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# Patient and caregiver experiences with advanced cancer care: a qualitative study informing the development of an early palliative care pathway

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## ABSTRACT

**Background** Palliative care is an approach that improves the quality of life of patients and families facing challenges associated with life-threatening illness. In order to effectively deliver palliative care, patient and caregiver priorities need to be incorporated in advanced cancer care.

**Aim** This study identified experiences of patients living with advanced colorectal cancer and their caregivers to inform the development of an early palliative care pathway.

**Design** Qualitative patient-oriented study.

**Settings/participants** Patients receiving care at two cancer centres were interviewed using semistructured telephone interviews to explore their experiences with cancer care services received prior to a new developed pathway. Interviews were transcribed verbatim, and the data were thematically analysed.

**Results** From our study, we identified gaps in advanced cancer care that would benefit from an early palliative approach to care. 15 patients and 7 caregivers from Edmonton and Calgary were interviewed over the phone. Participants identified the following gaps in advanced cancer care: poor communication of diagnosis, lack of communication between healthcare providers, role and involvement of the family physician, lack of understanding of palliative care and advance care planning.

**Conclusions** Early palliative approaches to care should consider consistent and routine delivery of palliative care information, collaborations among different disciplines such as oncology, primary care and palliative care, and engagement of patients and family caregivers in the development of care pathways.

## INTRODUCTION

Cancer is the leading cause of death in Canada, and colorectal cancer being the second most common type of cancer.<sup>1</sup> Patients living with advanced cancers often experience emotional distress, and have trouble coping with physical symptoms such as fatigue and pain.<sup>2,3</sup> Patients with advanced cancers often undergo potentially inappropriate ‘aggressive end of life care’ such as repeated hospitalisations, emergency department visits and admission to the intensive care unit within last month of life.<sup>4,5</sup> These types of interventions have been associated with lower quality of life for both patients and families in a number of studies.<sup>5–7</sup> As a result, most patients with advanced cancer prefer palliative treatments than life-extending care, and prefer to die at home.<sup>5</sup>

Palliative care is patient and family centred care that improves quality of life and addresses physical, emotional, social and spiritual needs of patients.<sup>8</sup> National and international organisations such as Choosing Wisely Canada<sup>9</sup> and the American Society of Clinical Oncology<sup>10</sup> recommend the integration of early palliative care services for advanced cancer care, 8 weeks into diagnosis.

Organisation and delivery of palliative care across jurisdictions are inconsistent, impacting quality of care received.<sup>11</sup> Variation in the timing and delivery of palliative care is often associated with ‘aggressive end of life’ care.<sup>12</sup> Efforts are underway to address this gap in care. The Palliative Care Early and Systematic (PaCES) programme, a province-wide initiative, is developing an early and

systematic palliative care pathway for patients with advanced colorectal cancer and families in Alberta, Canada.<sup>13</sup> The overall aim of this study is to inform the delivery of early palliative care by identifying gaps in care and the priorities of patients living with advanced colorectal cancer and their caregivers.

## METHODS

### Study design and participants

This study is a qualitative patient-oriented study. We conducted telephone semistructured interviews with patients with advanced colorectal cancer and family caregivers from May to November 2018, prior to implementation of an early palliative care pathway for advanced cancer (PaCES). Patients and their caregivers were approached at clinics by research team members to give consent to be contacted (at the two metropolitan, tertiary cancer centres in a Canadian province serving a population of about 4.3 million). Sampling was purposive and convenient because potential participants who had advanced colorectal cancer and met the inclusion criteria were approached at clinics by a member of the clinical research team, and given information about the study. Interested participants were asked to complete a consent to contact form for follow-up. Snowball sampling was employed as potential family caregiver participants could be identified by the patients we interviewed. The inclusion criteria for this study were patients with advanced colorectal cancer, greater than 18 years old with any of the following: (1) failed first-line chemotherapy (disease progression on imaging); (2) high symptom need (any score on the Edmonton Symptom-Assessment System Revised<sup>14 15</sup> greater than or equal to 7); (3) unable to receive first-line chemotherapy.<sup>13</sup> Dyad participants (patient and their family caregiver) and non-dyad participants were recruited and interviewed separately, in order to analyse individual accounts. A family caregiver was defined as a relative or friend of the patient (over the age of 18), whom the patient describes as their primary caregiver (someone providing unpaid assistance and support to the patient). Participants were offered a US\$20 gift card as a thank you for their participation.

### Interview guide

The interview guide was developed using the Person-Centred Care (PCC) framework<sup>16</sup> with feedback from clinician-researchers specialising in palliative care (AS, JS), a health service researcher (MS) and three patient and family advisors on the team (online supplemental appendix A—conceptual framework, online supplemental appendix B interview guide). All interviews were audio recorded and notes taken by a qualitative researcher (SA). Debriefing followed each interview to address any questions the participants might have. Interviews ranged from 20 to 90 min.

### Data analysis

Interviews were transcribed, and the data thematically analysed with the support of the qualitative analysis software, NVivo. We employed the six-phase thematic analysis process described by Braun and Clarke.<sup>17</sup> Coding was performed by two members of the research team (SA and SFN), using a mix of deductive, inductive and iterative coding strategies. Thematic saturation was achieved with the interviews, defined as no additional codes or themes were identified during data analysis.<sup>18</sup> We used member checking to increase credibility. This included asking participants to clarify responses during the interview and afterwards over the phone. Peer debriefing between team members was also employed to increase credibility. This process allowed for discussions on codes, themes and thematic saturation with team members. Complete records of the start of the research project to the end were kept, which includes audio recordings, transcripts and notes.

The delivery of palliative care is patient and family centred. The PCC framework provides a guideline for healthcare organisations on the delivery of quality of care to patients and families. This framework consists of specific domains categorised under structure, process and outcome, outlined by Donabedian's framework.<sup>19</sup> The PCC framework was used to guide the analysis of the findings from the interviews with patients and family caregivers.<sup>16</sup> The conceptual framework is included in online supplemental appendix A.

## FINDINGS

Of the 27 consent to contact forms collected, 22 participants were reached and confirmed for an interview (2 patients and 3 caregivers were not available for an interview). A total of 15 patients with advanced colorectal cancer and 7 caregivers (all spouses) were interviewed. Of those patients and caregivers, 9 were from one centre and 13 were from the other. We had men and women participants (13 women, 9 men) whose ages ranged from 43 to 72. Of the 15 patients, 11 women and 4 men were interviewed. Of the seven caregivers, three women and four men were interviewed. Three of those seven caregivers were spouses of three patients interviewed (three dyad participants, but interviewed separately). All patients were living at home at the time of the interview, and none of them had been referred to a palliative care specialist or palliative homecare.

Six main themes were identified in the analysis: (1) communication with and among care team (including communication of diagnosis); (2) relationship with healthcare providers; (3) meaning of palliative care; (4) patient and family engagement; (5) readiness for advance care planning; (6) access to care. Mention of participants will include both patient and caregiver, unless otherwise stated. Supportive quotes for each theme can be found in [table 1](#). [Figure 1](#) summarises the gaps identified in current advanced cancer care.

**Table 1** Supportive quotes for themes identified

Theme	Description	Quote
Communication with and among care team	Frustration with triage line (after hours care)	"it's very frustrating because I cannot call the oncologist or even, you know, even her nurse... most of the time I am trying to ask her nurse because I know that she can ask the oncologist, but it's very difficult to get to her, so every time they say that "if you have any questions just call" I go "oh no." Very frustrating. And sometimes you don't get a call back at all" (Patient B).
	Confusion regarding which care provider to see	"I had problems with my stoma—every time they change it, there's blood—I don't know if I should go to my family doctor or the guy who did the stoma. Like you know who do you go see?" (Patient D)
	Preference for communication with care team about patient's wishes	"Many times, my husband would go with me to the oncologist which is normal. But I was never asked if I wanted him in the room... there were many times where I wanted to discuss things by myself without him there and I was never asked" (Patient I)
Relationship with oncologist and cancer team	Improvement in relationship with oncologist	"The oncologist has since made good about telling us about other things that are out there and responding to some other things that we brought to his attention... immunotherapy and clinical trials and genetic testing for markers and tumors and those sorts of things. So between our efforts and his efforts, which have been really good in the last couple of years... that's how we've obtained further information" (Caregiver A).
Role of the family physician	Differences between the role of the Family Physician and oncologist	"it's sort of a specialized care and once he [family physician] knows for sure that we're in the right hands there's really not much that he can do that a specialist couldn't do sort of thing... he'd be the one to sort of adjust medications or add or take away depending on you know what's happening with general health. But as far as cancer treatments—well the person who sits in the driver's seat is the oncologist" (Caregiver E)
Meaning of palliative care	Care teams need to explain palliative care to patients	"I'm just going to say when people say palliative care... when it's a doctors and nurse you know, in some cases, maybe have to take the time to describe what that actually means. Because I think there is a maybe a scary connotation to the term for some people" (Caregiver B)
		"no one has explained it to me other than saying you know once you stop treatment, you'll go to palliative care. That's as far as they have said." (Patient I)
Patient and family engagement in care	Patient identifies ways they have maintained their autonomy and engaged in their care	"I just write down questions, related questions that don't take up a lot of their time... because it makes me feel like a participant in my care so it feels like I have some kind of control... I remember when they first offered me chemo... and it seemed irregular as to why they were offering it to me... and I said I think I will say no because I don't want it because I was gonna lose my hair and hands and I didn't want to lose my hands because I would lose my independence and my life would change drastically. So, I turned it down but felt power that I turned it down and had made a big decision" (Patient C).
	Caregivers as advocates	"even though we were communicating that this pain is pretty bad and I'd go with her to every appointment, so even when she downplayed it, I would make sure that the nurse and doctor understood it's bad, bad enough that she can't get out of the bed most days. We waited until like literally a month ago to have a meeting with the pain team at the hospital and I'm really confused as to why that would happen" (Caregiver B).
	Patient found checklist useful	"I've filled it out many times... I did get a call back from the hospital once or maybe twice, which was very reassuring because I knew that somebody was actually looking at it" (patient C).
	Checklist is not enough to capture patient symptoms	"I think it's more quantitative than qualitative... To me it doesn't really say a whole lot. You can't explain what's going on."
Readiness for advance care planning	Need to feel ready for Advance Care Planning conversations	"probably not until it's actually necessary. I know that sounds terrible, but I don't know if I could deal with it right away... I think it's one of those things that information can be provided and when I'm ready, or you know at least provided to my family." (patient H)
Access to care	Preference for phone appointments	"chemo treatment is not really fun so she's sick a lot of the time. It would be a heck of a lot easier for her if she didn't have to you know get in the car and drive across town to the hospital and sit in the waiting room for you know for half an hour, 45 minutes. I guess I'm curious why is it not feasible to do little things over the phone." (Caregiver B)

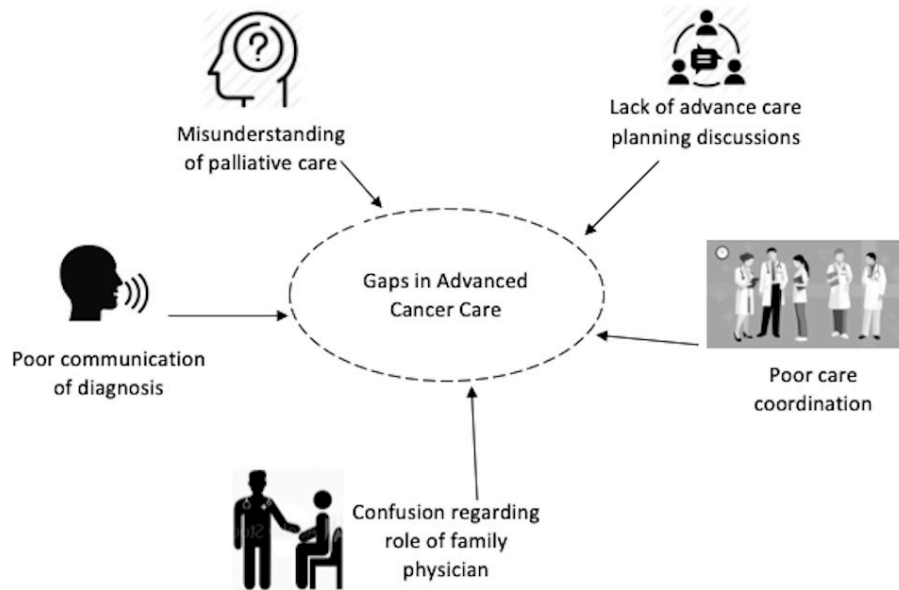
### Communication with and among care team

Most participants specified nurses, oncologist, family physicians, family members and friends as key members of their care team. One participant also mentioned other key members including their social worker and therapist. Communication with the care team and among care team members was important to patients and family caregivers. Participants mentioned a need for care integration (improved coordination of care) between their care providers, and some found it currently lacking in their cancer care. Some participants perceived lack of teamwork between different healthcare providers. One caregiver says: "We found that there's a real challenge in communication in terms of some departments in [health organization]. And so, if we have the oncology team and palliative team both involved in care... they need to be in sync." (Caregiver B)

Most patients knew who to call after hours, for instance some called the cancer clinic, triage line or emergency. However, some participants found calling someone after hours to be challenging due to lack of response, or delayed response.

### Communication of diagnosis

Hearing the diagnosis of advanced cancer was shocking for all participants, and many mentioned poor communication of the initial diagnosis. Some participants spoke about hearing about their diagnosis in uncomfortable situations and not feeling informed about what to expect. For instance, one participant mentioned hearing they had cancer over the phone: "actually, it was communicated to me through the phone initially. When they told me I had colon cancer, the doctor who had actually performed the colonoscopy called me." (Patient H).



**Figure 1** Gaps identified by patients and family caregivers in advanced cancer care.

Another patient mentioned being told after their surgery, “Well one guy [resident] comes up to me while I’m laying in bed and says—he was talking to somebody else. That’s how I heard. So, everything was a screw up. All my information was just casually overheard or by accident or something.” (Patient I)

Participants emphasised the need for clinicians to understand the patient perspective when delivering an advanced cancer diagnosis.

#### Relationship with oncologist and cancer team

Most patients mentioned seeing their oncologist/cancer team on a consistent basis (every 2–3 weeks). Most participants spoke of the importance of communicating with their oncologist and cancer team, and some participants mentioned they perceived improvement in the relationship with their oncologist over time. Patients and caregivers relied on their oncologist and cancer team (such as the nurses at the cancer centre) for information regarding their cancer diagnosis, treatment, medications. Participants also preferred to speak and see their cancer team for concerns about their care.

One participant spoke about how their oncologist made them feel in control: “I think we work together really well. I think that he, I mean it’s obviously his knowledge and I go with. I have faith in him so I go with his recommendations...but he makes me fully understand what those recommendations are. So, you know I feel as much in control of my future as I can.” (Patient G)

#### Role of the family physician

There were mixed responses from participants on how they felt about their family physician. Some participants expressed lacking trust in their family physician for their care, due to previous circumstances where they felt their care was lacking. For instance, a late

diagnosis, and not taking concerns of patients and families seriously. Other participants mentioned they found their family physician useful in ensuring they had all the information they needed, facilitating tests and going through goals of care. However, some participants found the role of the family physician during cancer care to be unclear, and sought the cancer team for most of their care. Some participants also found their specialist teams to be sufficient in providing their care, and didn’t find a need to seek their family physician. One family caregiver mentioned their family doctor should be made aware, but not play a huge role in cancer care “he should be made aware and you know be on top of it but it’s sort of a specialized care and once he knows for sure that we’re in the right hands there’s really not much that he can do that a specialist couldn’t do” (Caregiver E)

#### Meaning of palliative care

Patients and family caregivers were asked what the term palliative care meant to them. For some participants, they associated palliative care with end of life and death. Additionally, almost all participants did not consider themselves to be receiving palliative care or identify their care as including an early palliative approach to care. Participants mentioned palliative care having a negative connotation, impacting how patients and families view palliative care. For instance, one participant describes palliative care as, “somebody who is dying on their last legs, cannot do anything for themselves and end up in the hospice.” (Patient G)

There were other participants who viewed palliative care as more encompassing, and ongoing care. One participant described palliative care as ‘comfort care’, “I’d think of it as comfort care. You know probably less medical... more sort of helping patients deal with the

day to day” (Caregiver B). Another patient described how communicating with different care providers, and receiving cancer care for a long time changed her perception of palliative care. There were also some participants who were unsure what palliative care meant. Most participants noted palliative care was not extensively or adequately discussed with their healthcare team, and some mentioned hearing the term in an initial meeting by their healthcare providers, but never explained. Participants emphasised that care teams need to take time to explain palliative care to their patients, as people have different perceptions of what it means.

#### Patient and family engagement in care

Patients and family caregivers emphasised importance of being engaged in their care. Participants wanted to not only be informed about their diagnosis, treatment and care plan but also be an equal member of the care team, and engaged in shared decision-making. One participant notes how they conducted their own research beyond clinical appointments, “I use different sources. I talk to doctors. I am always asking questions. I am taking the time to go to different websites to try and find different clinical studies and I have done a lot of different types of research” (Patient A).

Being their own individual and having the capacity to make their own decisions were mentioned by most participants. Some family caregivers recalled instances where they felt their spouse (the patient) was not taken seriously, which resulted in delayed treatment. For instance, pain management was one aspect of care that two family caregivers found to be poor in current care.

Patient-reported outcome measures are one way to engage patients in their care. Patients were asked about the patient-reported outcome measure they filled at their appointments at the cancer clinic, specifically the ‘Putting Patients First’ checklist, which allows patients to rate their symptoms and other concerns.<sup>20</sup> Some patients found rating their symptoms allowed for reflection and opened the discussion with their healthcare providers. Most family caregivers helped their loved ones complete the checklist at the appointment. One caregiver mentioned there should be a checklist given to caregivers, as they are affected by their loved one’s illness too. Caregivers also noted that clinicians need to follow-up with patients after they fill out the checklist, even if patients rate their symptoms positively. For instance, one caregiver mentioned patients tend to underplay their symptoms, “when it’s a little pain, she’ll (patient) underplay just how bad the pain is and that actually had some consequences with it so I just want to recommend ... nurses and doctors really need to quiz the patient a little bit” (Caregiver B).

#### Readiness for advance care planning

Participants were asked about their views on advance care planning after the following definition was read

to them: “advance care planning is a way to help you think about, talk about and document wishes for healthcare in the event that you become incapable of consenting to or refusing treatment or other care”.<sup>21 22</sup> Most participants had not discussed advance care planning with their care providers. However, all participants noted the importance of planning for the future, and the importance of having these discussions with their care teams. Patients had mixed responses on the timing of discussions, as some preferred to have these discussions early on in their care, while others preferred to have advance care planning discussions near the end of life. Some participants perceived advance care planning as planning for end of life. One family caregiver spoke about the difficulties discussing future planning with their spouse (the patient), “I just know that with my husband. He doesn’t want to talk about it with me. I think it needs to be talked about and it’s very hard for me to have a conversation with him about it ...I’m a planner and he’s not and it’s a very hard subject to approach him on. He knows, he knows that he is gonna die at some time but then we all are, it’s just a matter of when” (Caregiver D).

However, all participants emphasised advance care planning discussions should be individualised to meet patient preferences and comfort level.

#### Access to care

Some participants discussed the distance to cancer care services as being a barrier. For instance, some participants spoke about appointments that would have been better as a phone call.

Additionally, most participants noted seeing more than one healthcare professional for their care (such as a therapist); however, most services were physically further apart from each other, “like the therapist. I have to really go across town to see her. I think when you’re diagnosed with something like that, having the support right there where you know you can just go to the next room” (Patient H).

## DISCUSSION

This study highlights current gaps in advanced cancer care related to the delivery of cancer care and early palliative care in Alberta and provides suggestions from the perspectives of patients and family caregivers on how these gaps can be addressed. The priorities mentioned by patients and family caregivers provide support for integration of an early palliative care approach in advanced cancer care. Patients and family caregivers highlighted the importance of communication in their experiences of cancer care, specifically communication that is respectful and compassionate. Communication between provider–patient is necessary for building good interpersonal relationships between healthcare providers and patients/families.<sup>23</sup> Most participants communicated with their cancer team consistently, and thus were able to develop a

trusting relationship with their cancer team. Those patients who had a negative experience regarding their diagnosis (eg, diagnosis delay), or did not communicate often with their family physician, were reluctant to receive care from their family physician.

Our findings aligns with Aabom and Pfeiffer.<sup>24</sup> They found that patients with advanced cancer often lose touch with their family physician, due to receiving treatment and developing relationships with their cancer team. In our study, some participants relied on their family physician for emotional and informational support. Similarly, Hall *et al*<sup>25</sup> found patients valued emotional, informational and instrumental support from primary care during cancer care (eg, medical information, reassurance about their experiences, practical and emotional support). Psychosocial needs such as managing daily life, emotions and social identity are often unmet in cancer treatment.<sup>24</sup> Family physicians are the first point of contact for patients into the healthcare system and are able to build long-term relationships. Therefore, family physicians should be involved in delivering primary palliative care such as psychosocial support to patients and their families. Family physicians play an important role, in collaboration with specialist teams (palliative care, oncology) to deliver all elements of effective early palliative care. However, when communicating and involving different healthcare teams (family physicians, specialist teams), attention to care coordination by clearly defining roles can mitigate confusion for both patients and families, and the healthcare teams themselves.

Patients and family caregivers in our study prioritised the need for elements of early palliative care. Our findings corroborate the benefit from an early palliative approach to care that is patient centred.<sup>7 26</sup> Elements of early palliative care include relationship and rapport building, helping patients cope with their illness and helping them to understand their illness.<sup>27</sup> Early palliative care focuses on patient engagement, information sharing and discussing preferences with regards to advance care planning, key concepts of patient-centred care.<sup>27</sup>

This study highlights a misunderstanding of palliative care. Most participants considered palliative care to be synonymous with end of life or death, and not as an added layer of support for people living with serious illness. From the patient's perspective, palliative care was not discussed with them at their appointments. Zimmermann *et al*<sup>28</sup> also found patients and caregivers misperceived palliative care to be synonymous with death in their study. Previous studies have found late referrals to palliative care services were inadequate for the provision of patient-centred care.<sup>29–31</sup>

Temel *et al*'s early palliative care intervention was associated with improved quality of life for patients with advanced cancer, as they were more likely to have discussed advance care planning (such as discussion of resuscitation preferences), experienced less

chemotherapy and longer hospice care.<sup>7</sup> Palliative specialist teams should work in collaboration with cancer teams and family physicians on presenting palliative care as an early support that can be implemented at all stages of an illness. The delivery of palliative care information should be consistent and routine, to mitigate stigma with the term. Based on our findings (negative perceptions of palliative care and mixed responses on the timing of advance care planning discussions), integration of an early palliative approach to care should be based on patient and caregiver needs. Participants valued the use of the *Putting Patients First* checklist to communicate with their cancer team about their symptoms and other concerns.

Currently, strategies to promote improved understanding of palliative care have been implemented in Alberta with the revision of patient education materials and digital resources. Additionally, a 'shared care letter' has been implemented in Calgary, highlighting the role of different care providers, including the family physician and oncologist in helping to manage care of patients.<sup>26</sup> The shared care letter aims to enhance communication between patients/families, family physicians and specialists to provide an effective early palliative approach to care.<sup>26</sup>

Most participants in our study had not discussed advance care planning with their care team, and therefore participant readiness for advance care planning discussions was mixed. Limited knowledge may impact timing of advance care planning discussions, a finding also mentioned by Shaw *et al*.<sup>32</sup> Advance care planning discussions need to be individualised to the patient.<sup>33</sup> An early palliative approach to care needs to embody patient and family engagement. Both patients and family caregivers from our study valued being involved in their care, and seen as an equal member of their care team. Thus, patient and family caregivers are being involved in the development of early palliative care pathways for advanced cancer in our province. Including patient and family advisors will allow for patient priorities to guide delivery of early palliative care. The implementation of an early care pathway in palliative care can improve patient and caregiver quality of life, improve symptom burdens and attend to needs of patients and families.

#### Strengths and limitations

A study strength is the patient-oriented methodology by including patient and family advisors and interviewing patients and family caregivers about their experiences to guide the development of the palliative care pathway.

We interviewed participants from two different geographical locations, thus telephone interviewing was most convenient, but it may present a potential limitation. One-time interviews limit rapport-building with participants hindering what they may share with the interviewer. However, Carr and Worth<sup>33</sup> found that

the quality of data obtained via telephone compared with face-to-face interviewing was not different.<sup>34</sup>

## CONCLUSION

This study identified patient and caregiver priorities for a provincial pathway to deliver early palliative care integrated with advanced cancer care. Key components prioritised by participants include patient-provider communication, care coordination and patient and family engagement in care. Participants wanted to be informed in shared decision-making and receive information about palliative care and advance care planning. Early palliative approaches to care should consider consistent and routine delivery of palliative care information, collaborations among different disciplines such as oncology, primary care and palliative care, and engagement of patients and family caregivers in the development of care pathways.

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**Data availability statement** All data relevant to the study are included in the article or uploaded as supplementary information. This study analyses qualitative data and the participants did not consent to have their full transcripts made publicly available. No additional data.

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