that the end-of-life needs of hematological patients can be met by the hematological team, particularly the clinical nurse specialist. The findings of the current study indicate that hematology nurse

specialists do not consistently perceive the involvement of another healthcare professional from the SPCT necessary for their patients. However, in case of complexity, hematology nurse specialists found the input of the SPCT beneficial. Nonetheless, several studies have confirmed that referral to the SPCT by a hematology team often occurs late in the course of the disease [26, 27].

Secondly, participants emphasize that patients with hematological malignancies often have a more unpredictable disease course than patients with solid cancer. As a result, treatment goals can shift abruptly from a primary focus on cure to discussions about end-of-life care. This unpredictability and rapid deterioration have also been identified as a significant barrier to the integration of palliative care in other studies [10, 11]. Although the lack of a clear starting point for palliative care and the difficulties of prognostication have been identified as barriers to its integration, a two-track approach, in which curative and palliative care pathways coexist, is seen as a significant facilitator. In this context, the two-track approach facilitates what is referred to as “timely palliative care” as it allows palliative care to be integrated early in the disease trajectory, regardless of prognostic uncertainty. This indicates that the identified barriers do not preclude the possibility or necessity of integrating palliative care for patients with hematological malignancies. Rather than hindering the integration of palliative care, the unpredictability and rapid deterioration of hematological malignancies should encourage advance care planning and discussions about palliative care, thereby ensuring that patients are adequately prepared for sudden changes. Verhoef et al. [28] similarly proposed a two-track approach, particularly for patients with hematological malignancies, to ensure the timely integration of palliative care. An integrated approach has also been proposed in cases of chronic advanced heart failure and chronic obstructive pulmonary disease (COPD), where similar difficulties, including the unpredictability of the disease course, have been reported [29, 30]. To address these challenges and provide optimal care for patients with cardiovascular disease, a set of guiding principles has been developed. These include the integration of palliative care alongside specialist cardiovascular care [31].

Thirdly, our findings show a reluctance to discuss palliative care due to the predominant focus on cure and the perceived ease of discussing potential treatments. There is also a concern that discussing palliative care may deprive patients of hope, as hope plays a pivotal role in enduring intensive treatments and any new treatment available is seen as a potential source of hope. This is consistent with the findings of Dowling et al. [32], who also indicated that hematologists’ hope of cure results in many patients with hematological malignancies being actively treated until the end of life. However, Cohen et al. [33] found that there was no association between advance care planning, including discussion of

end-of-life issues, and decreased patient hope. Furthermore, they showed that hope was even higher in patients who had palliative care discussions than in those without. They therefore pleaded for palliative care discussions and for clinicians not to hesitate to have them. The study by Olsman et al. [34] posits that healthcare professionals can incorporate different forms of hope, which facilitates communication and does not preclude honest discussions about prognosis or goals of care, which can lead to a better quality of care [34, 35]. Some participants expressed discomfort when discussing palliative care with their patients, with such conversations being a source of tension and unease for clinicians. This finding is in line with those of Hui et al. [36], who found that, compared to specialists in solid tumors, hematologists are less comfortable with certain aspects of palliative care, such as referring patients to hospice care and discussing the end of life.

Finally, predicting life expectancy for patients with other types of cancer has also become more difficult in recent years due to advances in treatment options such as immunotherapy and targeted therapy [37]. The unpredictability of toxicities and responses complicates the decision-making process for patients with advanced solid tumors, making the timely integration of palliative care even more crucial [38]. With the expansion of therapeutic options, patients with solid tumors are also faced with increasingly uncertain prognosis and different disease trajectories [37]. Consequently, they may encounter similar barriers to the timely integration of palliative care as those observed in hematological malignancy care.

Strengths and limitations

Participants of this study included clinicians who have received additional training and experience in palliative care, as well as those who have not received such training and have less experience in palliative care. Including both the perspectives of generalist and specialist palliative care provides a comprehensive overview of the challenges and attitudes to palliative care.

A limitation of the study is the method of participant recruitment, convenience sampling. As participants were recruited through the network of IKNL and via social media promotion, it is possible that those who responded were primarily healthcare professionals with an affinity for palliative care and resulted in self-selection bias. This might select for participants more open to discussing palliative care with their patients in their daily work, or are already effectively integrating palliative care, resulting in the overrepresentation of opinions and perspectives of those open to palliative care for this patient population. Nevertheless, several barriers emerged from the analysis, suggesting that the results may underestimate the problems. Moreover, future research is needed to get insights into the daily practice of care for these patients at the end of life, including defining

quality of care in end-of-life care for patients with hematological cancer. Furthermore, because data regarding palliative care are very scarce in patients with hematological cancer, more insights into the patients' perspective on palliative care and on the daily practice of providing palliative care to these patients is needed.

Conclusion

This study provides insight into the complexity of care for patients with hematological malignancies and the challenges their clinicians face in integrating palliative care into hematological malignancy care. For optimal integration, it is necessary to enhance the knowledge and awareness of palliative care among all hematological clinicians. A two-track approach, where both curative and palliative pathways coexist, could facilitate the integration of palliative care into hematological cancer care.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s00520-025-09715-z>.

Author contributions All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by B.M.B and L.B. The first draft of the manuscript was written by B.M.B. and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Data availability No datasets were generated or analysed during the current study.

Declarations

Ethics approval This study was performed in line with the principles of the Declaration of Helsinki. The study protocol was reviewed by the Medical Ethical Committee LDD, The Netherlands (nWMO-D4-2024-008). The METC has exempted this observational study from ethical review in accordance with the Dutch Medical Research Involving Human Subjects Act (WMO). Furthermore, the Dutch Personal Data Protection Act was followed in data collection and analysis procedures.

Consent to participate Participants were informed of their right to withdraw from the study at any time before the start of the interview. Written informed consent for participation and audio-recording was obtained from all participants prior to the interview, with assurances of anonymity and confidentiality.

Competing interests The authors declare no competing interests.

References

- Bray F, Laversanne M, Weiderpass E, Soerjomataram I (2021) The ever-increasing importance of cancer as a leading cause of premature death worldwide. *Cancer* 127:3029–3030. <https://doi.org/10.1002/cncr.33587>
- Sung H, Ferlay J, Siegel RL, Laversanne M, Soerjomataram I, Jemal A et al (2021) Global Cancer Statistics 2020: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin* 71:209–249. <https://doi.org/10.3322/caac.21660>
- Etkind SN, Bone AE, Gomes B, Lovell N, Evans CJ, Higginson IJ et al (2017) How many people will need palliative care in 2040? Past trends, future projections and implications for services. *BMC Med* 15:102. <https://doi.org/10.1186/s12916-017-0860-2>
- World Health Organization. Palliative care (2020) Palliative care [cited 2024 Mar 7]. <https://www.who.int/news-room/fact-sheets/detail/palliative-care>. Accessed 1 Nov 2024
- Zimmermann C, Swami N, Krzyzanowska M, Hannon B, Leigh N, Oza A et al (2014) Early palliative care for patients with advanced cancer: a cluster-randomised controlled trial. *The Lancet* 383:1721–1730. [https://doi.org/10.1016/S0140-6736\(13\)62416-2](https://doi.org/10.1016/S0140-6736(13)62416-2)
- Mathews J, Zimmermann C (2020) Palliative care services at cancer centres — room for improvement. *Nat Rev Clin Oncol* 17:339–340. <https://doi.org/10.1038/s41571-020-0374-2>
- Vanbutsele G, Pardon K, Van Belle S, Surmont V, De Laat M, Colman R et al (2018) Effect of early and systematic integration of palliative care in patients with advanced cancer: a randomised controlled trial. *Lancet Oncol* 19:394–404. [https://doi.org/10.1016/S1470-2045\(18\)30060-3](https://doi.org/10.1016/S1470-2045(18)30060-3)
- El-Jawahri A, LeBlanc T, VanDusen H, Traeger L, Greer JA, Pirl WF et al (2016) Effect of inpatient palliative care on quality of life 2 weeks after hematopoietic stem cell transplantation. *JAMA* 316(20):2094–2103. <https://doi.org/10.1001/jama.2016.16786>
- Integraal Kankercentrum Nederland (2023) Cijfers hemato-oncologie [cited 2024 Mar 7]. <https://iknl.nl/kankersoorten/hemato-oncologie/registratie>. Accessed 1 Nov 2024
- Wedding U (2021) Palliative care of patients with haematological malignancies: strategies to overcome difficulties via integrated care. *Lancet Healthy Longev* 2:e746–e753. [https://doi.org/10.1016/S2666-7568\(21\)00213-0](https://doi.org/10.1016/S2666-7568(21)00213-0)
- El-Jawahri A, Nelson AM, Gray TF, Lee SJ, LeBlanc TW (2020) Palliative and end-of-life care for patients with hematologic malignancies. *J Clin Oncol Off J Am Soc Clin* 20(38):944–953. <https://doi.org/10.1200/JCO.18.02386>
- Howell DA, Shellens R, Roman E, Garry AC, Patmore R, Howard MR (2011) Haematological malignancy: are patients appropriately referred for specialist palliative and hospice care? A systematic review and meta-analysis of published data. *Palliat Med* 25:630–641. <https://doi.org/10.1177/0269216310391692>
- Hui D, Didwaniya N, Vidal M, Shin SH, Chisholm G, Roquembourg J et al (2014) Quality of end-of-life care in patients with hematologic malignancies: a retrospective cohort study. *Cancer* 15(120):1572–1578. <https://doi.org/10.1002/cncr.28614>
- LeBlanc TW, Abernethy AP, Casarett DJ (2015) What is different about patients with hematologic malignancies? A retrospective cohort study of cancer patients referred to a hospice research network. *J Pain Symptom Manage* 49:505–512. <https://doi.org/10.1016/j.jpainsymman.2014.07.003>
- Boucher NA, Johnson KS, LeBlanc TW (2018) Acute leukemia patients' needs: qualitative findings and opportunities for early palliative care. *J Pain Symptom Manage* 55:433–439. <https://doi.org/10.1016/j.jpainsymman.2017.09.014>
- Kirtane K, Downey L, Lee SJ, Curtis JR, Engelberg RA (2018) Intensity of end-of-life care for patients with hematologic malignancies and the role of race/ethnicity. *J Palliat Med* 21:1466–1471. <https://doi.org/10.1089/jpm.2018.0152>
- Gebel C, Basten J, Kruschel I, Ernst T, Wedding U (2023) Knowledge, feelings, and willingness to use palliative care in cancer patients with hematologic malignancies and solid tumors: a prospective, cross-sectional study in a comprehensive cancer center in Germany. *Support Care Cancer* 31:445. <https://doi.org/10.1007/s00520-023-07914-0>

18. Quil TE, Abernethy AP (2013) Generalist plus specialist palliative care—creating a more sustainable model. *New England J Med* 368:1173–1175. <https://doi.org/10.1056/NEJMp1215620>
19. Tong A, Sainsbury P, Craig J (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 19:349–357. <https://doi.org/10.1093/intqhc/mzm042>
20. Braun V, Clarke V (2006) Using thematic analysis in psychology. *Qual Res Psychol* 3:77–101. <https://doi.org/10.1191/1478088706qp0630a>
21. ATLAS.ti Scientific Software Development GmbH. ATLAS.ti Mac. V. 24.1.1. <https://atlasti.com/>. Accessed 1 Nov 2024
22. El-Jawahri A, LeBlanc TW, Kavanaugh A, Webb JA, Jackson VA, Campbell TC et al (2021) Effectiveness of integrated palliative and oncology care for patients with acute myeloid leukemia: a randomized clinical trial. *JAMA Oncol* 7:238–245. <https://doi.org/10.1001/jamaoncol.2020.6343>
23. Potenza L, Scaravaglio M, Fortuna D, Giusti D, Colaci E, Pioli V et al (2021) Early palliative/supportive care in acute myeloid leukaemia allows low aggression end-of-life interventions: observational outpatient study. *BMJ Support Palliat Care* 8:2021–002898. <https://doi.org/10.1136/bmjspcare-2021-002898>
24. Giusti D, Colaci E, Pioli V, Banchelli F, Maccaferri M, Leonardi G et al (2023) Early palliative care versus usual haematological care in multiple myeloma: retrospective cohort study. *BMJ Support Palliat Care* 26:2023–004524. <https://doi.org/10.1136/spcare-2023-004524>
25. Bigi S, Borelli E, Potenza L, Gilioli F, Artioli F, Porzio G et al (2023) Early palliative care for solid and blood cancer patients and caregivers: quantitative and qualitative results of a long-term experience as a case of value-based medicine. *Front Public Health* 6(11):1092145. <https://doi.org/10.3389/fpubh.2023.1092145>
26. McCaughan D, Roman E, Smith AG, Garry AC, Johnson MJ, Patmore RD et al (2018) Palliative care specialists' perceptions concerning referral of haematology patients to their services: findings from a qualitative study. *BMC Palliat Care* 17:33. <https://doi.org/10.1186/s12904-018-0289-1>
27. Adersen M, Thygesen LC, Jensen AB, Neergaard MA, Sjøgren P, Groenvold M (2017) Is admittance to specialised palliative care among cancer patients related to sex, age and cancer diagnosis? A nation-wide study from the Danish Palliative Care Database (DPD). *BMC Palliat Care* 23(16):21. <https://doi.org/10.1186/s12904-017-0194-z>
28. Verhoef M, de Nijs EMJ, Ootjers CS, Fiocco M, Fogteloo AJ, Heringhaus C et al (2019) End-of-life trajectories of patients with hematological malignancies and patients with advanced solid tumors visiting the emergency department: the need for a proactive integrated care approach. *Am J Hosp Palliat Care* 37:692–700
29. Siouta N, Heylen A, Aertgeerts B, Clement P, Janssens W, Van Cleemput J et al (2021) Quality of life and quality of care in patients with advanced chronic heart failure (CHF) and advanced chronic obstructive pulmonary disease (COPD): implication for palliative care from a prospective observational study. *Prog Palliat Care* 29:11–19. <https://doi.org/10.1080/09699260.2020.1831248>
30. McIlvennan CK, Allen LA (2016) Palliative care in patients with heart failure. *BMJ* 353:i1010. <https://doi.org/10.1136/bmj.i1010>
31. Braun LT, Grady KL, Kutner JS, Adler E, Berlinger N, Boss R et al (2016) Palliative care and cardiovascular disease and stroke: a policy statement from the American Heart Association/American Stroke Association. *Circulation* 134:198–225. <https://doi.org/10.1161/CIR.0000000000000438>
32. Dowling M, Fahy P, Houghton C, Smalle M (2020) A qualitative evidence synthesis of healthcare professionals' experiences and views of palliative care for patients with a haematological malignancy. *Eur J Cancer Care (Engl)*. 29. <https://doi.org/10.1111/ecc.13316>
33. Cohen MG, Althouse AD, Arnold RM, Bulls HW, White DB, Chu E et al (2022) Hope and advance care planning in advanced cancer: is there a relationship? *Cancer* 128:1339–1345. <https://doi.org/10.1002/cncr.34034>
34. Olsman E, Leget C, Onwuteaka-Philipsen B, Willems D (2014) Should palliative care patients' hope be truthful, helpful or valuable? An interpretative synthesis of literature describing healthcare professionals' perspectives on hope of palliative care patients. *Palliat Med* 28:59–70. <https://doi.org/10.1177/0269216313482172>
35. Hui D, Bansal S, Park M, Reddy A, Cortes J, Fossella F et al (2014) Differences in attitudes and beliefs toward end-of-life care between hematologic and solid tumor oncology specialists. *Ann Oncol* 26:1450–1446. <https://doi.org/10.1093/annonc/mdvo28>
36. Hill DL, Boyden JY, Feudtner C (2023) Hope in the context of life-threatening illness and the end of life. *Curr Opin Psychol* 49:101513. <https://doi.org/10.1016/j.copsyc.2022.101513>
37. Geijteman ECT, Kuip EJM, Oskam J, Lees D, Bruera E (2024) Illness trajectories of incurable solid cancers. *BMJ* 384:e076625. <https://doi.org/10.1136/bmj-2023-076625>
38. An A, Hui D (2022) Immunotherapy versus hospice: treatment decision-making in the modern era of novel cancer therapies. *Curr Oncol Rep* 24:285–294. <https://doi.org/10.1007/s11912-022-01203-5>

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