

This is a repository copy of *Patient and professional experiences of palliative care referral discussions from cancer services:a qualitative interview study*.

White Rose Research Online URL for this paper:

<https://eprints.whiterose.ac.uk/166696/>

Version: Published Version

Article:

Pini, Simon A, Hackett, Julia orcid.org/0000-0003-1720-6665, Taylor, Sally et al. (4 more authors) (2020) Patient and professional experiences of palliative care referral discussions from cancer services:a qualitative interview study. *European Journal of Cancer Care*. e13340. ISSN 0961-5423

<https://doi.org/10.1111/ecc.13340>

Reuse

This article is distributed under the terms of the Creative Commons Attribution-NonCommercial (CC BY-NC) licence. This licence allows you to remix, tweak, and build upon this work non-commercially, and any new works must also acknowledge the authors and be non-commercial. You don't have to license any derivative works on the same terms. More information and the full terms of the licence here: <https://creativecommons.org/licenses/>

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.



ORIGINAL ARTICLE

Patient and professional experiences of palliative care referral discussions from cancer services: A qualitative interview study

Simon Pini¹ | Julia Hackett² | Sally Taylor³ | Hilary L. Bekker⁴ | Suzanne Kite⁵ | Michael I. Bennett¹ | Lucy Ziegler¹

¹Academic Unit of Palliative Care, Leeds Institute of Health Sciences, University of Leeds, Leeds, UK

²Martin House Research Centre, Social Policy Research Unit, University of York, York, UK

³The Christie NHS Foundation Trust, Manchester, UK

⁴Leeds Unit for Complex Intervention Development (LUCID), Leeds Institute of Health Sciences, University of Leeds, Leeds, UK

⁵Leeds Teaching Hospitals NHS Trust, Leeds, UK

Correspondence

Simon Pini, Academic Unit of Palliative Care, Leeds Institute of Health Sciences, University of Leeds, Worsley Building, Clarendon Way, Leeds, UK.
Email: s.pini@leeds.ac.uk

Funding information

National Institute of Health Research under the Research for Patient benefit funding stream.

Abstract

Objectives: The aim of this paper was to identify current barriers, facilitators and experiences of raising and discussing palliative care with people with advanced cancer.

Methods: Semi-structured interviews were conducted with patients with advanced cancer and healthcare professionals (HCPs). Patients were included who had and had not been referred to palliative care. Transcripts were analysed using framework analysis.

Results: Twenty-four patients and eight HCPs participated. Two overarching themes and five sub-themes emerged:

Theme one—referral process: timing and triggers, responsibility.

Theme two—engagement: perception of treatment, prognosis and palliative care, psychological and emotional preparedness for discussion, and understanding how palliative care could benefit present and future care.

Conclusion: There is a need to identify suitable patients earlier in their cancer trajectory, address misconceptions about palliative care, treatment and prognosis, and better prepare patients and HCPs to have meaningful conversations about palliative care. Patients and HCPs need to establish and communicate the relevance of palliative care to the patient's current and future care, and be clear about the referral process.

KEYWORDS

advanced cancer, complex intervention development, interviews, palliative care, qualitative, shared decision-making

1 | INTRODUCTION

Early access to palliative care is recommended for patients with advanced cancer, as well as being applicable to patients facing any life-threatening illness (Bakitas et al., 2017; Ferrell et al., 2017; Hui et al., 2018; Sorensen et al., 2019; World Health Organization, 2015). Randomised controlled trials have shown early access to palliative care can improve quality of life, reduce acute hospital admissions, minimise aggressive cancer treatments, enable patients to make

choices about their end of life care and have survival benefits over standard care (Bakitas et al., 2009; Brumley et al., 2007; Hui et al., 2018; Rabow et al., 2004; Temel et al., 2010; Zimmermann et al., 2014). An important challenge for cancer services is to adopt practices enabling conversations about palliative options, and referral to palliative services earlier in the management of these patients.

In the UK, community-based palliative care services are delivered by hospices, which are specialist palliative care inpatient units, commonly with a team of clinical nurse specialists and doctors who will

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited and is not used for commercial purposes.

© 2020 Authors. *European Journal of Cancer Care* published by John Wiley & Sons Ltd

visit patients at home and help to co-ordinate care. Patients with advanced progressive diseases are referred for symptom management and psychosocial support for them and their families, which can be provided in conjunction with, or instead of, their disease specialist clinical teams. There is significant evidence palliative care referrals happen late in cancer trajectories, resulting in unnecessary treatments and reduction in potential patient benefits. A retrospective cohort study of 42,758 decedents from 64 UK hospices showed the median number of days between referral to palliative care and death was 53 days for patients with cancer (Allsop et al., 2018). This study showed, despite the perceived need for early inclusion of palliative care, patients with cancer were being referred to specialist palliative services late in their illness trajectory. Involvement of skilled palliative services can facilitate patients realising end of life preferences, such as dying at home, early advanced care planning, effective communication and co-ordinated care. Early involvement of community palliative services can significantly reduce aggressive end of life care (Henson et al., 2016), reduce symptom distress (Wadhwa et al., 2018) and significantly improve quality of life (Ziegler et al., 2018).

Healthcare professionals (HCPs) often acknowledge the importance of timely referral (Johnson et al., 2011), but also recognise referral does not usually occur in practice until a patient is nearing the end of life or experiences an acute episode (Charalambous et al., 2014; Johnson et al., 2011). Referring to palliative services late in the cancer trajectory limits potential benefits to current and future care (Bennett et al., 2016; Wadhwa et al., 2018). Barriers to referral reported by professionals have included the following: availability of palliative care teams (Bakitas et al., 2017; Sorensen et al., 2019), attempts to delay the termination of active treatment (Charalambous et al., 2014), abandoning the patient (Charalambous et al., 2014), difficulty initiating the conversation about palliative care, lack of a "palliative champion" (Marie Bakitas et al., 2018) and lack of expertise in dealing with end of life issues (Marie Bakitas et al., 2018). A qualitative study of specialist palliative care doctors and nurses in the UK added further barriers to referrals including close clinician–patient relationships; lack of role clarity; end of life discussions happening too late; and policy and organisational issues (McCaughan et al., 2018).

Previous research has shown patient barriers can include misconceptions regarding the role of hospices and palliative care nurses (Randall & Wearn, 2005), assumptions that palliative care was only for patients at the very end of life, and a lack of appreciation of the breadth of services provided (Tomlinson et al., 2012). The misconceptions reported by some studies suggested palliative care should be explained in more detail when it is first introduced (Randall & Wearn, 2005).

Interventions to enhance clinical conversations, or support shared decision-making, aim to help services provide options in a balanced way, to support patients and professionals reaching decisions based on best practice and patient values (Bekker et al., 2003; Brown et al., 2016). An essential first phase in developing an intervention to improve conversations about palliative care referrals was to discuss current practices and experiences with patients and professionals. This paper will focus on the findings of the

qualitative study and provide recommendations to inform a future intervention.

2 | METHOD

2.1 | Design

A qualitative interview study of professional and patient experiences of palliative care discussions and referrals. Ethical approval for this study was granted by the Office for Research Ethics Committees, Northern Ireland in December 2017. Data were gathered during 2018, who both have extensive experience of collecting qualitative data from patients in oncology and palliative care settings.

2.2 | Sample

Patients were eligible to participate whether they had been diagnosed with cancer considered to be incurable, were 18 years of age or over, were able to speak and understand English and able to give written informed consent, and had experience of being referred to palliative care, or who had yet to be referred. Patients were recruited between February and April 2018 from a regional cancer centre or a hospice, both in the north of England. Health professionals were eligible if they were providing care to adult cancer patients as an oncologist, general practitioner, clinical nurse specialist or palliative care doctor.

2.3 | Procedure

Eligible patients were identified and approached by oncologists, clinical nurse specialists or research nurses, and their details passed onto the research team if they consented to participate. Healthcare professionals from oncology and palliative care were approached by members of the research team and co-applicants. All participants were given information in advance about the intention of the study and the details of the researchers. Patients could choose to be interviewed in their own homes or in a participating hospice. Healthcare professionals were interviewed in their places of work. They were asked to reflect on their experiences of referring patients to palliative care and their views on working with these services.

Different semi-structured interview schedules were used for patients who had or had not been referred to palliative care and for HCPs (see File S1–S3). Interview schedules were created in collaboration with patient advisers and the clinical and research expertise within the research department. All participants were asked about their diagnosis background, their current treatment/care, their understanding of palliative care and their information needs/preferences. Those who had already been referred were asked to reflect on their experience of the referral process and how their thoughts about palliative care may have changed over time. Those who were yet to be referred were asked their thoughts on the prospect of

TABLE 1 Participant demographics and clinical details

Patients N = 24			
Gender	Male =13	Ethnicity	White British =23
	Female =11		White Eastern European =1
Age	Mean =72	Experience of palliative care	Yes =16
	Range =54-84		No =8
Cancer diagnosis	Prostate =5	Interview location	Own home =19
	Breast =3		Hospice =5
	Upper GI =3	Interview duration	Mean =44.27 Range =19-72
	Kidney =3		
	Lung =3		
	Lower GI =2		
	Renal =2		
	Bladder=1		
	Myeloma =1		
	Pancreatic =1		
Healthcare professionals N = 8			
Gender	Female =5	Job role	Specialist oncology nurse =2
	Male =3		Specialist palliative care nurse
			Oncologist =2
			Palliative clinician =2
			GP =1

being referred to palliative care. Interviews were audio-recorded and transcribed verbatim. Transcripts were anonymised, and pseudonyms were used on all study documents.

2.4 | Analysis

NVIVO version 10 was used to store and organise the transcriptions. Transcripts were analysed using for the following five stages of framework analysis (Ritchie et al., 1994): familiarisation; identifying a thematic framework; indexing; charting; mapping; interpretation. One researcher carried out all five stages of this process for all transcripts, with second coding conducted by another member of the team on 25% of the sample (four patient interviews and two healthcare professionals). Data from patients and HCPs were combined to provide a more complete picture of the referral conversations and process in order to inform the development of a decision-making or consultation aid.

3 | RESULTS

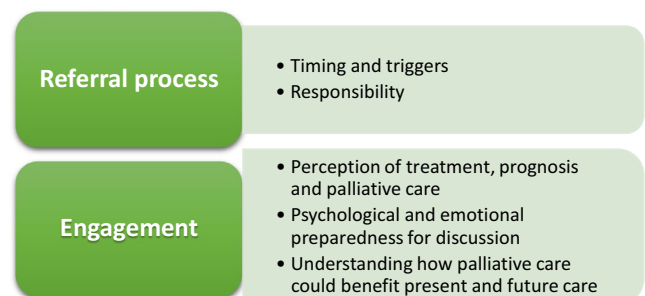
3.1 | Recruitment and interview data

Table 1 shows demographic details of the 32 participants. There was equal representation of gender and ten diagnostic groups, the most common being prostate cancer. Despite efforts to include a diverse

sample, the majority of participants were white British. Two-thirds had already been referred to palliative care services. The majority of interviews were conducted in the patient's home, and the mean duration was 44 min.

3.2 | Thematic framework

Two overarching themes emerged from the combined transcripts of patients and HCPs: referral process and engagement (Figure 1). These themes will be discussed in turn, with reference to sub-themes and example extracts (for additional extracts see Figure 2).

**FIGURE 1** Thematic framework

3.2.1 | Referral process

Participants described who initiated conversations about referral, when the conversation was held and what factors triggered the need for the introduction of palliative care.

Timing and triggers

Healthcare professionals reported referrals usually occurred “very close to the end of life”. However, some patients acknowledged the timing of the introduction of palliative care is complicated. If it happened when a patient was not prepared, or did not see the relevance,

then it could be frightening and distressing, but also damaging to the relationship with the HCP, whereas if it happened too late, then the patient could feel they had missed potentially beneficial services and care, or been exposed to unnecessary treatment.

“I think it's one of them things that if you did it too early you could scare the living daylights out of somebody. If you did it too late and then something happened to you you'd be in the wrong again 'cos you've missed out, then you say why weren't we told this.”—

Patient 2.

Theme 1 – Referral Process	
Timing and triggers	<p><i>“it's a kick in the teeth... 'you're going to die soon, yeah, push off, go talk to this lot they'll sort you out'. It's dismissive, it's irrelevant and it is a disservice both to the people that provide the palliative care and do a fantastic job and to people like me who aren't [ready] yet” – Patient 9</i></p> <p><i>“I don't think it's a case of abandoning hope...they haven't had the opportunity to understand that palliative care can be about so much more” – Patient 3</i></p> <p><i>“I didn't have much choice really...there was nothing else left” – Patient 21</i></p> <p><i>“palliative care is only relevant when you need somebody to stop excess pain” – Patient 19</i></p> <p><i>“a significant portion of our patients get referred very close to the end of life” – HCP 2</i></p>
Responsibility	<p><i>“the person to give it would be that nurse 'cos she's part of the care team you know, she knows what's happening, and you've got quite a good relationship with her, so she'd be quite a good person to have that conversation with because you built up that rapport” – Patient 10</i></p> <p><i>“I would assume a referral to palliative care is more for support and help rather than the medical side, because I assume that the medical side will still come from [the main cancer centre]” – Patient 6</i></p> <p><i>“I think because we all know that services are stretched, you don't feel confident that you're going to get the response you need as swiftly as you need it” – HCP 1</i></p> <p><i>“why would I risk the patient's wellbeing and comfort in the hope that it might give them a better outcome when actually I don't know that it will</i></p>

FIGURE 2 Example interview extracts

	<p><i>and I know that I've got control over the other end so I'll just carry on dealing with it" – HCP 1</i></p> <p><i>"if you've had a conversation with a consultant to say you know "I'm really sorry we can't give you anymore treatment I'm really sorry your disease has come back" and the CNS is taking you off for a conversation and at the end said "look you know I think you would benefit from a referral"...they've just not heard that conversation" – HCP 4</i></p>
Theme 2 - Engagement	
Perception of treatment, prognosis and palliative care	<p><i>"when I first heard I was really upset because they only gave me 5 months, but then I started having chemo and I just kept going on and I began to feel invincible" – Patient 3</i></p> <p><i>"I was told at one point I had about 18 months to live...but that came from a third party and I proved them wrong, that was 15 years ago... and I'm going to carry on fighting" – Patient 1</i></p> <p><i>"Yes and well I think most people do don't they? They think of [the Hospice] and think you're going there to die" – Patient 23</i></p> <p><i>"they obviously got something out of it by going to the hospice and talking to people there and doing jigsaws and things like that which I would absolutely hate" – Patient 11</i></p> <p><i>"I don't think patients necessarily know what they want...they don't know what's available, what it might achieve and therefore they can't make a real valued decision" – HCP 1</i></p> <p><i>"when you get people on their own, they almost always want to know...where they don't want to know, it's to protect other people" – HCP 5</i></p>
Psychological and emotional preparedness for discussion	<p><i>"to be absolutely honest I've shied away from that because, well once you talk about palliative care, that's</i></p>

FIGURE 2 Continued

Patients who had experienced palliative care almost unanimously wished it had happened earlier and the reality of being involved in these services was significantly different to their prior perceptions. When discussing the timing of their referrals, many said the conversation happened around common trigger points, such as exhaustion of treatment options, uncontrolled and increasing pain, progressive scan results, acute hospital admissions or events, physical or psychological limitations, or concerns voiced by professionals, family or friends. HCPs highlighted the same common trigger points, the most prevalent being exhaustion of curative treatment options.

"it's probably three paths actually; you become not curative and switch emphasis, or you've had curative treatment and then you recur or relapse, or you're palliative at the point of diagnosis...for all three routes, the point at which you intervene with palliative care you know is wildly is different isn't it"–

HCP 4.

Healthcare professionals acknowledged the referral criteria and process varied depending on specific diagnosis groups, the professional

	<p><i>serious” – Patient 14</i></p> <p><i>“I’ve got a grown up son and a daughter, my daughter lives at the bottom of the road...and they both keep in touch and they both make sure that their elderly mother’s occupied, so I’ve got a good family support network..” – Patient 15</i></p> <p><i>“almost always if there’s a family of half a dozen people, there’d be somebody in there who takes the view that by stopping treatments that might change the way in which the cancer grows, we are making death inevitable and were we to continue to do things which might change the way in which the cancer grows, death might just not be inevitable” – HCP 1</i></p>
<p>Understanding how palliative care could benefit present and future care</p>	<p><i>“As soon as you know if it’s going to be helpful, you need it...yeah soon as you know it’s going to be, you’re going to benefit from the...care given” – Patient 4</i></p> <p><i>“that information for me 3 years ago...it would have been so wrong. That would have been the mental image I would have had in my head for these 3 years that I didn’t need...when I need it that’s when it’s appropriate” – Patient 19</i></p> <p><i>“if you’ve run out of medicine they give you that straight away...they also tell you what’s best, how to take it and what not to do and what you can expect” – Patient 20</i></p> <p><i>“you’re keeping me alive to keep me sat in a hospital waiting room, what’s the point...I really appreciate the fact that you’re keeping me alive but I want to be alive to have a life” – Patient 5</i></p> <p><i>“there’s also the knowledge that it’s helping you live life while you’re here, and then when it comes to the end it will be coped with and managed” – Patient 17</i></p>
	<p><i>“I’d like to stretch out how long I’ve got left for about another 2 years ‘cos my daughter wants to get married” – Patient 21</i></p>

FIGURE 2 Continued

making the referral and the needs and resources of the service receiving the referral.

Responsibility

Patients described a variety of professionals introducing palliative care to them, including hospital-based consultants, hospital-based nursing staff, GPs and community-based nursing staff. Patients

preferred palliative care to be introduced by someone who they had “built up a good rapport with”.

Healthcare professionals discussed the importance of having regular experience in conducting palliative care conversations. Depending on job role, this could be difficult for HCPs and could result in a degree of anxiety about what to cover, how and who to refer, and how the patient might respond.

"I think it's about how often they have these conversations and of course the more practiced they are, the more confident they feel, so it will also depend on where you are"—

HCP 2

Patients had different preferences for, and understanding of, who had responsibility for their care after a referral. Some did not want to fully leave the care of the hospital-based oncology services because of their perception of the cancer expertise of the team and their familiarity with the professionals and settings.

Several HCPs were not confident a referral to community palliative care would be accepted or reliably meet the needs of patients. Some acknowledged services varied geographically and were often oversubscribed, which could result in delays or refusals of referrals. These factors resulted in some HCPs retaining control over the care of patients they would otherwise like to refer. HCPs thought this was a particular problem for patients who had no more active treatment options, had a poor prognosis, but were not currently struggling with significant physical symptoms.

It seemed patients had been given a degree of choice within the referral process, although some were happy for it to be a decision taken by the professionals. However, the extent to which patients were aware a referral had been made and what would happen as a result of the referral was variable. This resulted in some patients feeling uninvolved in the process and surprised or distressed by subsequent contact from palliative healthcare professionals.

"[the nurse said] 'Well a referral will have been made', I said well if it has no one's told me about it, and that really, really upset me"—

Patient 8.

Some HCPs recognised this could be a problem and often attributed it to patients "*just not being able to hear that*" because of the distressing nature of the conversations.

3.2.2 | Engagement

Patient and HCP interviews showed patients arrived at conversations about palliative care with different states of preparedness to engage with this subject. The data suggested their state of preparedness was influenced by their perception of their treatment, prognosis and palliative care, their psychological and emotional position and their understanding how palliative care could improve their present and future care.

Perception of treatment, prognosis and palliative care

Many patients' perception of the relative success of their current treatment and the availability of future treatments appeared to influence their interaction with palliative care conversations. Some

patients linked treatment to hope, and therefore, maintaining active treatment was akin to maintaining hope.

"it's one thing being told you've got cancer, but knowing that you're going to get chemotherapy you know you've got hope. It's another when erm all hope's gone" –

Patient 3

This association appeared stronger when the patient experienced treatments working successfully to control symptoms and/or had previously moved from one treatment to another with a perception of success.

Some patients were not ready to accept their prognosis and that there were no longer viable curative options. In some cases, the patient thought treatment was curative whereas the HCP had always viewed it as palliative. Patients sometimes referenced distressing experiences of originally being told their prognosis and how they had outlived those predictions. This left some patients with a level of distrust surrounding prognostic estimates, which meant they were not as willing to accept the need to discuss palliative care.

Patients who were pre-referral demonstrated a lack of awareness of the nature of palliative care services, with most describing it as care reserved for the very end stages of life. HCPs described how this could make it difficult for patients to engage in conversations and make informed decisions. The stigma around palliative care was not simply about death and dying, but also about an emphasis on sharing feelings and engaging in activities, which could be barriers to hospice referrals for some patients.

Psychological and emotional preparedness for discussion

Some patients discussed intentionally avoiding thinking about the future or the possibility treatment may not be successful. Patients with this approach were not emotionally or psychologically prepared to entertain these thoughts or take the first steps to have these types of conversations, often thinking that "*once you talk about palliative care, that's serious isn't it*".

Patients often linked their need for palliative care to the strength of the existing support around them. They either had good support around them and therefore did not need a hospice referral, or they lived alone and valued the extra support.

"They're there, because I've got nobody else, I'm on my own, so it's done me good, really good" –

Patient 14

Some HCPs highlighted the influence family or friends had on a patient's perception of palliative care by pushing to maintain active treatment and the associated hope of long-term survival.

Understanding how palliative care could benefit present and future care

When patients recognised the benefit of palliative care to managing their symptoms, particularly pain, this seemed to be a

significant facilitating factor in palliative involvement. The majority of patients who were pre-referral said they would only want to be referred “as soon as you know it's going to be helpful”, and often stated this would be a last resort. Some HCPs agreed they only raised palliative care when it became clearly relevant to the patient's current situation.

“there's so much to talk about, that if they don't need it now then why are we talking about it?”—

HCP 1

Patients needed to see how palliative care could improve their current care. For some, this involved easier access to prescriptions, and quicker responses to queries. Patients had different perspectives on the benefit of regular contact with the main cancer centre. Some felt anxious about reducing contact with their regular oncology team. Others welcomed the opportunity to have fewer appointments, be in a less busy environment, and have their care in more local services.

Patients who had been referred to palliative care also explicitly and implicitly described how being in the hospice setting gave them a positive feeling of being cared for and nurtured. This was often through factors like friendly and attentive staff, home-cooked food, enjoying the company of others, engaging in activities, and being in a comfortable and peaceful setting.

“I think the reality is that in hospital it's process led, it's system led and I think at [the Hospice] it is more patient led, they are prepared to do things that are much more patient focussed”—

Patient 17.

Some patients were receptive to palliative care because of worries about end of life. Those patients who wanted to avoid dying in hospital, and had accepted their palliative prognosis, seemed grateful for specialist help with planning their end of life care. Patients in this situation valued the opportunity to build familiarity with palliative care staff and settings in advance.

Some patients discussed having personal milestones they wanted to be healthy enough to attend, such as the marriage of a son or daughter, or seeing grandchildren. These factors became a primary focus for some and facilitated their engagement with palliative treatments.

4 | DISCUSSION

This study identified factors important to patients, HCPs, services and consultation when moving between cancer treatments and palliative options. These factors will inform the development of a future intervention to improve the practice of discussing palliative care with patients with advanced cancer. A strength of this study was the sample of patients who had been referred to palliative care services and those who had not, which allowed the opportunity to collect retrospective and prospective accounts of these experiences. The

inclusion of HCP experiences identified similarities with patient perceptions of early discussion of palliative care.

Timely introduction of palliative care is an important facilitating factor to successful referrals (Fliedner et al., 2019; McCaughan et al., 2018; Taylor et al., 2018); however, our study showed the timing of these conversations remains difficult for patients and HCPs. Dedicating time to discussing a patient's current perception of their health, treatment and prognosis has been shown as a key underlying factor in successful palliative care trials (Bakitas et al., 2017) and can enhance understanding of palliative services and the relevance to future care (Fliedner et al., 2019). Research suggests referrals to palliative care could be enhanced by regular prognostic conversations with patients following any progressive scan results in the cancer pathway, so it becomes a familiar conversation (Singh et al., 2017). Wentlandt et al encourage routine ‘preparation dialogue’ between patients, HCPs and families to help prepare for all aspect of the dying process (Wentlandt et al., 2012). Although this could result in an additional hour spent with each patient per month and extra burden on already pressured services (Bakitas et al., 2017). Due to the potentially distressing nature of these conversations, and the complexities of patient, HCP and service factors, it seems a specific approach to the introduction of palliative care may be needed to minimise distress and facilitate patient engagement. A recent structured intervention to introduce palliative care showed patients found this approach beneficial despite initial distress about the subject, but also suggests little is known about how patients experience these types of interventions (Fliedner et al., 2019).

Our findings resonate with evidence from other research and suggest a future intervention to support successful discussions about palliative care earlier in the referral process needs to include the following elements for both patients and HCPs: emotionally prepared for the conversation, appreciation of treatment options and prognosis, a clear understanding of the potential relevance of palliative care to the individual patient's current and future care needs, and an understanding of the referral pathways.

For patients to appreciate the relevance of palliative care to their current and future care, they need to accurately understand what palliative care means. Several studies suggest assessing and understanding patient perspectives to better involve them in decision-making around palliative care (Bakitas et al., 2017; Fliedner et al., 2019). Patients and HCPs discussed barriers relating to issues of stigma and misunderstandings around palliative care, which has also been shown in previous research (Randall & Wearn, 2005; Tomlinson et al., 2012). Despite the term palliative care still being stigmatised in the minds of patients, only 21% of HCPs in a recent study supported renaming the specialty “supportive care” (Sorensen et al., 2019). As well as stigma about palliative care, our study showed patients could have misconceptions about their treatment or prognosis, and were often emotionally and psychologically unprepared for the conversations. Our study also showed the influence family and friends could have on the patient's perception of palliative care. Indeed, a recent intervention encouraged empowering patients to engage their social networks in future care planning (Fliedner et al., 2019).

Palliative care clinicians have been shown to assess patient understanding more frequently and comprehensively than oncologists (Thomas et al., 2019); however, it is often the primary oncologist who delivers prognostic information to patients and starts conversations about palliative care (Wentlandt et al., 2012). Our study supported other research highlighting the importance of palliative care being introduced by a healthcare provider with a good relationship with the patient (Fliedner et al., 2019).

Patients and families often find the range of professionals and services involved in palliative cancer care overwhelming (Jarrett et al., 2017). There is also evidence of confusion within community and hospice palliative care services themselves about who has responsibility for patient care, which can hinder continuity of care for patients and successful integrated care (Payne et al., 2017; Sorensen et al., 2019). Our study showed confusion also exists around the process of referral, so even when a patient had a conversation about palliative care resulting in a referral to palliative services, they were sometimes unaware a referral had been made or what this process entailed.

5 | CONCLUSION

Our study suggests there is a need to identify suitable patients earlier in their cancer trajectory, address misconceptions about palliative care, treatment and prognosis, and better prepare patients and HCPs to have accurate and meaningful conversations about palliative care. Patients and HCPs need to establish and communicate the relevance of palliative care to the patient's current and future care, and this could be more successful when the patient is emotionally prepared for the conversation and understands the factors involved. HCPs need to consider who has the most appropriate relationship with the patient, be clear who will have responsibility for patient care post-referral, and ensure the patient understands the referral process. We will use these findings to inform the development of an intervention to improve the timing, content and clarity of palliative care conversations. This will enable patients to access appropriate services at an appropriate time and decide this in active collaboration with their HCPs.

6 | LIMITATIONS

The limitation of this study is it includes participants from only one area in England. It is likely there is geographical variability in palliative care practices, which will influence patient and HCP experiences and implementation of future interventions. The demographics of our sample also made it difficult to assess the known influence of cultural beliefs on people's perspective on palliative care.

CONFLICTS OF INTEREST

There are no conflicts of interest for any authors of this paper.

ORCID

Simon Pini  <https://orcid.org/0000-0001-8455-3240>

REFERENCES

- Allsop, M. J., Ziegler, L. E., Mulvey, M. R., Russell, S., Taylor, R., & Bennett, M. I. (2018). Duration and determinants of hospice-based specialist palliative care: A national retrospective cohort study. *Palliative Medicine*, 32(8), 1322-1333.
- Bakitas, M., Dionne-Odom, J. N., Pisu, M., Azuero, A., Babu, D. S., Gansauer, L. J., Sullivan, M. M. (2018). *Integrating the ENABLE early palliative care approach in community cancer centers: Results of an implementation trial*. American Society of Clinical Oncology.
- Bakitas, M. A., El-Jawahri, A., Farquhar, M., Ferrell, B., Grudzen, C., Higginson, I., Temel, J. S., Zimmermann, C., & Smith, T. J. (2017). The TEAM approach to improving oncology outcomes by incorporating palliative care in practice. *Journal of Oncology Practice*, 13(9), 557-566. <https://doi.org/10.1200/jop.2017.022939>
- Bakitas, M., Lyons, K. D., Hegel, M. T., Balan, S., Barnett, K. N., Brokaw, F. C., Byock, I. R., Hull, J. G., Li, Z., Mckinstry, E., Seville, J. L., & Ahles, T. A. (2009). The project ENABLE II randomized controlled trial to improve palliative care for rural patients with advanced cancer: Baseline findings, methodological challenges, and solutions. *Palliat Support Care*, 7(1), 75-86. <https://doi.org/10.1017/S1478951509000108>
- Bekker, H. L., Hewison, J., & Thornton, J. G. (2003). Understanding why decision aids work: Linking process with outcome. *Patient Education and Counseling*, 50(3), 323-329.
- Bennett, M. I., Ziegler, L., Allsop, M., Daniel, S., & Hurlow, A. (2016). What determines duration of palliative care before death for patients with advanced disease? A retrospective cohort study of community and hospital palliative care provision in a large UK city. *British Medical Journal Open*, 6(12), e012576. <https://doi.org/10.1136/bmjopen-2016-012576>
- Brown, E. A., Bekker, H. L., Davison, S. N., Koffman, J., & Schell, J. O. (2016). Supportive care: Communication strategies to improve cultural competence in shared decision making. *Clinical Journal of the American Society of Nephrology*, 11(10), 1902-1908.
- Brumley, R., Enguidanos, S., Jamison, P., Seitz, R., Morgenstern, N., Saito, S., McIlwane, J., Hillary, K., & Gonzalez, J. (2007). Increased satisfaction with care and lower costs: Results of a randomized trial of in-home palliative care. *Journal of the American Geriatrics Society*, 55(7), 993-1000. <https://doi.org/10.1111/j.1532-5415.2007.01234.x>
- Charalambous, H., Pallis, A., Hasan, B., & O'Brien, M. (2014). Attitudes and referral patterns of lung cancer specialists in Europe to specialized palliative care (SPC) and the practice of early palliative care (EPC). *BMC Palliat Care*, 13(1), 59. <https://doi.org/10.1186/1472-684x-13-59>
- Ferrell, B. R., Temel, J. S., Temin, S., & Smith, T. J. (2017). Integration of palliative care into standard oncology care: ASCO clinical practice guideline update summary. *Journal of Oncology Practice*, 13(2), 119.
- Fliedner, M., Zambrano, S., Schols, J. M., Bakitas, M., Lohrmann, C., Halfens, R. J., & Eychmüller, S. (2019). An early palliative care intervention can be confronting but reassuring: A qualitative study on the experiences of patients with advanced cancer. *Palliative Medicine*, 33(7), 783-792. <https://doi.org/10.1177/0269216319847884>
- Henson, L. A., Gomes, B., Koffman, J., Daveson, B. A., Higginson, I. J., & Gao, W. (2016). Factors associated with aggressive end of life cancer care. *Supportive Care in Cancer*, 24(3), 1079-1089. <https://doi.org/10.1007/s00520-015-2885-4>
- Hui, D., Hannon, B. L., Zimmermann, C., & Bruera, E. (2018). Improving patient and caregiver outcomes in oncology: Team-based, timely,

- and targeted palliative care. *CA: A Cancer Journal for Clinicians*, 68(5), 356–376.
- Jarrett, N., Porter, K., Davis, C., Lathlean, J., Duke, S., Corner, J., & Addington-Hall, J. (2017). Palliative care patients' perceptions of the work involved in understanding and managing the network of care provision surrounding them. *BMJ Support Palliat Care*, 7(2), 133–139. <https://doi.org/10.1136/bmjspcare-2014-000781>
- Johnson, C., Girgis, A., Paul, C., Currow, D. C., Adams, J., & Aranda, S. (2011). Australian palliative care providers' perceptions and experiences of the barriers and facilitators to palliative care provision. *Supportive Care in Cancer*, 19(3), 343–351.
- McCaughan, D., Roman, E., Smith, A. G., Garry, A. C., Johnson, M. J., Patmore, R. D., Howard, M. R., & Howell, D. A. (2018). Palliative care specialists' perceptions concerning referral of haematology patients to their services: Findings from a qualitative study. *BMC Palliat Care*, 17(1), 33. <https://doi.org/10.1186/s12904-018-0289-1>
- Payne, S., Eastham, R., Hughes, S., Varey, S., Hasselaar, J., & Preston, N. (2017). Enhancing integrated palliative care: What models are appropriate? A cross-case analysis. *BMC Palliat Care*, 16(1), 64. <https://doi.org/10.1186/s12904-017-0250-8>
- Rabow, M. W., Dibble, S. L., Pantilat, S. Z., & McPhee, S. J. (2004). The comprehensive care team: A controlled trial of outpatient palliative medicine consultation. *Archives of Internal Medicine*, 164(1), 83–91. <https://doi.org/10.1001/archinte.164.1.83>
- Randall, T. C., & Wearn, A. M. (2005). Receiving bad news: Patients with haematological cancer reflect upon their experience. *Palliative Medicine*, 19(8), 594–601.
- Ritchie, J., & Spencer, L. (1994). Qualitative data analysis for applied policy research. In A. Bryman & R. G. Burgess (Eds.), *Analyzing qualitative data* (pp. 173–194). Abingdon: Routledge.
- Singh, S., Cortez, D., Maynard, D., Cleary, J. F., DuBenske, L., & Campbell, T. C. (2017). Characterizing the nature of scan results discussions: Insights into why patients misunderstand their prognosis. *Journal of Oncology Practice*, 13(3), e231–e239.
- Sorensen, A., Wentlandt, K., Le, L. W., Swami, N., Hannon, B., Rodin, G., & Zimmermann, C. (2019). Practices and opinions of specialized palliative care physicians regarding early palliative care in oncology. *Supportive Care in Cancer*, 1–9.
- Taylor, S., Wyld, L., Ziegler, L., & Bennett, M. I. (2018). Is patient information on palliative care good enough? A literature review and audit. *Cancer Nursing Practice*, 17(4).
- Temel, J. S., Greer, J. A., Muzikansky, A., Gallagher, E. R., Admane, S., Jackson, V. A., Dahlin, C. M., Blinderman, C. D., Jacobsen, J., Pirl, W. F., Billings, J. A., & Lynch, T. J. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *New England Journal of Medicine*, 363(8), 733–742. <https://doi.org/10.1056/NEJMoa1000678>
- Thomas, T. H., Jackson, V. A., Carlson, H., Rinaldi, S., Sousa, A., Hansen, A., Kamdar, M., Jacobsen, J., Park, E. R., Pirl, W. F., Temel, J. S., & Greer, J. A. (2019). Communication differences between oncologists and palliative care clinicians: A qualitative analysis of Early, Integrated Palliative care in patients with advanced cancer. *Journal of Palliative Medicine*, 22(1), 41–49.
- Tomlinson, K., Barker, S., & Soden, K. (2012). What are cancer patients' experiences and preferences for the provision of written information in the palliative care setting? A Focus Group Study. *Palliative Medicine*, 26(5), 760–765.
- Wadhwa, D., Popovic, G., Pope, A., Swami, N., Le, L. W., & Zimmermann, C. (2018). Factors associated with early referral to palliative care in outpatients with advanced cancer. *Journal of Palliative Medicine*, 21(9), 1322–1328.
- Wentlandt, K., Burman, D., Swami, N., Hales, S., Rydall, A., Rodin, G., Lo, C., & Zimmermann, C. (2012). Preparation for the end of life in patients with advanced cancer and association with communication with professional caregivers. *Psycho-Oncology*, 21(8), 868–876.
- World Health Organization (2015). *Strengthening of palliative care as a component of integrated treatment within the continuum of care*. 2014. 134th session. EB134, 7.
- Ziegler, L. E., Craigs, C. L., West, R. M., Carder, P., Hurlow, A., Millares-Martin, P., Hall, G., & Bennett, M. I. (2018). Is palliative care support associated with better quality end-of-life care indicators for patients with advanced cancer? A Retrospective Cohort Study. *British Medical Journal Open*, 8(1), e018284. <https://doi.org/10.1136/bmjopen-2017-018284>
- Zimmermann, C., Swami, N., Krzyzanowska, M., Hannon, B., Leigh, N., Oza, A., Moore, M., Rydall, A., Rodin, G., Tannock, I., Donner, A., & Lo, C. (2014). Early palliative care for patients with advanced cancer: A cluster-randomised controlled trial. *Lancet*, 383(9930), 1721–1730. [https://doi.org/10.1016/s0140-6736\(13\)62416-2](https://doi.org/10.1016/s0140-6736(13)62416-2)

SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

How to cite this article: Pini S, Hackett J, Taylor S, et al. Patient and professional experiences of palliative care referral discussions from cancer services: A qualitative interview study. *Eur. J. Cancer Care*. 2020;00:e13340. <https://doi.org/10.1111/ecc.13340>