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The communication experiences of persons referred to specialist palliative care services and their carers: A descriptive phenomenological study

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Abstract

Objectives. Effective communication during specialist palliative care (PC) referral is linked to improved health outcomes. Initiating a conversation about PC is difficult and poor communication can lead to stigma. The aim of this descriptive phenomenological study was to explore the communication experiences of persons referred to specialist PC services and their carers and explore strategies to improve such experiences.

Methods. Purposive sampling was used to recruit 17 participants who were either receiving specialist PC and/or caring for someone who was receiving specialist PC. Participants were recruited from a hospice. Inductive thematic analysis was conducted.

Results. Four themes were identified: (i) The why, who, what, when, where, and how of PC referral; (ii) initial thoughts and feelings about referral to PC; (iii) enhancing the communication of PC referral; and (iv) addressing practical needs during PC referral. Participants were referred either through their general practitioner or oncologist. Initially, participants linked PC referral to death. This perception changed when participants started availing of the services. Compassion, empathy, hope, privacy, in-person communication, individualized referral, and information dosing were identified as building blocks for effective communication. Participants stressed the importance of raising public awareness of PC and addressing the practical needs of individuals being referred.

Significance of results. The communication of PC referral should be tailored to meet the individual needs of patients and carers. Delivering clear and simple information is important to help patients and carers understand and accept the referral.

Introduction

Palliative care (PC) focuses on providing relief from the symptoms and stress of a serious illness, regardless of prognosis. It can be initiated at any stage of the illness and can occur alongside curative treatments (Center to Advance Palliative Care 2024). Hospice care is a specific type of PC defined in some jurisdictions as the care offered to patients during the last six months of life (Sheikh et al. 2022). In Ireland, where the current study was conducted, hospice care is offered regardless of prognosis. It is defined as "the care offered to patients when the disease process is at an advanced stage. The term may be used to describe either a place of care (i.e., institution) or a philosophy of care, which may be applied in a wide range of care settings" (Health Service Executive 2012, p. 4). In Ireland, specialist PC services are provided by an interdisciplinary team specialized in PC under the leadership of a consultant physician in palliative medicine (Health Service Executive 2012). Specialist PC can be offered in several settings including hospitals, hospices, community-based services, outpatient clinics, and at home (Radbruch et al. 2020).

Early referral to PC is associated with improved symptom control, mood, quality of life, and carer satisfaction (Temel et al. 2010; Zimmermann et al. 2014). Patients who access specialist PC early are more likely to participate in decisions about end-of-life care and less likely to receive futile treatments (Haun et al. 2017; Temel et al. 2017). Of the 40 million people globally in need of PC, only 14% are in receipt of it (World Health Organization 2020). Timely referral to specialist PC remains problematic (Hui et al. 2018). Late referral leads to suboptimal symptom management, increased suffering, failure to discuss or adhere to advance care planning, and unplanned hospital deaths (Hausner et al. 2021; Humphreys and Harman 2014).

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Table 1. Semi-structured interview guide

Main questions	Probes
I would like you to think back to the time you had your first conversation around involving palliative care. Can you talk to me about that?	Who was involved in the referral/initial communication? Who was with you when you were referred? Where did you get referred? When did you get referred? Why were you referred?
What were your initial thoughts and feelings when palliative care was first recommended?	You mentioned [answer], why do you think these were your initial thoughts and feelings about palliative care?
Have your thoughts and feelings about palliative care changed over time?	If yes, how? If no, why not?
How did your doctor (or other healthcare professional) discuss palliative care with you?	Language used, tone, demeanor, and so on.
What did you think about the timing of your referral to palliative care?	Was it late? early? should have happened sooner?
Is there anything that you would change about the way your doctor (or other healthcare professional) discussed palliative care with you?	If yes, what would you have liked them to say?
Do you have any recommendations to improve the way palliative care is communicated to patients, their families, and significant others?	Language, tone, recommended format to deliver the information, person delivering the information, timing, place, and so on.

With the growing aging population and high prevalence of chronic illnesses, the demand for PC is set to rise exponentially. It is therefore imperative that issues around timely access to PC are addressed. Several barriers to patients' access to timely PC exist, with communication serving as a key barrier to timely PC delivery (Back 2020; Sarradon-Eck et al. 2019). Despite population-level preferences of more than 70% who want to be informed about options regarding PC if faced with a serious illness, patients and caregivers report inadequate communication about PC (Collins et al. 2018a, 2018b). Clinician-reported communication barriers include fears of diminishing patients' morale, prognostic uncertainty, perceived lack of adequate training for such discussions, and difficulty judging the appropriate timing of these discussions prevents clinicians from practicing early referral to PC (Schildmann et al. 2013; Von Roenn et al. 2013). In their systematic review, Hui et al. (2012) reported a lack of clear-cut definitions as well as terminological confusion for many important terms used in the supportive and palliative oncology literature. This compounds the difficulties faced by clinicians in interpreting the evidence.

The communication landscape in the context of early PC delivery is therefore fraught, with communication representing both, a core component of and barrier to early PC referral. As a result, patients often have unmet information needs and misconceptions about PC (Gace et al. 2020). The aim of this study was to explore the communication experiences of persons referred to specialist PC services and their carers and explore strategies to improve such experiences.

Methods

A descriptive phenomenological study was conducted (Holloway and Galvin 2017). Purposive sampling was used to recruit adults receiving specialist PC within a hospice and/or their carers (i.e., someone providing ongoing and significant levels of care to a person due to illness, disability, or frailty) (Health Service Executive 2023). Participants were eligible for inclusion regardless of when the PC referral took place and regardless of the setting to which they were first referred.

Participants were recruited from a university hospital and hospice in the south of Ireland. Study posters with the contact details of the researchers were displayed in the hospice. The clinical team in the hospice invited persons receiving PC and carers to participate. Interviews were arranged with interested individuals.

Study documents were reviewed by three members of Voices4Care; a group comprising persons receiving PC, carers of people with PC needs, and citizens interested in PC (All Ireland Institute of Hospice and Palliative Care 2023). The study was approved by the Clinical Research Ethics Committee at University College Cork (ECM 08/2023/PUB). Participants provided written informed consent and were provided with the contact details of the hospice's department of family support and social work.

Data were collected by a senior academic between August and December 2022 using a semi-structured interview guide (Table 1). Socio-demographic data were collected using a questionnaire. Data collection was flexible, accounting for the preferences of persons receiving specialist PC, work commitments of carers, and COVID-19 restrictions. Participants chose to be interviewed either individually or within a dyad, in the hospice or virtually. Interviews were audio-recorded, lasting around 40 min.

Data collection and analysis were concurrent to identify emerging themes. Data were analyzed in NVivo (QSR International Pty Ltd 2020), using inductive thematic analysis (Braun and Clarke 2006). Each transcript was read and relevant excerpts were extracted then coded. Over 600 codes were generated and transferred to a coding sheet (Saab et al. 2022). Similar codes were grouped to form sub-themes, which were then used to construct themes. Interviews with persons receiving PC, carers, and dyads were coded separately, then triangulated.

To enhance credibility and dependability, codes were cross-checked by two researchers and data saturation was sought (Lincoln and Guba 1985). Transferability was enhanced through thickly describing the study procedures and seeking data saturation (Amankwaa 2016). Confirmability was improved through source triangulation where the experiences of persons receiving PC, carers, and dyads were compared to tell a rich and comprehensive story (Patton 1999). Reflexivity was enhanced through memoing (McGrath 2021), whereby the interviewer audio-recorded his reflections on the process and content of each interview.

Results

Participants

Authors believed that data saturation was achieved at the 12th interview. A 13th interview was conducted to confirm data saturation. Of the 13 interviews, six were conducted with persons receiving PC,

Table 2. Socio-demographic characteristics of study participants (N = 17)

Characteristic		
Age in years: mean (range)	60.4	(36–85)
	N	**%**
Role in current study		
Person receiving palliative care	10	58.8
Carer	7	41.2
Carer's relationship with the person receiving palliative care		
Spouse	4	57.1
Daughter	2	28.6
Parent	1	14.3
Gender		
Female	11	64.7
Male	6	35.3
Nationality		
Irish	17	100
Marital status		
Married	12	70.6
Single	3	17.6
Divorced	2	11.8
Primary diagnosis		
Cancer	16	94.1
Neurological disease	1	5.9
Time since first palliative care referral		
<1 month ago	5	29.4
1–3 months ago	1	5.9
4–12 months ago	7	41.2
>12 months ago	4	23.5

four with dyads, and three with carers, yielding a sample size of 17 participants. Most interviews (n = 9) were conducted in-person. Participant characteristics are presented in Table 2.

Four themes emerged from the data: (i) The why, who, what, when, where, and how of PC referral; (ii) initial thoughts and feelings about referral to PC; (iii) enhancing the communication of PC referral; and (iv) addressing practical needs during PC referral (Table 3). The letter "P" is used to present findings from persons receiving PC, the letter "C" is used for carers, and the letter "D" for dyads.

Theme 1: The why, who, what, when, where, and how of PC referral

Participants provided a detailed account of their experience of specialist PC referral. They discussed reasons for the referral (why), the referrer (who), characteristics of the referrer (what), timing of the referral (when), the place of referral (where), and the way referral was communicated to them (how).

Complications from the primary diagnosis and its treatment were among the most cited reasons for PC referral. Loss of independence and the increased complexity of needs were also mentioned as triggers for referral. This led some participants to believe that referral to PC was the only option and, at times, the last resort:

> *"…over in* [hospital], *one of the doctors said to me 'you are not going to be able to manage on your own at the moment' and I was saying 'why not?' and he said 'no you are not' but then I realised no way because it was actually taking three of them to take me in and out of the bed. So that was when it* [PC] *was discussed"* (P4).

In most cases, participants were referred by their general practitioner or consultant. Fewer were referred by public health nurses or contacted directly by the PC team. For some, PC was first mentioned by an acquaintance who was familiar with the services:

> *"It was suggested that they...well, I suppose it was by the GP* [general practitioner] *originally, that the* [hospice] *nurses would come out to the house to see my husband and it evolved from there then that the nurse who was coming to us, she suggested my husband would benefit maybe by going into* [hospice]*"* (C3).

Referrer characteristics varied, with some participants describing their referrer as *"sensitive"* (C1), *"compassionate"* (D2), *"kind"* (D3) and *"open"* (P1). Negative experiences of referral were also reported whereby some participants believed that their referrer had poor communication skills, particularly when PC was first introduced:

> *"He* [doctor] *was examining me, and he saw…my biliary drain and he said 'gosh.' It just be the first or second time I was with him, I was nauseous, very nauseous, and he said, 'you need help now, and you should get on to your oncologist about palliative care.' I went 'palliative care?!' As bad as I knew I was, palliative care is something I didn't want to listen to at that time because I was fighting away. Although I knew I was terminal, I think he could have given me stages…he could have said 'do you know about palliative care?'…that was a little bit…strong…because I mean you are…vulnerable anyway, when you are the patient sitting there…he is very nice, but he just didn't have the proper approach…"* (P2).

In terms of timeliness of the referral, there was a split in responses, with some participants believing that the timing was right for them, since an earlier referral would have been distressing:

> *"We were fighting hard. We were fighting really hard, and it wasn't until we had those final scan results that we realised the way things were going, and if she had been referred to palliative care before that point, I think it would have been quite distressing"* (C2).

Others reported delays in PC referral caused either by the referral process taking longer than anticipated or by patients concealing the severity of their symptoms:

> *"It's not that anybody did anything wrong, God knows they did not. I think I done wrong because I wouldn't tell people things – I'm an awful man for holding stuff...it is hard to get it out. If I'm in pain, I like to be on my own. I don't like suffering in front of other people…and...that's the reason why I think it* [PC] *could have been given earlier, because nobody knew, but when they found out they acted quick"* (P5).

For many, PC referral took place in a shared hospital room. As a result, concerns around privacy and dignity were expressed:

> *"My husband was onto me…this person wants to see you and this person... I said, 'listen…what we were told* now [about PC referral], *that is my private business…I'm not a circus act, I'm not going to be sat here inside in the bed in the hospital, or otherwise, and have people traipsing in and out, looking at me and saying, 'ah God love her, and the poor creature'…I thought it was monstrous to be told behind a curtain, a paper curtain…it's awful"* (P3).

Table 3. Themes, sub-themes, and sample codes

Themes	Sub-themes	Sample codes
The why, who, what, when, where, and how of palliative care referral	Why: Reasons for referral	• Complications from the primary diagnosis and/or treatment
		• Loss of independence and increased need for help/assistance
		• Palliative care as the only option
	Who: The referrer	• Referral by general practitioners and consultants/ oncologists
		• Referral by Public Health/Home Care Nurses
		• Direct contact from the hospice
		• Referral by a neighbor
	What: Referrer characteristics	• Sensitive, supportive, and compassionate
		• Casual and open
		• Withholding and/or not conveying information clearly
		• Poor communication skills/lacking compassion and empathy
	When: Timing of referral	• Referral timing was right
		• Delays and stress relating to timing
	Where: Place where the referral occurred	• In the hospital
		• At home
	How: The way referral was communicated	• Referral in the presence of a carer
		• Distress caused by referral without the presence of a carer
		• Lack of privacy during referral
Initial thoughts and feelings about referral to palliative care	Shock, surprise, and confusion	• Shock when palliative care was first discussed
		• Surprise and unexpected referral
		• Confusion after the first palliative care conversation
	Fear	• Fear of the hospice, the unknown, and of death
		• Terror when initially told about the hospice
		• Fear of loss of independence
	Initial hesitation and lack of readiness	• Initial refusal to go to the hospice because of hope
	Acceptance/expected referral	• No shock or surprise
		• Referral needed to happen
		• Took referral in stride
Enhancing the communication of palliative care referral	Compassion, empathy, and hope	• Allocate sufficient time to give information to allow everyone to process it
		• Talk about palliative care with hope
		• Compassion and empathy are key when delivering information
		• Understand the people you are speaking to
	Privacy during communication	• Give the information in a family room
		• Information about palliative care should be given in private area
	In-person communication	• Cannot replace in person interaction
		• Verbal communication is better
		• Talk about palliative care face to face

(*Continued*)

Table 3. (*Continued.*)

Themes	Sub-themes	Sample codes
	Individualized person-centered referral	• Breaking the news about palliative care depends on the person
		• No ideal situation to give information about palliative care
	Information dosing	• One chunk of information
		• One thing at a time
		• Give information slowly so patients can understand
	Dedicated persons to communicate the referral	• Have a nurse that just deals with your case
		• Consultant should be the one to discuss palliative care
		• Liaison person to communicate rather than an oncologist
		• Somebody who is specifically tasked to give information
	Perspectives on carer involvement in the referral	• Have support of partner there when having conversation about palliative care
		• Family member should be with you to talk about referral
		• Just the doctor is needed to talk about palliative care unless the person wants somebody else
	Preference for early referral	• Earlier input from palliative care would have helped
		• Discussing and involving palliative care early
	Informing the public about palliative care	• Try [hospice] and can leave if you do not like
		• Take the word palliative out of information given because it scares people
		• Education to understand palliative care and its benefits
Addressing practical needs during palliative care referral	Lack of clarity around practical and social support entitlements	• Blind to what we were entitled to
		• List of entitlements is needed to make people aware
		• Learned about entitlements accidentally
	Addressing financial concerns	• Do not want to think about finance when you are sick
		• Head cleared once finances were sorted
	System-level changes	• Change the healthcare system to be more proactive
		• Same music when waiting for [hospice] to answer phone. Use different music
		• Nurse name tags could be bigger to help patients read them in [hospice]
	Booklets, leaflets, and videos	• Booklet with common questions and entitlements
		• Booklet using simple and broken-down English
		• Leaflet explaining practicalities and positivity of palliative care
		• Videos and case studies to show benefits of palliative care

Some participants were referred at home by an acquaintance who was a healthcare professional. This was perceived as positive. Persons receiving PC and their carers were often *"pretty adamant that we were told* [about PC] *together"* (D2). Others, however, were referred on their own with no prior preparation and without the presence of a carer. Words like *"distressing"* (C2) and "*impersonal"* (C2) were used to describe such referrals.

Theme 2: Initial thoughts and feelings about referral to PC

PC referral often came *"as a big shock"* (D1) and was unexpected among participants who were still *"living a life"* (P2). Such feelings were frequently underpinned by societal and cultural misbeliefs around the hospice being exclusively a place where patients *"comfortably die"* (D4) and are "*never going to come out"* (P6). Feelings of hopelessness were discussed by some participants who initially believed that a referral to PC meant giving up hope:

> *"She* [patient] *was asked herself…would she move to* [hospice]*? And she said, 'no' because we were still extremely hopeful. But then the next day she was extremely tired. She wasn't getting any sleep...the decision was to go there* [hospice] *to have privacy and peace and to be able to get some sleep...we were still a bit hopeful…but I guess we knew ourselves from speaking with the doctors that things weren't looking good…"* (C2).

For other participants, admission to the hospice meant *"leaving* [their] *independence out in the car park"* (P2). The same participant, however, changed her perspective once she started availing of the services:

> *"What you have to do is turn the page and open the book properly – and let them* [healthcare team in the hospice] *in to care for you…no good battling it in a quiet nice way, open up, and the day I realised that – and I opened up and I just sort of said well, 'they can have what is left of me now'* [laughing]*"* (P2).

Dealing with their diagnosis over the years led some participants to become hardier and acceptive of death. For them, PC referral did not come as a shock and was indeed expected:

> *"I think I knew I was going to come* [to the hospice]*, because I knew that phone call was going to come because of the stages I was at and how much cancer was in my system…I wasn't totally shocked that I got the phone call"* (D1).

Theme 3: Enhancing the communication of PC referral

The importance of compassion and empathy and the value of allocating sufficient time to communicate the referral were highlighted:

> *"Back to our old friends compassion and empathy, I think they are really key…have someone who is compassionate and empathetic and can really convey that* [PC referral]*…you need to allocate a sufficient amount of time…so that the person or the people in the group who are hearing this* [referral] *can sit with it and maybe you can process it a little bit together, as opposed to having it a rushed option…in like 90 seconds, or three minutes, and 'oh I have to go now'"* (D2).

One participant recommended that medical students *"should have an aptitude leaving their academic abilities out of it altogether...in communication"* (C2). The importance of openness and honesty during referral and beyond was also discussed:

> *"Open and honest and timely communication is so important in palliative care – not just from the point of referral, but the whole way through"* (C1).

Instilling hope during the referral was emphasized

> *"You could say palliative for a little while giving hope to the person…if you're terminal like I am…so saying, 'listen why don't we try palliative care for a little while with you and see how you get on'…"* (P2).

The environment in which the information about PC referral is delivered was discussed. Privacy was particularly mentioned as key:

> *"Definitely private – not in a public, an open ward. It should be either in a clinic or a private ward. Definitely private. I wouldn't be inclined to do it in a public place"* (P4).

Participants believed that conversations about PC must happen verbally and in person:

> *"With me verbal is always much better than anything written down. Because the human touch is there…anyone can read a page…but someone talking to you heart-to-heart is a human. It is a human trait we all have, one-to-one…"* (P2).

The "one size fits all" approach was perceived as ineffective in broaching the referral. Instead, participants suggested that the referral should be individualized:

> *"…it's different for everybody. Some people are really private, and they want to hear that* [PC referral] *on their own. Some people are super vulnerable, and they'd like to have as much support around them as possible. So, I imagine there's no best way that suits everybody…it would totally depend on the type of person you are and the type of relationships that you have…"* (D2).

There was a divide in responses to the question regarding information dosing whereby some participants preferred that information regarding the referral is delivered in *"one chunk"* (D4), while others wanted the information to be delivered slowly:

> *"Give it* [information about referral] *to me slowly, that I can understand, and I know what you're saying to me, and I can understand it. Because I'm not a person for taking things into my brain. They go in and they go faster than they go in"* (P6).

When asked about the ideal person to deliver the information about referral, responses also varied. Participants recommended either the doctor, nurse, or a person specifically tasked with communicating the PC referral:

> "*I have* [nurse] *as I call her 'my cancer nurse.' If I need to know anything and if I think of something I can just ring* [nurse] *up 'you know* [nurse]*, I'm not feeling well today, what can I do to sort this out?' And* [nurse] *will get back to me – she can answer me there and then, or sometimes she might have to get back to me and say 'look, do this and this,' If you could have that as well for the* [hospice] *it would be great. I felt as if there was a connection there…"* (D1).

While most participants preferred that a carer is present during referral, others stated that this decision should be made by the person being referred to PC:

> *"Everybody wants somebody there. You have to have moral support, you have to have family support…you take that away, and leave a vulnerable person on their own, with white coats all around him, telling him what he's going to do...with his special set of difficulties...it's very, very wrong"* (D4).

Early PC referral was deemed crucial, particularly when the person being referred is still relatively stable and can develop rapport with the referrer. One bereaved carer said:

> *"Early referral is better…the patient is relatively well, stable, and they can develop a rapport with the person speaking about palliative care…I feel that we could have discussed some of the deeper stuff, the more real stuff if there had been a palliative input kind of earlier on in the journey because when we got to that point, and actually dad deteriorated a huge amount once he was referred to palliative care, there wasn't really time or space to do a lot of that"* (C1).

Theme 4: Addressing practical needs during PC referral

Several participants were unaware of the social support entitlements and benefits that they were eligible for and had to look these up themselves:

> *"We came out blind out of the hospital. There were people who were telling us what we were entitled…there should be a list, basically given that you may be entitled to this, this, this, this, or this. So, if you are made aware of what's there, and then if you want to apply then you can apply, and you may be entitled and then you may not, but at least you'd be aware of what's there…"* (D1).

As a result, this dyad developed a booklet with the list themselves and shared it with another person who was going through a similar experience:

> *"There's a friend of mine now going through it* [PC] *with her daughter and I gave her the list that we had, that we went through, and she was very appreciative of it. She didn't know which way to turn"* (D1).

When probed on how information on PC and entitlements can be delivered, participant provided several practical recommendations. A *"small little booklet to explain to people what palliative care is and what it's all about"* (P3) was recommended. Leaflets were also recommended, mainly to demystify the hospice and highlight the *"positivity of palliative care"* (C3). A video was recommended by one participant to educate the public about PC:

> *"Videos I suppose with case studies, and things like that would work well…what are the…benefits of palliative care from a family members aspect or point of view, or a patient, and yes to take some of the fear of the unknown away from...for people"* (C1).

Even when participants were aware of entitlements, benefits, and services available to them, they expressed frustration due to bureaucracy and the effort and time it took them to avail of such services:

> *"Looking at Social Services, I had to fight. I fought for over six weeks to get rent allowance, down in* [county]. *Six weeks! And every time you fill in a form, 'oh no, this is the wrong form, you've got to fill in that form,' and then you fill in that form and 'oh no, this is the wrong form, you should have filled in the first form.' I said, 'but I gave you all.' So I took all the forms that they gave me, three different types of forms…60 pages!"* (P1).

Participants called for a *"more proactive instead of reactive"* (P1) healthcare system. Recommendations for system-level changes varied widely. For instance, one carer made the following recommendation:

> *"The nurses there* [in the hospice], *they wear their names obviously, but I think they could be bigger. People can't...well certainly my husband can't read them, and it's nice if you're talking to somebody you can say, whether it's so and so..."* (C3).

Discussion

Participants recalled a spectrum of emotions when referencing referral to PC; ranging from welcoming the referral as assisting with managing loss of independence and the increased complexity of needs, to referral being a shock, something they feared and did not want to hear. Such negative emotions often coupled the term "palliative care" with societal and cultural misbeliefs around the hospice being the end of the line, exclusively a place where patients do not leave and die comfortably. In their systematic review of 28 studies, Saretta et al. (2022) highlighted several barriers to effective PC communication with older people, including a reticence to engage in the conversation, limited suitable occasions, and lack of time in acute settings for conversations to introduce PC. They also highlighted the potential confusion in terminology between PC, end-of-life care, and hospice care. Such confusion and resulting stigma may be rooted in the history of the evolution of PC from the "hospice movement" (Hui et al. 2022; Ryan et al. 2020). In their review, Hui et al. (2022) acknowledged that PC is a scare resource and maximizing the impact on patients requires timely referral, which is rooted in the prevention of suffering paradigm where possible. Thus, there is a need to increase awareness of PC as incorporating expertise in improving outcomes early in the course of illness right through to planning for and supporting end-of-life care.

In their qualitative study of oncology providers' perspectives of navigating the introduction to the PC team, Collins et al. (2022) acknowledged that this is a longitudinal interdisciplinary team discussion rather than a once-off discussion characterized by using judiciously selected and pre-prepared language; framing PC in terms of symptom control and as additive to usual care. Scherrens et al. (2022) explored family carers' ($n = 16$) perspectives and found that the family carers' social influence, knowledge of and attitudes towards PC can be determinants that can contribute to their loved one starting PC.

Robust evidence supporting early PC referral for patients with advanced cancer continues to emerge with subsequent evidence that substantial improvement in early referral rates have been noted in some studies (Hausner et al. 2021). This, however, is not uniform internationally and could be improved by having symptom scores and prognostic parameters to make referral more routinized (Müller et al. 2022); implementation of a PC referral system (Pigni et al. 2022); and early and progressive integration of PC into the patient pathway which is based upon the needs of patients and the evidence underpinning optimal care. Such system-level interventions are contingent on important and early two-way evidence informed open person-centered conversations about PC which introduce patients and their families to PC and its benefits early in the course of a life limiting illness.

Limitations

The sample was relatively homogenous, limiting the transferability of findings. Due to COVID-19 restrictions, in-person interviews were conducted while wearing a surgical face mask and some interviews were conducted virtually, adding a barrier to communication.

Conclusions

Addressing challenges to communication is key to ensuring timely and smooth transition into specialist PC services. Sensitivity, support, compassion, openness, and privacy were highlighted as the cornerstones of conversations around PC referral. While the use of communication frameworks like the setting, perception, invitation or information, knowledge, empathy, summarize or strategize framework can help facilitate such conversations (Kaplan 2010), the way PC referral is communicated should be tailored to meet the individual needs of patients and carers. Communication training of clinicians is key to ensuring effective communication of specialist PC referrals.

Hope-shifting can help address feelings of hopelessness experienced during referral. This involves instilling hope through the introduction of achievable short-term goals such as ensuring comfort, reducing suffering, and managing complex symptoms like pain (Hagerty et al. 2005).

Future real-world research should focus on strategies to overcome barriers to early PC referral, with an emphasis on effective communication. Societal and cultural misbeliefs surrounding PC ought to be explored in greater depth and addressed accordingly. The voice of both, persons receiving PC and carers must be captured in such research.

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