

Initial perceptions of palliative care: An exploratory qualitative study of patients with advanced cancer and their family caregivers

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Abstract

Background: Despite evidence for early integration of palliative care for people with advanced cancer and their families, patterns of late engagement continue. Prior research has focused on health professionals' attitudes to palliative care with few studies exploring the views of patients and their carers.

Aim: To explore initial perceptions of palliative care when this is first raised with patients with advanced cancer and their families in Australian settings.

Design: Cross-sectional, prospective, exploratory qualitative design, involving narrative-style interviews and underpinned by an interpretative phenomenological framework.

Setting/participants: Purposively sampled, English-speaking, adult patients with advanced cancer ($n=30$) and their nominated family caregivers ($n=25$) recruited from cancer services at a tertiary metropolitan hospital in Melbourne, Victoria, Australia.

Results: Three major themes evolved which represent the common initial perceptions of palliative care held by patients with advanced cancer and their carers when this concept is first raised: (1) diminished care, (2) diminished possibility and (3) diminished choice. Palliative care was negatively associated with a system of diminished care which is seen as a 'lesser' treatment alternative, diminished possibilities for hope and achievement of ambitions previously centred upon cure and diminished choices for the circumstances of one's care given all other options have expired.

Conclusion: While there is an increasing move towards early integration of palliative care, this study suggests that patient and caregiver understandings have not equally progressed. A targeted public health campaign is warranted to disentangle understandings of palliative care as the 'institutional death' and to reframe community rhetoric surrounding palliative care from that of disempowered dying to messages of choice, accomplishment and possibility.

Keywords

Qualitative research, patient, caregiver, cancer, perception, attitude, palliative care

What is already known about the topic?

- Late engagement with palliative care continues despite growing evidence of the benefits of early integration of palliative care for patients with advanced cancer and their carers.
- There are several barriers to palliative care integration which span across patient, family, health professional and health system factors.
- Few studies in Australia and internationally have explored the perceptions of palliative care held by patients with advanced cancer and their caregivers.

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What this paper adds?

- Current perceptions held by patients and carers continue to perpetuate notions of palliative care as exclusively end-of-life care, which is understood to mean the dying phase consisting of final days in a hospital facility.
- Palliative care was negatively associated with a system of diminished care which is seen as a 'lesser' treatment alternative, diminished possibilities for hope and achievement of ambitions previously centred upon cure and diminished choices for the circumstances of one's care given all other options have expired.
- Commonly feared aspects of dying such as limited choices for care, increasing dependency and being hospitalized, have in turn, come to be associated with the care of the dying and hence be incorporated into understandings and narratives about palliative care.

Implications for practice, theory or policy

- While there is increasing health system focus on early integration of palliative care in order that benefits are realized, this study suggests that understandings of patients and carers have not equally progressed.
- In order that we reduce the significant stigma that remains associated with palliative care, there is a clear need for a targeted public health campaign aiming to change the narrow understandings of palliative care and reframe underlying narratives of disempowered dying.

Introduction

Palliative care is an approach which aims to maximize the quality of life of people living with serious illness and their families. Accordingly, faced with the likelihood of death from serious illness, patients report clear preferences that align with the goals of palliative care.^{1,2} Specifically, patients want to know what to expect, feel prepared for death, have pain and symptoms controlled, have support for family and have the opportunity to achieve a sense of 'life completion'.² In addition, a majority of patients report a desire to die outside hospital^{3,4} and are opposed to medical interventions resulting in poor health, valuing quality as well as extension of life.¹

An increasing number of Phase II⁵⁻⁷ and Phase III⁸⁻¹¹ controlled studies have confirmed the benefits of early integration of palliative care for people with advanced cancer and their families. Yet, data from several countries including those thought to have 'well integrated' palliative care systems¹² suggest a continuation of late referral.¹³⁻¹⁵ Australian data are consistent with these patterns, with initiation of palliative care occurring at a median of 30 days prior to death¹⁶⁻¹⁸ and often in the final hospital admission.¹⁹ Late engagement occurs despite significant contact with the health system, with 70%–89% of patients with cancer being hospitalized in the final months of life.^{20,21}

A number of studies have reviewed and identified barriers to palliative care integration and highlight several dynamic factors relating to patients, families, physicians and the health system,²²⁻²⁴ which are negotiated in the context of strongly held public attitudes to death and dying.²⁵ However, a majority of the prospective studies informing our understanding have focused on the views of health professionals.²⁶⁻³¹ These studies commonly cite physician fears of upsetting patients or destroying hope associated with presumed negative attitudes towards palliative care as a key barrier to the introduction of palliative care.²⁸

By contrast, there is a paucity of studies exploring the perceptions of palliative care held by patients with advanced cancer and their family caregivers.³²⁻³⁵ One recent Canadian study reported patients and caregivers initially associate palliative care with death, hopelessness, dependency and end-of-life comfort care for inpatients.³⁵ Given the limited evidence base, we aimed to explore initial perceptions of palliative care when this is first raised with patients with advanced cancer and their family caregivers in Australian settings. This was conducted with a view towards developing future education interventions or strategies that may improve early integration, access and community involvement in palliative care.

Methods**Design**

This study utilized a cross-sectional, prospective, exploratory qualitative design. Reporting was guided according to the consolidated criteria for reporting qualitative studies (COREQ).³⁶ Ethical approval was obtained from the Human Research Ethics Committee at St Vincent's Hospital Melbourne (LRR 070/15), and all participants provided written consent.

Study setting

Participants were recruited from cancer services at a tertiary metropolitan hospital in Melbourne, Victoria, Australia. In this system of care, patients may access disease-directed therapies and palliative care concurrently. Specialist palliative care teams are available via referral to the hospital-based consultation service, physician-led outpatient clinics, inpatient palliative care beds, as well as home-based nursing

services. All patients recruited for this study were eligible to access these palliative care services as required.

Participants

Participants were adults (>18 years) diagnosed with selected common, non-curative solid malignancies (metastatic lung, prostate or breast cancer) or high-grade, relapsed non-Hodgkin's lymphoma (NHL) and their nominated family caregivers. Caregivers were spouses, relatives or friends involved in the patients' care and a subset were interviewed during bereavement. Bereaved caregivers were known to the treating hospital as the next of kin for a previously eligible patient who died 6 months to 2 years earlier. All participants were required to speak English and be able to provide informed consent, with no significant cognitive, psychiatric or physical morbidity that would inhibit their participation.

Recruitment and data collection

Consecutive patients attending inpatient and outpatient services of oncology, haematology and palliative care were screened for potential eligibility and then purposively sampled. A broad range of perspectives was sought across a number of socio-demographic and clinical factors, including patient's diagnosis, functional status, setting of care and prior exposure to palliative care. A research nurse independent from usual care approached selected patients about study inclusion during a hospital visit. Permission was also sought to approach a nominated carer. Bereaved carers were invited to participate by letter from the former treating physician and those who opted in were then contacted for an interview.

In-depth, exploratory interviews of 40–120-min duration were conducted by one interviewer (A.C.) from June 2015 to March 2016 using techniques from narrative interviewing.³⁷ Narrative-style interviews use storytelling as a specific technique to elicit experiences around a particular topic and begin with one broad leading question, namely, 'Perhaps to begin you could tell me a little about your cancer story'. Particular topics of interest (e.g. palliative care) are then prompted for at an appropriate time in response to relevant issues that may arise within the participants' freely narrative dialogue.³⁷ Thus, interviews were characterized by long stretches of unbroken talk by the research participant, in between the interviewer reflecting back narrative themes and drawing out or focusing in on more tentative connections to developing ideas.³⁷

Flexibility in the interview guide allowed the interviewer to carefully navigate difficult topics raised within the interview as appropriate. In particular, initial attitudes to palliative care were explored in different ways depending on the person's previous experience with this service. For those not yet referred to palliative care, participants' first reactions to this service were elicited when this

concept was raised within the interview. For those who had previously accessed palliative care at the time of interview (patients, $n=14$; carers, $n=13$), participants' were prompted to reflect on their initial reaction when this service had first been introduced to them.

Interviews were held in a setting preferred by the participant (home, $n=8$; outpatient, $n=18$; inpatient, $n=29$). When a patient and their carer both opted to participate, a dyad interview was undertaken if requested, and data were analysed separately ($n=7$). Interviews were recorded and transcribed verbatim before being analysed. Data collection occurred simultaneously with preliminary immersion in the data and continued until participants ceased to introduce new concepts and saturation was determined.

Data analysis

Analysis of interview data was conducted using methods from interpretative phenomenology. This specific framework was selected due to its focus on the individual's perception of experience, enabling a rich and novel understanding of individual's initial attitudes to palliative care that builds upon our current knowledge.³⁸ Grounded in symbolic interactionism,³⁹ interpretation is central to this analysis form, with the themes identified derived from the analyst's personal interaction with, and interpretation of the meaning of interview dialogue.³⁸ Initial immersion in the data was undertaken by one author (A.C.) to obtain a sense of the whole. Two investigators (A.C. and J.P.) performed the initial identification of the title themes, which were later discussed and refined together with a third investigator (S.-A.M.).

A cyclical approach to analysis was taken, beginning with particular examples and overtime developing more general categorization as follows: (1) individual transcripts were repeatedly read. (2) Emerging 'title themes' arising from the text that captured the essence of what was said were noted. (3) Where relevant, connections between the emerging title themes were formed to develop clusters of titles that shared common elements, thus developing major or subordinate themes. (4) New title themes appearing in later interviews were tested against previous interview data. (5) Once all interviews were individually analysed, master lists of themes from each interview were then analysed together to form consolidated themes across the data set.³⁸ Analysis derived a number of key themes, and this article reports the first part of analyses arising from the full data set, focusing on initial understandings of palliative care when the concept was first raised.

Results

Participant characteristics

A total of 489 consecutive oncology patients were screened for potential study inclusion, and from this cohort, 48

Table 1. Characteristics of participants at time of recruitment ($n=55$).

Characteristics	Patients, n (%)	Family carers, n (%)
	$n=30$	$n=25$
Age in years, median (range)	62 (37–86)	59 (21–78)
Sex, female	17 (57)	18 (75)
Married or partnered	15 (50)	18 (72)
Australian country of birth	21 (70)	17 (68)
Home residence: alone (patient); with patient (carer)	8 (27)	15 (63)
Regionality		
Metropolitan	21 (70)	18 (75)
Regional/rural	9 (30)	7 (25)
Patient's primary tumour site		
Lung	10 (33)	11 (46)
Prostate	5 (17)	4 (17)
Breast	10 (33)	5 (21)
Non-Hodgkin's lymphoma	5 (17)	5 (21)
Median time since patient diagnosis of advanced cancer (range), months	10 (3–96)	
Patient's performance status		
ECOG score 0–1	15 (50)	8 (33)
ECOG score 2	8 (27)	4 (16)
ECOG score 3–4	7 (23)	7 (28)
Deceased	–	6 (24)
Setting at recruitment		
Outpatient oncology/haematology	14 (47)	6 (24)
Inpatient oncology/haematology/surgery	10 (33)	8 (33)
Inpatient palliative care	6 (20)	5 (20)
Bereavement	–	6 (24)
Primary reason for hospital admission		
Treatment	18 (60)	7 (28)
Symptom management	7 (23)	9 (36)
End-of-life care/bereavement	5 (17)	9 (36)
Previous referral to palliative care	14 (47)	13 (52)
Relationship to patient		
Spouse or partner	–	13 (52)
Son/daughter	–	8 (32)
Other	–	4 (16)

ECOG: Eastern Cooperative Oncology Group.

eligible patients were purposively approached. Upon meeting, 5 patients were too unwell for interview though nominated their carer for participation, leaving 43 eligible patients. Of these, 6 declined involvement in the study, resulting in a response rate of 86% (37 of 43 were eligible). Subsequently, two patients rapidly deteriorated and died, two patients had increased breathlessness and were unable to participate and three patients were having treatment at an alternative hospital site and unavailable for interview. The final patient cohort comprised 30 people (57% female) aged a median of 62 years with an advanced cancer diagnosis of metastatic breast ($n=10$), lung ($n=10$) or prostate ($n=5$) cancer or relapsed NHL ($n=5$; Table 1).

Of the 48 patients approached for family carer inclusion, 19 did not have an available carer or chose not to

nominate someone, and 3 were considered to be inappropriate for interview, leaving 29 eligible carers. Of these, 3 carers declined involvement in the study, resulting in a response rate of 90% (26 of 29 were eligible). Subsequently, five carers became unavailable for interview. The final carer cohort comprised 25 family carers including 19 current and 6 bereaved carers (75% female) who were mostly spouses (52%) aged a median of 59 years.

Initial perceptions of palliative care

Three major themes evolved from the analysis ($n=55$), revealing the common perceptions of palliative care initially held by patients with advanced cancer ($n=30$) and their family carers ($n=25$): (1) diminished care, (2)

Table 2. Diminished care.

Non-medically focused care	Palliative care is basically <i>just</i> a nurse system to look after patients. (P21) I think that palliative care is the nursing care you get right at the end of your life when you could be taken into hospice. (P9)
Only pain relief	I thought palliative care was very basic ... you know, <i>just</i> a bed in a hospital where someone was attached to a morphine pump and that's where they stayed until they passed away. (C20) Palliative care is <i>just</i> a waiting process where they control the pain, so you're not in pain, and then you just waste away. (C14)
Focus on comfort	I think the underlying thing is <i>just</i> to make sure I'm <i>comfortable</i> at this stage. (P34) Palliative care is when you go into a hospital, and get looked after so you're <i>comfortable</i> , and then that's it. (C15)

Table 3. Diminished possibility.

A place to wait for death	Palliative care is <i>just</i> the <i>place</i> you go but you don't come home. (P10) I assumed palliative care was <i>just</i> a <i>place</i> to pass away, if you couldn't go back home or the services weren't in place for you to go back home. (C20)
An end to perceived hope	A lot of people don't see palliative care see as a treatment option, it's not a treatment option, it's that end of the line, like this is it. I think of a lot of the other therapies and medicines and things like that, they see is a hope whereas palliative care is not hope. (BC2) I know it [palliative care] is the start of the slippery slope. (P31) The term 'palliative care' is frightening, cause it's the dead-end road for you. (C05)
A time of dependency	Palliative care is services for people when they can no longer do things themselves. (P33) Palliative care is people <i>doing things for you</i> towards the end. (P03) Palliative care is for people who need help – they're at the stage where they could pass away, and they need help. (BC1)

diminished possibility and (3) diminished choice. These perceptions represent participants' initial reactions or responses to palliative care when this concept was first raised.

The themes were consistent across patient and caregiver groups and reveal the inherently negative and commonly held initial understandings of palliative care as being inpatient nursing care when there are no other anti-cancer treatment options available. Across the prevailing themes, an overall narrative of 'disempowered dying' evolves whereby commonly feared aspects of dying such as limited choices for care, increasing dependency and being hospitalized, have in turn, come to be associated with the care of the dying and hence be incorporated into understandings and narratives about palliative care.

Diminished care. The theme 'diminished care' reveals participants' underlying views of palliative care as non-medically focused and has come to be considered even non-'expert' care (Table 2). Most participants reported notions of palliative care as nursing-led care in an institution at the end of life and described it as 'basic care', or 'just' pain relief or 'just' focus on 'comfort'. Notably, participants frequently used the term 'just' when referring to palliative care, with implications of being perceived 'lesser', or more basic or inactive care compared to alternative possible 'active' care teams. Participants did not report perceptions of palliative care that recognized it as a *medical* speciality delivered by a multi-disciplinary team

and provided, in part, by doctors with specialist training in pain and symptom management.

Diminished possibility. The theme 'diminished possibility' describes how participants perceived palliative care as a place to wait for death, given an end to earlier hopes for survival, and now expected increasing dependency on others for care (Table 3). The mention of palliative care was therefore understood by participants as 'time is running short' or 'the start of dying', perceived by most to mean that time was now limited to days or weeks of life. With the cessation of anti-cancer treatments that were previously pursued as a means of continued hope for cure, the initiation of palliative care was associated with limited possibilities to achieve one's goals. Similarly, increasing dependency on others was now expected since earlier held hopes for survival had ceased.

Diminished choice. The last theme, 'diminished choice' reflects participants' perceptions of palliative care as something that is forced upon them by the health system when no other choices for care remain (Table 4). Narratives about palliative care as diminished individual choice were commonly entangled with perceptions of 'institutionalized dying' or what people perceive it is like to die in hospital. Specifically, if dying in hospital, it was understood that 'they' (the institution/palliative care) got to choose the terms of the death including if and when they needed to 'put you somewhere'. In line with this

Table 4. Diminished choice.

Institutionalized dying	Mum was so incredibly fearful of palliative care and the institution not listening to her needs. For mum, palliative care was associated with this fear of someone's going to decide how I feel as I die. She was very careful of getting into the hospital palliative care system and people not listening to her. She was very concerned that if she got into that process that that would happen. (BC3) My first reaction to palliative care is that you're dying and <i>they're</i> going to put you somewhere. But maybe that's not what it means? (P28)
Choice limited to 'controlled dying' (euthanasia) or 'dying out of control' (palliative care)	Palliative care ... what's that? Nah! No, I don't want them. I've got enough doctors ... They'll tell me I'm not allowed to mow my lawn or something. Nah. No, not worried about doing that. (P26) Mum was just absolute fear of being out of control of her care and pain ... I think that the euthanasia debate drove mum's fears about palliative care because it portrays this whole thing about, 'I don't have the right to do what I want ...' It appeared like either you've got that option which is the no pain, I'm in control, I don't have to live through stuff ... or this other option which is you go into something you've got no influence, no say, it's all terrible. It's that kind of extremes. (BC3)
Care for when you're <i>told</i> no other choices remain	I think the community conversation about palliative care has to be about choice. It can't just remain, as it's currently perceived, where you're either dying in pain or we put you down. There hasn't been that conversation around how, with palliative care, you can actually die with dignity. (BC5) If things got worse, I might ask for assisted dying or I might ask my doctors for palliative care. (P16) Palliative care is when you're <i>told</i> , 'Okay, she needs palliative care now, goodbye'. And then we go into this room, and wait. (C09) Palliative care is when the <i>hospital</i> says, 'There's nothing more we can do'. (C20)

understanding, choices were accordingly understood to be limited to one of the two polarized options: a 'controlled, painless death', that is, euthanasia, or, the 'slow, painful hospital death beyond my control', that is, palliative care.

Discussion

This study is among the first in Australia and internationally to directly address the initial perceptions of palliative care held by patients with advanced cancer and their family carers when this concept was first raised and prior to engaging with these services. While there is increasing health system focus on early integration of palliative care in order that benefits are realized, this study suggests that understandings of patients and carers have not equally progressed.

Current perceptions held by patients and carers continue to perpetuate notions of palliative care as exclusively end-of-life care, specifically understood to mean the dying phase consisting of final days in a hospital facility. Additionally, palliative care is negatively associated with a system of diminished care which is seen as a 'lesser' alternative, diminished possibilities of hope for cure of their disease and diminished choices for the circumstances of one's care given all other options have expired.

While some of these themes are consistent with those recently reported by advanced cancer patients and families in Canada,³⁵ there were also some novel findings of interest with regard to palliative care being perceived as the 'institutional death'. Inherent in this understanding is a lack of awareness of the full range of palliative services available including the provision of community care. Additionally, it is interesting that palliative care has come

to represent a loss of personal choice associated with the medical system *telling* a person how and where their death will occur, with the circumstances of one's death being broadly seen as beyond one's own control.

Ironically, avoidance of the 'hospitalized death' is indeed a key reason why palliative care was pioneered.⁴⁰ Moreover, an important part of the role of palliative care is to enhance end-of-life experiences through provision of information, management of symptoms and goal setting for hopes beyond the medical paradigm with its focus on disease cure. With the achievement of such goals and a focus of promoting quality of life to enable a person to live to their fullest in their place of choice until their death, palliative care can thereby enhance individual choice at the end of life in a creative way.⁴⁰

Given the results of this study, it is important to highlight that these perceptions exist within the context of an increasing public debate regarding legalized euthanasia and physician-assisted suicide. The prominent media campaign surrounding this issue has resulted in highly polarized community views, and it is plausible that this has negatively influenced peoples' views of palliative care as diminished choice in contrary to the established aims of the speciality. A significant opportunity exists for palliative care to drive a separate, focused public education campaign to enable informed community choice around end of life. Others have previously suggested that we must be more proactive in tailoring our message about what we do and the benefit it offers to patients, families and providers.⁴¹ The need for this task clearly remains and the results of this study could directly inform such an endeavour.

While this study builds upon the limited evidence base to explore patient and caregiver perceptions of palliative

care, there are some limitations that should be acknowledged. Although the sample comprised 17 participants (31%) who were born outside of Australia, all participants were English-speaking and thus the results likely do not represent the understandings of palliative care held by different minority cultural groups or indigenous populations, and this should be the focus of a future study. Additionally, as a single-site study with patients attending services at a tertiary hospital setting, it is possible those predominately receiving the mainstay of their care in the community may have different views.

However, the purposive sampling technique ensured a wide variety of perspectives were sought across time, including those at different stages of advanced illness, site of residence, family support and history of palliative care engagement. Moreover, the in-depth nature of the inquiry by a person independent of the treating team and phenomenological analytic methods used enabled the development of important new insights into patient and carer views of palliative care. While participant's perceptions may change over time particularly following engagement with palliative care, this analysis specifically focused on initial reactions to allow exploration of implications for models of early integration and inform development of future public education initiatives.

In conclusion, the findings of this study provide a benchmark for patient and family caregiver understandings of palliative care in Australia. Despite increasing health system recognition of the importance of integrating palliative care into routine quality cancer care, the bigger challenge of how to improve understandings of patients and their carers' remains. Until such time, the task of referral to palliative care will continue to be a complex education, information and communication task – one frequently avoided, met with resistance and continually undertaken late in the illness course. Significant opportunities remain to disentangle understandings of palliative care as the 'institutional death' and reduce the significant stigma that remains associated with palliative care. There is clear need for a targeted public health campaign aiming to change the narrow understandings of palliative care, reframing underlying narratives from those of disempowered dying to messages of choice, accomplishment and possibility.

Declaration of conflicting interests

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