Palliative care physicians' perspectives on transferring patients to nursing homes and communication strategies to facilitate this transition: A qualitative study

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Abstract

Background: As modern medicine extends the life expectancy of patients with life-limiting illnesses and health system resource pressures intensify, palliative care physicians increasingly need to transfer stable patients from specialist palliative care units to nursing homes. The experience of palliative care physicians in decision-making and communicating with patients and families about the need for this transition is underexplored in the literature.

Aim: This study aimed to explore the experiences of and communication techniques used by palliative care physicians as they consider and discuss nursing home placements for their patients.

Design: A qualitative approach using semi-structured interviews was used. Interviews were transcribed verbatim and analysed using thematic analysis.

Setting/participants: Purposive sampling was used to recruit 18 Australian palliative care physicians known for their interest or strength in communication skills across a range of palliative care settings.

Results: Themes emerged from domains of physician experience (abandonment, systemic pressures, prognostic uncertainty, exacerbation of loss, and restoring resilience) and communication strategies (forecasting, checking in, provide context, and acknowledging grief).

Conclusion: This study highlights the tension Australian palliative care physicians experience when transferring palliative care patients to nursing home and the complexity involved in decision-making. Physicians identified several communication strategies to engage patients and families to ease the transition.

Keywords

Communication, palliative care, palliative medicine, hospices, nursing homes, physician–patient relations, qualitative research

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What is already known about the topic?

- The transition of any patient to a nursing home can be a difficult experience for families and patients.
- The provision of palliative care to nursing home patients is not always perceived by families to be as consistently well provided as that given in hospitals or at home.
- One qualitative study from the United Kingdom suggests that specialist palliative care providers struggle with the complex issues involved in moving patients to nursing homes and the best way to communicate this to patients and carers.

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What this paper adds?

- Palliative care physicians from Australia also experience clinical and moral challenges when making decisions to transfer patients to nursing homes.
- An exploration of communication strategies used by Australian palliative care physicians in discussing nursing home transfer with patients and families/caregivers.

Implications for practice, theory or policy

- Better integration of palliative care services and nursing home care is needed.
- The communication strategies used by palliative care physicians in this study may be useful for other providers when discussing the transition of patients who require a palliative approach to their care to nursing homes.

Introduction

Death comes to all. However, within the culture of modern medicine, adept at extending the prognosis of even the most serious illnesses, it is increasingly likely that death will be preceded by disability. Palliative medicine has positioned itself as a specialty that cares holistically for patients with a life-limiting illness. But as the lines between chronic disease, dying and disability become increasingly blurred, palliative care physicians find themselves caring for a subset of patients who are symptomatically stable but have a functional state no longer compatible with care at home. Thus, palliative care physicians are increasingly being called upon to initiate nursing home placements for their patients. The placement of a palliative care patient in a nursing home is laden with increased complexity and difficulty. At an individual level, a nursing home environment is generally viewed as the least desirable place to die[1] and research suggests palliative care patients who die in nursing homes are perceived by family members to have worse outcomes in terms of morbidity and suffering.[2]

Worldwide, the number of older people is increasing in both absolute and relative terms.[3] Unsurprisingly, advancing age is associated with increased likelihood of accessing nursing home facilities.[4] Perception of nursing homes in Australia and abroad is generally poor – both from within the health community and the broader population.[5,6] Concerns about standards of care, cost, and workforce stress have all been identified as contributing to the notion of a nursing home as a last resort.[4] However, globally, advancing age, multiple medical comorbidities and the lengthening of prognosis in the chronically critically ill are forecast to intersect with a societal decline in the availability of informal carers.[3,4] Thus, in the coming decades, it is anticipated that an increasing sector of the population will have care needs that exceed what can be managed in a community setting – even with maximal familial and government support.[3,4]

The transfer of a person to a nursing home is a significant event in the life of that person and their caregivers. In a palliative hospital context, there are added layers of complexity – as patients and families may expect that the palliative care unit will be the final home for the patient.[7] The news that a patient may need to leave a palliative care unit for a nursing home has the potential to destabilise trust, as well as create a new paradigm of loss. The process can also be associated with feelings of abandonment and/or guilt in patients and families.[8,9] In families already experiencing anticipatory grief, it is imperative that the discussions surrounding nursing home transfer are handled as sensitively as possible.

It is known that palliative care providers struggle with the decision to transfer their patients to nursing homes.[10] The authors are unaware of any prior research that investigates the communication strategies used by palliative care physicians when negotiating this difficult conversation. This Australian study aims to explore and describe the perspectives of palliative care physicians with regard to the challenges experienced and communication techniques used when discussing the transfer of their patients to nursing homes from a mix of settings.

Methods

Semi-structured interviews were conducted with palliative care physicians regarding their experiences in discussing nursing home transfers with their patients and caregivers. An interview methodology was chosen for its ability to provide rich data.

Setting

The term 'nursing home' refers to a long-term residential care facility that caters to people whose care needs exceed what is possible in the community setting. Long-term, 24-h care in the community is only available in Australia as a privately funded resource and is thus prohibitively expensive

for most socio-economic groups. Nursing homes in Australia are funded by a mix of federal and private funding. Palliative care units in Australia are largely sub-acute hospitals, funded by state governments, and are not resourced to accommodate long-term care for patients whose symptoms are stable but whose care needs exceed what is manageable in the community setting.

Participants and recruitment

All participants were Australian palliative care physicians who were purposively sampled by the authorship team based on (1) a range of experience working in different palliative care settings and (2) strength/interest in communication skills. An invitation to participate in the study was emailed to physicians through a neutral third party (an administration assistant at the authors' organisation). Participant information sheets and consent forms were attached to the initial email. Email addresses were obtained through professional networks. Passive snowballing recruitment also occurred as some participants informed colleagues of the research. Potential participants were able to contact the primary researcher (H.S.) directly via telephone or email to express interest in participating.

Ethics

Ethical approval was granted by the University of Sydney Human Research Ethics Committee (approval no. 2015/884 granted on 15 December 2015). All participants received an information sheet and signed an informed consent form.

Interview procedure

All interviews were audio-recorded by H.S. either in person at participants' workplace or via telephone. H.S. was an advanced trainee in palliative medicine in Sydney, New South Wales, at the time of undertaking the research.

Participants were asked about the challenges inherent in the discussion and whether there were particular communication strategies they drew upon in order to successfully engage with the patient and family. The interview guide is shown in Appendix 1. Data were collected until no new themes emerged and data saturation was achieved. Participants were provided with an opportunity to review their transcripts; however, none chose to do so.

Analysis

All transcripts were de-identified by H.S. prior to being reviewed by the other researchers. The transcripts were analysed drawing from the approach of thematic analysis and grounded theory.[11] H.S. inductively analysed the data by identifying and recording concepts in all transcripts. H.S.

Table 1. Demographic characteristics of participants (*N* = 18).

Gender	
Male	7
Female	11
State	
New South Wales	12
Victoria	3
Queensland	1
Western Australia	2
Location type	
Capital city	13
Regional area	5
Patient setting	
Inpatient	5
Acute hospital	6
Community	2
Mix	5
Length of experience in palliative medicine (years)	
Range	1–34
Mean	16
Median	17
Religious affiliation	
Nil	5
Christian	6
Catholic	4
Methodist	1
Atheist	1
Buddhist	1

developed the coding structure with assistance from J.M.C., B.C.F. and S.V.N. until it captured all concepts about participants' perspectives on transferring patients to nursing homes. H.S. compared concepts within and across interviews, grouped similar concepts into themes and then refined the coding structure through discussion with all authors who also read transcripts. Themes that arose from the transcripts were discussed and compared among the authors to ensure consistency of interpretation and improve rigour of data analysis. Qualitative data analysis software was not used; however, Microsoft applications Word and Excel were used to sort data and search/analyse for themes.

Results

A total of 27 invitations were sent to potential participants. Overall, 18 palliative care physicians consented to participate and were interviewed between July 2016 and August 2017. Six participants were interviewed in person with the remaining 12 interviewed via telephone. Interviews ranged from 20 to 70 min in duration (mean = 26 min). Of the 18 physicians interviewed, 9 were known to the interviewer through professional networks. Of the nine physicians who were approached but did not participate, none responded to the request for interview. Participants' demographic characteristics are shown in Table 1.

Table 2. Domains and themes.

Domains	Themes
Physician experience	Abandonment
	Systemic pressures
	Prognostic uncertainty
	Exacerbation of loss
	Restoring resilience
Communication strategies	Forecasting
	Checking in
	Provide context
	Acknowledging grief

Various themes emerged from the data analysis under the domains of physician experience and communication strategies. These are displayed in Table 2 and discussed in detail below.

Physician experience

Abandonment. Most physicians interviewed referred to abandonment as a key difficulty inherent within the conversation for physician, patient and families. There was a sense from the physician's perspective that the decision to transfer a patient into another facility adds to the patient's burden of loss and is thus potentially a betrayal of the ethos of palliative care:

> Yeah I think it's one of the most difficult conversations that we have as palliative care clinicians, is that, we talk about other people abandoning them – other consultants, teams, abandoning their patients, well this is now abandoning the patient type of talk that we're doing. We're saying we provided you with this fantastic care and we're not going to leave you, we're going to be with you all the way and then we say a nursing home can look after you. (Participant 10)

A perceived difference in the standard of palliative care between palliative care units and that available in nursing homes added to the sense of guilt felt by physicians:

> … the pressure, there's this subterranean pressure all the time to see, you know, what's the discharge plan, what's the discharge plan which I feel that we're beginning to collude with the whole health system process of managing beds and not patients and I really struggle with that … One of the challenges is often these people are going to facilities where the staff have no idea about symptom control, end of life care or we worry about the lack of registered nurses for breakthroughs and things like that, particularly given that the Government has now decided you don't need to have 24-hour registered nurses to run aged care facilities, when 30% of the patients are on opiates. (Participant 8)

Family/caregiver guilt also arose within this subtheme as physicians reported witnessing the moral dilemma that families grapple with – wanting to care for the sick person but lacking the financial, emotional or skill resources to cope with the care needs:

> … there's guilt associated with going to a nursing home for families that feel like they can't provide that level of care at home … (Participant 6)

Systemic pressures. Many palliative care physicians acknowledged the impact of broader resource stress in compelling the nursing home conversation. Physicians discussed the tension between caring for the needs of individual patients while balancing the resources of a stretched public hospital system:

> … so this is the pointy end of saying this is the rationalisation of our resources and at the same time as we're doing that we recognise that actually it's not that they're not in need of what we have. I think that's the thing. They might not need it as much as someone else but it's not that they don't need it. (Participant 15)

At the other end of the transfer, the ability of nursing homes to cope with the care needs of patients being transferred from specialist palliative care units was also consistently expressed as a concern:

> I think that one of the really difficult things is that because there's such a difference in the standard of care between most nursing homes and most palliative care units that the staff including myself and nursing staff and junior staff feel very guilty about having to do this and we feel like we are colluding in a health care system that does not value the vulnerable and the sick and we're being made to be bed managers rather than advocates for the individual patient. It's part of a very broad structural problem about how we're dealing with the vulnerable. (Participant 8)

In particular, in Australia, federally established standards for staffing ratios in nursing homes do not require the presence of a registered nurse overnight.[12] Physicians interviewed expressed that this is especially problematic for patients who need restricted medications and therefore require access to a registered nurse in order to have these drugs administered:

> I've got another patient who's got COPD who has six or seven breakthroughs of opiates per day and I worry about her in terms of I know nursing homes say that they can handle that but our nurses (and we've got far better nursing ratios in palliative care units), struggle to get her breakthroughs when she needs them. How when you look at the nursing home staffing ratios are they really going to handle that? And that is my concern. (Participant 3)

Prognostic uncertainty. Many physicians reported grappling with accurate prognostication in the face of multi-faceted illness:

If a patient has chronic airways disease or are at the point of death one day will get up and go for a walk a week later and do that six times and you're never quite sure which is the final terminal admission and which is another recovery. (Participant 13)

The difficulty in predicting prognosis is further exacerbated by the perception that an inter-facility transfer may erode the patient's fragile physiological reserve and thus catalyse an earlier-than-anticipated decline:

Well the risk relates to change in place and whether it expedites death in the sense that for some people it's a very unsettling situation, uncertain, and I think that potentially it offsets their emotional balance to the point that they sometimes give up the desire to live because they don't see any particular future or can't anticipate enjoyment in that setting ... (Participant 2)

Exacerbation of loss. Participants worried about imposing further loss on the patient who endures the financial and emotional stress of transferring to a nursing home, only to succumb to their illness before being able to establish a real sense of belonging. Physicians recognised that the movement of a patient to a nursing home is symbolic of yet another loss in a patient population who are likely to have suffered many layers of loss:

I think they need to be psychologically quite robust because moving into a nursing home is essentially acknowledging another loss. You're losing your home, you're losing a degree of independence and if you're already staggering along with a number of other losses then you don't want to load this additional one on top. (Participant 4)

Restoring resilience. In contrast to other sub-themes, there was recognition that a nursing home environment has the potential to be a positive experience for patients and their families. In particular, the refocussing of care back onto 'living' and all the social benefits that arise from living within a community were felt to be important benefits:

They were very happy with how she transitioned to residential care because they felt she was – like it's her normal clothes every day, expected to be in her normal clothes every day; there was an expectation that she would have a life not that she was being tucked up to die. (Participant 12)

Communication strategies

Forecasting. The majority of physicians interviewed for this study felt it was important to raise the possibility of the need for a nursing home early in the clinical relationship as a means of 'softening the blow' if a decision was ultimately made to proceed with placement:

I tell them that, we are a short stay unit in the in-patient unit and if your mother does stabilize you may have to consider other options so we set the scene so people are not surprised when all of a sudden you come to hospice and why are we talking about nursing homes. That's a really important communication strategy that you set the expectations early on. (Participant 11)

Although most participants used early preparation as an initial communication strategy, one interviewee did not agree with this approach and indicated that the development of trust was a more important first step:

I think the worst time to do it is the first day you meet them and I know that some services will have that conversation when someone is admitted so they don't think that they can stay there indefinitely. I don't agree with that approach. I think you need to get to know the patient, get to know the patient clinically and what the particular medical problems are, but just as important to get to know the patient and the family and develop that rapport and develop trust and then the discussion is a lot easier. (Participant 7)

Checking in. The importance of ongoing evaluation of the patient's progress, needs and goals, and, crucially, checking the patient's (and their family's) insight into their overall situation and care needs was frequently cited as a useful tool in helping physicians' to frame the nursing home discussion:

I think it's about finding out what everybody's understanding of the situation is, that's the most important thing. An understanding of what the care needs are, what the prognosis is, what the desires of the patients are, whether we actually are able to meet those desires or not so finding out what everybody understands, what everybody thinks and what everybody's goals are and then coming to a negotiation about what's feasible and possible. (Participant 5)

Provide context. Drawing a broader picture of health resources and external pressures was consistently raised as a strategy – particularly when the nursing home conversation was met with resistance. Participants found contextualisation helped patients and families understand the stressors in the health system, which are, in part, driving the conversation:

A colleague once gave me a really useful tip ... she sometimes says, "Look, the average length of stay here is 12 days" and then that is quite helpful for people to realise it's not them being singled out. Actually, this is how this Palliative Care Unit is and this is where most people are and actually it can't be looking after people for four months. (Participant 15)

Acknowledging grief. Participants recognised that the transfer to a nursing home often resembles an additional loss for patients and their families. The direct acknowledgement of this loss and emotional distress, as well as an

exploration of the source(s) of distress, were raised as important strategies in trying to help patients and their families transition to an acceptance of the situation. Physicians noted that the conversation may need to be revisited multiple times to allow a period of adjustment and opportunities for patients and families to ask questions and explore options:

> I find it's often a very emotionally charged space … so it's emotion before cognition so in other words acknowledging the emotional impact and content of the conversation is the first thing I do otherwise you can't move forward with any information giving or any information gathering so we address the emotional content first. (Participant 2)

Discussion

This study has identified the angst that Australian palliative care physicians experience, and the difficulties and nuances involved, when making a decision to transfer palliative care patients to nursing homes. It also highlighted various strategies that participants utilise to optimally communicate this decision to patients and families.

A recurring theme that emerged was a lack of trust in the ability of nursing homes to consistently provide timely and adequate palliative care. Staffing in nursing homes has previously been an area identified as a potential barrier to provision of palliative care in these facilities.[13–15] Similarly, previous research has indicated that families feel nursing homes are less able to cope with patient deterioration[16] and end-of-life prediction[17] despite generally having longer-term relationships with their patients. This aligns with the fears of physicians in our study, as they find themselves in the predicament of needing to move patients who 'are not dying fast enough' or with enough overt suffering to justify a palliative care bed. The emotional toll that these decisions take on palliative care physicians should not be understated; it is known that palliative care providers are at risk of professional burnout.[18]

Difficulty in prognostication was also highlighted as an area of stress when making decisions about transferring patients to nursing homes.

The palliative care provider must confirm the presence of a life-limiting illness, while simultaneously conveying the reality that a patient's symptoms and prognosis do not currently fit the needs of an inpatient unit susceptible to bed and fiscal pressures. The inexact science of predicting prognosis was acknowledged – as was the worry that the transfer itself could destabilise the patients' clinical picture and lead to an earlier-than-expected decline. Non-malignant conditions were felt to be particularly problematic – as the frequent exacerbations of fragile organ systems heightens the difficulties in differentiating between a recoverable exacerbation and a terminal one. This is a phenomenon that has been borne out in previous studies.[19,20]

As the global population ages and modern medical practices extend the life expectancy for complex diseases, it is likely that palliative care physicians will increasingly need to transfer patients with an uncertain prognosis to nursing homes. This notion sits as a problematic thorn in the side of palliative care whose mandate dictates that it cares for the whole person – encompassing the realms of psychosocial, spiritual, as well as physical well-being.[21] The transfer of patients to institutions that represent a further step towards frailty and dependency may be an erosion of a patient's dignity.[22,23] Furthermore, research reveals that Australians would prefer to die at home – with a nursing home being the least preferred place to die.[24] Thus, an uncomfortable dissonance evolves between palliative care's aims and its actions.

It may have high ideals, but, like other medical disciplines, palliative care is increasingly vulnerable to systemic pressures of broader hospital resources. The difficulty for palliative care lies in its conscious awareness of adding to the burden of loss and grief – measures that are known to impact on discrete physical symptoms such as pain.[25] The variable availability of palliative care in nursing homes is a structural challenge that has been examined in Australia and elsewhere.[26] A recent literature review of the experience of patients and family members in the United Kingdom suggests that a nursing home transfer was overwhelmingly a negative experience[27] – although the review also noted that there is very little high-quality research in this area. Better integration of palliative care and institutionalised care could mitigate many of the concerns of the physicians interviewed for this study – and perhaps ease some of the clinical and moral tension.

However, there was also a general acknowledgement that living in a nursing home could be a positive experience. The potential to develop long-term relationships with staff and other residents and the 'de-medicalisation' of the patient's situation were felt to be benefits that could arise in a nursing home. However, these benefits were only deemed possible if the patient maintained a period of stability and level of function that enabled them to engage meaningfully in the broader social and cultural environment of the nursing home – a notion that aligns with prior research.[28]

Communication skills are known to be an essential component of the provision of quality palliative care.[29] To date, no literature exists on how to address the conversation on transferring patients to nursing homes from specialist palliative care settings and a key aim of this study was to explore communication strategies used by a range of palliative care physicians in Australia. Not surprisingly, the strategies used by the physicians in this setting were in line with previous communication techniques validated for breaking bad news.[30,31]

The subtheme of 'Providing Context' appears, however, to be unique to this situation in palliative care circles. In

particular, the refocussing of attention away from the individual and his or her needs and onto the structures and stressors of the broader hospital system is a paradigm shift away from the usual 'modus operandi' of palliative care. Invoking the pressure of an outside influence affords palliative care physicians the capacity to (partially) outsource responsibility for the decision to transfer an individual to a nursing home setting and perhaps therefore minimises the erosion of trust in the patient–doctor relationship.

Strengths and limitations of the study

This study enriches understanding of the challenges faced by physicians as well as outlining communication strategies used in handling this sensitive discussion.

The study had some limitations. Physicians who declined to participate may hold different views as to the challenges of the issue at hand. Although the authors tried to ensure that a broad scope of palliative care physicians were included, most physicians who agreed to be interviewed practised in urban settings in New South Wales, Australia. Three of the four researchers are palliative care physicians. However, the fourth researcher (S.V.N.) provided a non-clinical perspective along with expertise in qualitative research.

Future research should explore the experiences of patients and their families in response to the conversation to provide a holistic view. Ongoing research into better integration of palliative care and nursing home care is also needed.

Conclusion

The emerging tension between caring for the individual patient without abrogation of responsible allocation of a finite number of hospital beds is illustrated by the rich narratives of the physicians interviewed in this study. This study reinforces the emotional and moral burden that palliative care physicians feel in transferring their patients to nursing homes. In carrying out the conversation, palliative care physicians drew upon diverse communication strategies known to be helpful in situations of breaking bad news. The intersection of palliative care and nursing home care is an increasingly important dynamic. Ongoing research is needed to help determine how palliative medicine and nursing homes can be part of a seamless transition of care for patients approaching the end of life and not one that represents a vexatious dilemma for patients, their caregivers and the physicians who care for them.

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Appendix 1

Interview guide

Introduction

  Interview format

   1. Initial reactions and experience of discussing transition of a palliative care patient to a nursing home

      (a) Could you please describe briefly any experiences you have had with transitioning palliative care patients to a nursing home? *(Prompts: Training, facilitated discussions, how did it/ they come about and what happened as a result? Who was involved in the discussion?)*

   2. Decision-making in nursing home placements

      (a) What sort of patients do you typically decide may need a discussion about transitioning to a nursing home?

      (b) What factors do you account for in making this decision?

      (c) What decisions are the more easy/most difficult – why?

   3. Personal experience of ACP process

      (a) What communication strategies have you found useful in initiating dialogue regarding transitioning to a nursing home placement?

      (b) What sort of reaction is typical from the patient and or caregiver when they receive this news?

      (c) What communication strategies do you use when the discussion is met with resistance from the patient and or their caregiver?

      (d) Do you feel that the discussion regarding transitioning a palliative care patient to a nursing home is a difficult one? Why or why not?

      (e) Have you had experience discussing this with patients from different cultural backgrounds? (e.g. *CALD, Aboriginal or Torres Strait Islander). How is this different? What modifications need to be made when approaching ACP in these settings?*

4. Suggestions for ACP process and materials
   (a) How do you think nursing home placements should be introduced to people with a terminal diagnosis – why?
   (b) Who should initiate nursing home placement discussions? Who should be involved in the discussions (i.e. which health professionals, which family members/others) – why?
   (c) When do you think is the best time to start nursing home placement discussions? How often should it be re-discussed? At any particular time points? – Why?
   (d) What do you think are the benefits/risks of transitioning a palliative care patient to a nursing home? – Why?
   (e) Can you suggest how to evaluate, measure or test these benefits and risks?
5. Close
   (a) Is there anything else that you think might be important to add?