

BMJ Open The role and significance of nurses in managing transitions to palliative care: a qualitative study

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ABSTRACT

Objectives: Nurses are generally present, and often influential, in supporting patient and family acceptance of medical futility and in assisting doctors in negotiating referral to palliative care. Yet the specificities of the nursing role and how nurses may contribute to timely and effective referrals is not well understood. This study aimed to systematically explore hospital-based nurses' accounts of the transition to palliative care, and the potential role of nurses in facilitating more effective palliative care transitions.

Design: Qualitative study using semistructured interviews.

Setting: Two health services with public as well as private clinical environments in a major metropolitan area of Australia.

Participants: Hospital-based nurses (n=20) who regularly work with patients at the point of referral and in managing transitions to palliative care.

Results: Four significant themes emerged from thematic analysis. These include: (1) professional dynamics and the roles played by nurses in initiating the transition to palliative care; (2) the value of nurses' informal interactions in timely and effective transitions; (3) the emerging challenge of managing task-oriented nursing versus intense emotional nursing work at the point of medical futility and (4) the emotional burden experienced by nurses within this clinical context. Nurses self-reported occupying critical albeit complex roles in the management of medical futility and the transition to palliative care. They reported experiencing significant emotional burden in balancing interpersonal and interprofessional relationships during this time.

Conclusions: The results suggest that nurses may be utilised in a more formalised and systematic fashion in the context of managing medical futility and the need to topicalise the transition, with the focus shifted away from medical referrals towards more team-based and patient-centred timely transitions. Further research focused on the experiences of doctors, allied health professionals, patients and families is required to provide a broader interdisciplinary understanding of futility and contributions to the negotiation of palliative care.

INTRODUCTION

Transitioning patients to palliative care from life-prolonging interventions can be a

Strengths and limitations of this study

- Provides depth of insight into informal and undocumented roles and responsibilities in the context of futility.
- Highlights the crucial roles played by nurses in initiating and managing transitions to palliative care.
- Exposes the significant emotional burden of nursing work at this clinical transition.
- The sample size, which while appropriate for a qualitative study, could be expanded through other sites and exploration of non-nursing perspectives.

difficult aspect of clinical work,^{1 2} with significant patient and family distress reported in studies of negotiating futility.^{2 3} The difficulties some health professionals experience in topicalising the need for palliative care,^{2 4-6} and resistance among patients and their families,⁷⁻⁹ can contribute to this care transition being poorly communicated and/or negotiated.^{10 11} Clinical evidence has pointed to the benefits of early and well-managed transitions to palliative care in terms of quantity and quality of life.^{2 12} While the role and perspectives of doctors have been previously explored,^{4-6 13} the role of nurses at the point of futility and referral to palliative care has been virtually ignored in the clinical literature. Specifically, their role in the very sensitive work of negotiating futility and in facilitating patient transitions to palliative care. Our aim in this study was to systematically examine nurses' self-reported accounts of supporting the transition to palliation in a context whereby adherence to best-practice guidelines for more effectively and timely transitions are being urgently called for.^{12 14}

Nursing and the transition to palliative care

The lack of attention paid to the nursing role in transitioning patients to palliative



care is surprising given the presence of nurses at the patient's bedside. This is particularly the case for patients who have few remaining life-prolonging intervention options available, as caring duties typically include addressing their medical and psychosocial needs.^{15 16} The decision to refer a patient to palliative care is often a medical responsibility—that of the treating physician—who then leads the initial conversation about prognosis and treatment viability with the patient.^{6 8 13 17 18} In reality, however, conversations about referral and the transitions that follow involve formal and informal communication, and involve contributions from doctors, nurses and allied health professionals.^{5 19} The roles that different health professionals play in such contexts is not well understood, despite there being an important team-driven dynamic in terms of managing timely and effective transitions.²⁰ Previous work has shown that some doctors rely heavily on nurses to directly prompt them as to the need for referral to palliative care.⁴⁻⁶ This largely informal delegation of responsibility provides little explanatory basis for teaching about, or streamlining, doctor–nurse professional practices around referral to palliative care. The roles and experiences of nurses thus need to be systematically examined in order to provide an understanding of current practice as well as best-practice guidance.

The nurse–patient relationship and emotional work

In exploring the transition to palliative care, a crucial aspect of service delivery is the nurse–patient relationship. Effective transitions to palliative care entail high levels of psychosocial as well as medical support,¹⁶ and nurses are well-placed to observe and support the psychosocial well-being of patients and families. This type of caring work has considerable potential for emotional burden and fatigue among nurses.^{15 16} Transitions to palliative care have been shown to be challenging for all stakeholders,^{1 3 8} and managing the professional–patient–family relationship in such contexts can be difficult.^{21 22} For nurses, displaying appropriate emotions is central to the nurse–patient relationship.²³ Nurses regularly care for patients within intimate and emotional circumstances, and as such require and display distinct caring skills that are highly valuable in effective transitions.^{16 24} During the transition to palliative care, caring tasks can include verbal and body language, which reassures the patient, displays of sympathy and empathy, or holding the hand of a family member. Indeed, nurses have been shown to be more in tune with patients' suffering and grief than medical staff in certain contexts.²⁵⁻²⁷ Less attention, however, has been focused on how nurses experience this kind of work within the context of ceasing life-prolonging treatment and transitioning to palliative care.²³

METHODS

This qualitative study was developed to explore a range of nurses' experiences of caring in the transition to palliative care. The objective of the study was to

systematically explore hospital-based nurses' accounts of the transition to palliative care, and the potential role of nurses in facilitating more effective palliative care transitions. We define the transition to palliative care as the referral and transfer to the care of a palliative care service. This transitional process may entail initial or ongoing consultation with a palliative care specialist within the current clinical setting, but eventually involves movement to another setting under the care of a palliative care service. Nurses who were frequently involved in working with patients at the point of referral to palliative care were approached to take part in a qualitative semi-structured interview to discuss their experiences and perspectives. The transition to palliative care is a particularly emotional, sensitive and difficult period for all stakeholders and face-to-face interviews have been shown historically to be a feasible and effective means of documenting experiences and perceptions of care in the last few weeks of life.^{28 29} Furthermore, a qualitative design allows documentation of complex personal and interpersonal challenges, conflicts and successes.³⁰ The purposive sampling strategy was facilitated by Nurse Unit Managers who provided information forms to nurses who might be interested in participation. The information form outlined the aims and objectives of the project and described the background of the researchers, then invited potential participants to voluntarily contact the researchers directly if willing to participate. The information form also outlined that potential participants would be in no way disadvantaged by electing not to participate in the study and could withdraw their participation at any time, for any reason, without penalty. Of the 30 nurses who were approached, 20 agreed to participate. A range of areas of specialty were represented within this sample, including medical oncology, haematology, general medicine, radiation oncology and supportive/palliative care. The sample also included a range of levels of seniority, from junior and newly qualified nurses (n=4) and clinical nurses (n=10), to more senior coordinators and Nurse Unit Managers (n=6). There were 18 female and 2 male participants, aged from early 20s to late 50s. Participants provided written consent for the interviews to be digitally audio-recorded and transcribed verbatim and in full. The interviews took place in private office spaces within the hospitals, lasted between 30 and 60 min, and were designed to explore the following domains: the basis of nursing practice at points of transition; interacting with patients/family about palliative care and the end of life; intraprofessional and interprofessional dynamics evident in the transition to palliative care; and the emotional and interpersonal impacts on nurses at this point in care. We continued interviewing until the point of data saturation was reached.³¹ The researchers conducted member checking during the interviews by frequently summarising and restating participants' views and experiences to enhance reliability through allowing the participant to confirm or query the researcher's understanding.

Analysis

A systematic thematic content analysis was conducted using NVivo 9 software, into which all interview transcripts were imported. The thematic analysis of the data was driven by a framework approach, which included the following steps: (1) familiarisation—in which the researchers reviewed the manuscripts; (2) identification of framework—key themes and issues identified around which the data was organised; (3) indexing—application of themes to text; (4) charting—use of headings and subheadings to build up a picture of the data as a whole and (5) mapping and interpretation—in which associations were clarified and explanations worked towards.³¹ Independent coding of the data was provided initially by members of the research team, which was then cross-checked to facilitate the development of themes, moving towards an overall interpretation of the data. Analytic rigour was enhanced by searching for negative, atypical and conflicting or contradicting cases in coding and theme development.^{31–33} Inter-rater reliability was ensured by integrating a number of research team members in the final analysis.^{31 34} All audio recordings, transcripts, coding reports and notes were retained and added to documentation of research aims, design and sampling, and recruitment processes and practices to form an audit trail.

RESULTS

We report on the themes emergent from our systematic analysis of the interviews. All of the nurses interviewed spoke at length and in considerable detail of their experiences and views on caring for patients approaching the end of life, and their families. It was clear from the interviews that nursing work at this time had the potential to be emotionally draining, time-consuming and complex in terms of managing professional, inter-professional and nurse–patient relationships. Our analysis revealed four predominant themes: (1) in the nursing role in the transition to palliative care; (2) emotional support and effective transitions; (3) managing task-oriented nursing and supporting patients in transition and (4) the emotional burden of managing the transition to palliative care.

Professional roles and relationships: the nursing role in the transition to palliative care

The nurses offered detailed accounts of their perspectives on the nursing role and experiences therein during the transition to palliative care. This included the self-reported skills and approaches most valuable in caring for patients and families at this difficult time. Examples of indicative quotes related to participants' views on the role of nursing in the transition to palliative care are provided in [table 1](#).

A predominant theme throughout the interviews was the value in nurses' input into initiating referral. That is, their position close to the patient privileged nurses in

terms of noticing physiological or psychosocial issues, which may prompt timely referral. As such, a core element of nursing work in this context lay in the nurses' ability to closely observe the patient and be proactive in terms of communicating with doctors or other health professionals within the department. Approximately half of the nurses talked about taking an active role in initiating or prompting referral, whereas the others felt less confident approaching doctors. This role was talked about as linked to the responsibilities of nurses in terms of patient well-being. The interviews revealed the nurse–patient relationship as key to the maintenance of psychosocial well-being, and this was particularly pertinent given the emotionally fragile state of patients and family members at this time. In this way, nurses, particularly compared with doctors, were viewed as holding the predominant responsibility for reassuring patients and their families, ensuring they were coping,

Table 1 Indicative quotations

Participant	Example quotation
#9	I think because us as nursing staff will spend the majority of time with them. Being here as well we do hourly roundings, so we are always in there, like at least every hour if not half-an-hour, doing things for these patients
#12	So from a nursing perspective we're often encouraging early palliative care referrals, and one of the stumbling blocks we get is because often the patients have multiple practitioners involved in their care. So they can have surgeons, medical oncologists and radiation oncologists, it's quite difficult for us to deem who the appropriate person is to make that decision
#13	I actually always go, when I find out a bit about the patient and what support they've got, I will say to the consultant or whoever "have you mentioned palliative care? This person could probably benefit from it. Is it alright if..."—no I just don't ask if it's alright actually
I:	And can anyone do that?
#13	Yeah. But I don't know if they're confident enough to do it...And it all depends on the person, how proactive and how confident they feel
#14	The news is just devastating and it's hard for the patient to think about the future, and their family. And it's about trying to look ahead for the future, with increasing disabilities and how they're going to manage that and who's out there, and who can support them. So I think the nurse's role is absolutely crucial, you're chasing a doctor to go in with them to sit down and give news

Professional roles and relationships: the nursing role in the transition to palliative care.

and beginning to accept their diagnosis and prognosis. This responsibility was viewed by the majority of participants as a core value of nursing, and was highly valued. That is, their presence at the bedside enabled the development of positive relationships with patients, which were viewed as a crucial element of the care trajectory. The core values of nursing (ie, alleviating suffering, maintaining dignity and comfort) shaped nurse–patient conversations, which were a key element of ‘being there for the patient’. As discussed in more depth below, the position of nurses not only enabled them to observe patients (and thus help facilitate the initial referral to palliative care), but also to engage in emotionally supporting patients and families through the transition.

Talking to patients and families: emotional support and effective transitions

Communication with patients is crucial to effective referral to palliative care.^{9 10 13} Such communication can be fraught with difficulties, but can also carry significant meaning and value in terms of effective transitions. During the interviews, the nurses talked about their experiences talking to patients and their families, and the skills they used in order to manage such conversations to improve transitions. Indicative quotations from the interviews are provided in [table 2](#).

Having a physical presence at the bedside was talked about as crucial to supporting the patient and family through the transition, particularly in terms of effective communication. Spending time with patients and

families constituted a core task in smoothing the transition, both in terms of medical and psychosocial needs. All of the nurses indicated the significance of dual considerations when considering referral to palliative care, incorporating considerations of pain and symptom management and broader well-being (in a psychological as well as practical sense). The nurses viewed themselves as ideally placed to talk to patients and listen to any concerns during this transitional period. These included conversations about mortality and futility, as well as talk about family members’ capacity to provide care at home, or ongoing practical care needs. Effective transitions were facilitated by opportunities for the nurses to talk (and listen) to patients and their families beyond the initial point of referral and throughout the transitional period (often a number of days at least). Thus, in contrast to medically driven decisions about the need for palliative care, the transition was characterised by helping patients to understand their situation. In addition, the provision of emotional support was positioned as vital for family members, and the nurses were ideally located (and motivated) to offer such support. However, as discussed in the following section, there was a range of factors which impeded the nurses in providing sufficient support in their daily work.

Managing task-oriented nursing and supporting patients in transition

Being present for patients and their families through communication and emotional support was central to

Table 2 Indicative quotations

Participant	Example quotation
#17	To support and listen, and a lot of family support. We give a lot of support to partners and kids. It’s just the simplest little question, “how’s it going? How are you going?” And I often say “it’s just as tough on you isn’t it?” And they always say “oh thank god someone’s asked me how I’m going!” And then if they need a little bit of help somewhere, refer. That’s what you do. And lots of hugs, we give a lot of hugs here. We do! But lots of listening, I think just listening, active listening...
#3	Lots of talking with patients and making sure everything’s connected I guess, that everyone’s aware of what they need to be aware of...It’s part of nursing, because I’m talking to them, I’m assessing them and looking at how they’re going in their day-to-day lives, what their symptoms and side-effects are. But also it’s, you know I’m lucky in my role that I can just sit down and spend twenty minutes, half-an-hour, whatever they need, just talking about everything. Things like services and needing things at home
#18	So a lot of them we have to explain, even though we say the word “palliative” some people still get quite freaked out about that, and we have to say “but there’s various stages of palliative care.” So once you kind of reassure them that look it’s just the avenue or the pathway that we’re going down now
#4	Because I’m basically the only palliative care nurse here, they [patients/families] all get my phone number. So many of them will ring me just to chat about things, they might start to ring for their pain, but by the end of their conversation they’re talking about some of the end-of-life discussions, or their families are. “What can I expect?” you know. “Where do you think we’re headed?”
#14	Particularly the partners, the wives, the husbands and the partners. I have an open door policy, and quite often they’ll come in and sit in the seat and cry their eyes out. “How am I going to tell our children? What’s the best way of telling our children? How am I going to tell his mother?” They’re at a total loss, “what can we do about this? Will I need to sell my house? Should I sell my house?” All these things are flowing out, and I give them time to talk through all these kind of issues

Talking to patients and families: emotional support and effective transitions.

the nurses' descriptions of effective transitions to palliative care. However, the majority of nurses also talked about the challenges of providing such assistance within their day-to-day nursing work. Time constraints were frequently discussed, with the majority of nurses noting the difficulties of providing emotional support for patients in addition to their other clinical and bureaucratic daily tasks. As shown in the indicative quotations in table 3, there was a common view that regular interactions with patients and families enabled 'better' transitions, yet this was undermined by workload. Moreover, daily tasks also impeded the nurses from actively working alongside doctors. This issue was talked about as critical, as a team approach to communication and supporting patients transitioning to palliative care was considered ideal. Daily tasks and patient loads constrained nurses from regularly attending doctor-patient consultations, which was viewed as affording the potential to best communicate with the patient and family about their transition. Ensuring that doctors and nurses were 'on the same page' was cited as crucial for best practice. Moreover, the ability to spend more time with doctors was also viewed as a vital part of passing on information about the patient/family circumstances to doctors. The intimate patient access afforded to nurses was significant, but limited in value without regular communication with doctors. Managing time effectively was talked about as stressful, particularly because supporting patients transitioning to palliative care necessarily entailed considerable emotional work.

Emotional work: the burden of managing the transition to palliative care

As shown in the sections above, nurses play a crucial role in managing the transition to palliative care. In this

section, we explore the burden of such intimate involvement. The majority of the nurses' interviews revealed the difficulties experienced as a consequence of nursing for patients transitioning to palliative care, as illustrated in table 4.

It was clear that the nurses empathised and identified with many of their patients, and experienced a range of emotions including sadness, grief, frustration and fatigue. Indeed, much energy was put into emotionally supporting patients and families, and in maintaining their own psychosocial well-being. The nurses talked about the challenges of managing their own mood and demeanour around patients. Displays of emotion needed to be constantly reassessed when working with patients within the same unit who may be approaching the end of life alongside those undergoing curative treatment. Balancing hope and futility, and the according expressions of emotion required considerable thought and attention.³⁵ Indeed, the burden of such work was clear throughout the interviews. The maintenance of emotional composure was talked about as a day-to-day skill and challenge. The majority of the nurses talked about struggling with the extent to which they would (or should) get emotionally involved with patients and families transitioning to palliative care. Indeed, the majority of the nurses spoke at length about their own self-imposed rules and boundaries in terms of interpersonal connections, particularly in terms of managing the potential for compassion fatigue and/or burnout.^{36 37} Only a minority of the nurses viewed emotional work with patients as straightforward or easily managed. A key element of the emotional toll of this work lay in the responsibility the nurses felt to emotionally support patients and their families. That is, they felt a professional expectation to take on the vast majority of

Table 3 Indicative quotations

Participant	Example quotation
#10	I think it's better if we interact more with them [patients]. But sometimes the workload hinders us from talking to the doctor, going with a doctor. I think it's better if one of the nurses go on the ward rounds with the doctor so we know what's been said, we get the right information through them [patients]
#11	Yeah I think it definitely takes its toll, especially with heavy workloads. I mean when someone is palliative you want, well every patient you want to do everything you can. But especially when it's coming towards the end and families are upset, you want to be able to sit with them for half-an-hour and just be there for them. But with heavy patient loads you just don't get to, I mean you can offer them cups of tea and that every now and again, but to sit with that one patient for say half-an-hour, it's almost impossible because you have every other patient to consider as well
#14	Sometimes I'm thinking on my feet, because as the [senior nurse] here, I'm thinking "oh god I've got ten minutes and I've got to be elsewhere," and I know I've really got to be elsewhere with that. But you don't want that person to think they're not getting 100% from you. People are constantly knocking at the door when you're talking to people. But I think it's just important that they know that you're there for them, and you can also give them information and passing them on to the appropriate person
#16	You don't have time to think about it [not being able to answer all of the patient/family questions] because you've got to go to your next patient who might be having curative intent treatment... If you've got someone who's dying with a really you know, family that need a lot of support, yet you're trying to hang a bag of chemo on time, and making sure that your own output is spot on, and then you've got three other patients you have to get out of bed and shower, I mean you're stressed to the max

Managing task-oriented nursing and supporting patients in transition.

**Table 4** Indicative quotations

Participant	Example quotation
#11	I find it very hard personally because I think finding the right words to say can be a bit difficult sometimes. I think particularly for the family, just discussing what's important for the patient to discuss with the family, if they're able to discuss with their family what they want, because I think the families can sometimes not take into consideration what the patients want and push for more treatments if the patient doesn't want the treatment. I find that they can be very pushy in that sense. But in terms of bringing it up it is hard...It's tough. I find it really tough
#4	But when it starts to you know, sometimes even the best of palliative care, some doctors are okay with it, but other doctors you know, some people are crying all through their consultation, it takes its toll on them too. Because they don't have anyone to debrief with either
#16	At the time on the ward, you don't have time to think about it because you've got to go to your next patient who might be having curative intent treatment, so you've got to be positive. You've got to learn how to respond to things, and be emotional at the appropriate times. If you're happy, you're a happy person, you're in a good mood and you're upbeat, you can't go into that room with a patient who's dying and be smiling "hey how are you all going? Is everyone okay?" because to them it's not. But then you go into the next room, you can't go in there sombre, you need to be positive for that patient without being unrealistic. So it's like you just put on a different mask
#6	I find it really difficult. I'm getting better. I guess the more, in this role I've had more exposure to it so. But you never feel comfortable about having those discussions. I've got siblings that are the age of people, or they're my age that are having treatments. So it's a bit, I'm pretty raw, like if I get upset I'll get upset in front of them. It doesn't worry me, and it doesn't worry them. It shows you care, I think
#20	I've seen a couple of young nurses become quite unhinged at an event and I just don't know...I don't feel there's that support for the younger girls anymore, or older girls, or anyone really. And from my perspective yes I do get very upset, but I realise that things come to an end. And the positive is that if I can do everything I can, then that's great. Because you spend time with the families...It's quite you know, you've got to have a bit of downtime

Emotional work: the burden of managing the transition to palliative care.

emotional support work. This pressure to enact emotional work was compounded by a perceived lack of emotional support for the nurses themselves.

DISCUSSION

Ensuring timely and effective transitions to palliative care has significant benefits for patient quality and quantity of life, and for family members' well-being.^{12 38} Nurses are crucial to such referrals.^{19 39} This study provides a means for better understanding the significant roles played by nurses in the referral and transition of patients to palliative care. The findings of this study demonstrate the unique access to patients afforded to nursing staff, in the structure of their role as well as emerging from the core values and practice of nursing. The findings also highlight the benefits of nurses who are oriented to providing psychosocial support for patients and families in transition. A key process identified here was interpersonal access to patients and their families. By being present at the bedside, and with a willingness to talk and listen, the nurses held the advantage of uncovering crucial information on the emotional and practical contexts of each patient. The benefits of such knowledge and understanding (particularly when communicated to the treating physician) was viewed as enabling the transition to palliative care (and planning therein) to be tailored to each individual patient.

The findings presented here highlight the importance of effective communication between health professionals for palliative care planning.¹ While the nurses we interviewed talked about being well-placed to inform treating physicians around initiating referral, around half of the nurses lacked confidence in such communication. As has been shown in studies elsewhere,^{1 20 39} although nurses may be significantly involved in transitions to palliative care, there may be a lack of, or variability in, opportunities for them to contribute towards decision-making around referral, which is widely considered to remain within the remit of the treating physician. The self-reported data from this study highlighted nurses as well situated within the ward to gain unique knowledge and understanding around patient and family context. Yet, a number of practical and professional factors impeded nurse–doctor communication.⁴⁰ As such, our findings support those of other studies that have highlighted the benefits of interprofessional communication and team-based approaches to referral, enabling nurses to have greater opportunity for input into often complex and ambiguous consultant-led decisions.^{1 20 41 42} It is likely that such approaches would improve referrals and transitions through more timely and better communicated referrals, and by placing more emphasis on psychosocial factors.

In addition to the potential for nurses to have significant input into decision-making around initial referral, our findings also reveal the critical roles played by

nurses in operationalising the processes necessary for successful transitions.⁴³ While it was clear that the decision to refer was led by the treating physician, the nurses in this study viewed tasks associated with managing the transition itself as primarily their own responsibility. A key element of this work was the ability to empathise and identify with patients and families. This management of emotion is an important nursing skill^{24 27 44 45} that is arguably under-recognised and underutilised in the context of referral and transition to palliative care. Nurses represent a significant resource in this area, and their expertise could be more actively drawn on by doctors and other health professionals to assist with positive professional–patient communication and negotiation. In contexts where doctors frequently struggle with breaking bad news to patients and their families,^{1 17 22} nurses can and do play a pivotal role in smoothing transitions and maintaining psychosocial well-being.⁴⁶ However, while the values of nursing shape such expertise, nurses should not carry the burden of emotional work with patients in isolation. Ultimately, the interviews revealed the considerable burden of responsibility of nursing to maintain and manage the psychosocial well-being of the patient and family at the point of futility and transition to palliative care. Moreover, it was clear from the interviews that there was, at times, a perceived lack of support from other health professionals and the hospital in terms of supporting them in their work. That is, this important emotional work involved in helping patients transition to palliative care was viewed as predominantly the responsibility of nursing staff.

This study has several limitations. Although our sample of nurses includes representation of a range of specialty areas and levels of experience and seniority, it only captures the experiences of participants from two health services with public as well as private clinical environments in one Australian city. As such, our findings cannot be generalised to other nurses in other settings despite providing indications of themes and theoretical insights likely to resonate across other settings. Furthermore, the sample of nurses was self-selected. Our findings therefore may not represent the views or experiences of less-experienced nurses in these contexts or those with less interest in palliative care. Given the findings presented here, further research focused on the experiences of doctors, social workers, patients and families is required to provide a team-based understanding of negotiating referral and transition to palliative care. In practice, nurses can be utilised in a more formalised and systematic fashion in the context of potential futility and the need to topicalise palliation by shifting the focus away from purely ‘medical referrals’ and focusing on ‘team-based’ and ‘patient-centred’ timely transitions. Nursing staff also require support, given the emotionally challenging nature of their work, particularly in managing the potential for professional compassion fatigue and burnout.^{36 37} Supervision alongside a team-based approach to transitioning patients may

better support nurses to emotionally as well as clinically support patients during this difficult time.

Contributors The project was designed and developed by all authors. Data was collected by AB and EK. Data analysis was led by EK and AB, with input from all authors. All authors contributed to the drafting and revising of the manuscript, and approved the final version of the manuscript.

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REFERENCES

- Gott M, Ingleton C, Bennett M, *et al*. Transitions to palliative care in acute hospitals in England: qualitative study. *BMJ* 2011;1:42–4.
- Melvin C, Oldham L. When to refer patients to palliative care: triggers, traps and timely referrals. *J Hosp Palliat Nurs* 2009;11:291–301.
- Ahmed N, Bestall J, Ahmedzai S, *et al*. Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. *Palliat Med* 2004;18:525–42.
- Broom A, Kirby E, Good P, *et al*. Specialists' experiences and perspectives on the timing of referral to palliative care: a qualitative study. *J Palliat Med* 2012;15:1248–53.
- Kirby E, Broom A, Good P, *et al*. Medical specialists' motivations for referral to specialist palliative care: a qualitative study. *BMJ Support Palliat Care* 2014;4:277–84.
- Broom A, Kirby E, Good P, *et al*. The art of letting go: referral to palliative care and its discontents. *Soc Sci Med* 2013;78:9–16.
- Quill T, Arnold R, Back A. Discussing treatment preferences with patients who want “everything”. *Ann Intern Med* 2009;151:345–9.
- Kirby E, Broom A, Good P, *et al*. Families and the transition to specialist palliative care. *Mortality* 2014. Published Online First: 13 May 2014. doi: 10.1080/13576275.2014.916258
- Bowman K. Communication, negotiation, and mediation: dealing with conflict in end-of-life. *J Palliat Care* 2000;16:S17–23.
- Anderson W, Kools S, Lyndon A. Dancing around death: hospitalist-patient communication about serious illness. *Qual Health Res* 2013;23:3–13.
- Back A, Young J, McCown E, *et al*. Abandonment at the end of life from patient, caregiver, nurse, and physician perspectives. *Arch Intern Med* 2009;169:474–9.
- Temel J, Greer J, Muzikansky A, *et al*. Early palliative care for patients with metastatic non-small-cell lung cancer. *New Eng J Med* 2010;363:733–42.
- Broom A, Kirby E, Good P, *et al*. The troubles of telling: managing communication about the end of life. *Qual Health Res* 2014;24:151–62.
- Clayton J, Hancock K, Butow P, *et al*. Australia and New Zealand Expert Advisory group: clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of life-limiting illness, and their caregivers. *Med J Aust* 2007;186: S77–108.
- Morita T, Miyashita M, Kimura R, *et al*. Emotional burden of nurses in palliative sedation therapy. *Palliat Med* 2004;18:550–7.
- Skilbeck J, Payne S. Emotional support and the role of clinical nurse specialists in palliative care. *J Adv Nurs* 2003;43:521–30.
- Barclay S, Maher J. Having the difficult conversations about the end of life. *BMJ* 2010;341:c4862.
- Oberle K, Hughes D. Doctors' and nurses' perceptions of ethical problems in end-of-life decisions. *J Adv Nurs* 2001;33:707–15.
- Benbenishty J, Ganz F, Bulow H. Nurse involvement in end-of-life decision making: the ETHICUS study. *Intensive Care Med* 2006;32:129–32.



20. Marsella A. Exploring the literature surrounding the transition into palliative care: a scoping review. *Int J Palliat Nurs* 2009;15:186–9.
21. Arnold B. Mapping hospice patients' perception and verbal communication of end-of-life needs. *BMC Palliat Care* 2011;10:1.
22. Hanratty B, Lowson E, Holmes L, et al. Breaking bad news sensitively: what is important to patients in their last year of life? *BMJ Support Palliat Care* 2012;2:24–8.
23. Bailey C, Murphy R, Porock D. Professional tears: developing emotional intelligence around death and dying in emergency work. *J Clin Nurs* 2011;20:3364–72.
24. Broom A, Kirby E, Good P, et al. Negotiating futility, managing emotions: nursing the transition to palliative care. *Qual Health Res*. In press.
25. Ablett J, Jones R. Resilience and well-being in palliative care staff. *Psychooncology* 2007;16:733–40.
26. Fillion L, Tremblay I, Truchon M, et al. Job satisfaction and emotional distress among nurses providing palliative care. *Int J Stress Manage* 2007;14:1–25.
27. Sandgren A, Thulesius H, Fridlund B, et al. Striving for emotional survival in palliative cancer nursing. *Qual Health Res* 2006;16:79–96.
28. Steinhauser K, Barroso J. Using qualitative methods to explore key questions in palliative care. *J Palliat Med* 2009;12:723–30.
29. Timmerman S. There is more to dying than death. In: Bourgeault I, Dingwall R, de Vries R, eds. *The Sage handbook of qualitative methods in health research*. LA: Sage, 2010:19–33.
30. Clark D, Ingleton C, Seymour J. Support and supervision in palliative care research. *Palliat Med* 2000;14:441–6.
31. Pope C, Ziebland S, Mays N. Analysing qualitative data. In: Pope C, Mays N, eds. *Qualitative research in health care*. 3rd edn. Oxford, UK: Blackwell Publishing, 2006:63–81.
32. Ezzy D. *Qualitative analysis: practice and innovation*. London: Routledge, 2002.
33. Fitzpatrick R, Boulton M. Qualitative research in health care: the scope and validity of methods. *J Eval Clin Pract* 1996;2:123–30.
34. Morse J. "Perfectly healthy, but dead": the myth of inter-rater reliability. *Qual Health Res* 1997;7:445–7.
35. Clayton J, Hancock K, Parker S, et al. Sustaining hope when communicating with terminally ill patients and their families: a systematic review. *Psychooncology* 2009;17:641–59.
36. Potter P, Deshields T, Divanbeigi J, et al. Compassion fatigue and burnout: prevalence among oncology nurses. *Clin J Oncol Nurs* 2010;14:E56–62.
37. Najjar N, Davis LW, Beck-Coon K, et al. Compassion fatigue: a review of the research to date and relevance to cancer care providers. *J Health Psychol* 2009;14:267–77.
38. Haines I. Managing patients with advanced cancer: the benefits of early referral for palliative care. *Med J Aust* 2011;194:107–8.
39. Bach V, Ploeg J, Black M. Nursing roles in end-of-life decision making in critical care settings. *West J Nurs Res* 2009;31:496–512.
40. Puntillo K, McAdam J. Communication between physicians and nurses as a target for improving end-of-life care in the intensive care unit: challenges and opportunities for moving forward. *Crit Care Med* 2006;34(11 Suppl):S332–40.
41. Coombs M, Addington-Hall J, Long-Sutehall T. Challenges in transition from intervention to end of life care in intensive care: a qualitative study. *Int J Nurs Stud* 2012;49:519–27.
42. Ronaldson S, Devery K. The experience of transition to palliative care services: perspectives of patients and nurses. *Int J Pall Nurs* 2001;7:171–7.
43. Long-Sutehall T, Willis H, Palmer R, et al. Negotiated dying: a grounded theory of how nurses shape withdrawal of treatment in hospital critical care units. *Int J Nurs Stud* 2011;48:1466–74.
44. Bolton S. Changing faces: nurses as emotional jugglers. *Social Health Illn* 2001;23:85–100.
45. Froggatt K. The place of metaphor and language in exploring nurses' emotional work. *J Adv Nurs* 1998;28:332–8.
46. Henderson A. Emotional labor and nursing: an under-appreciated aspect of caring work. *Nurs Inq* 2001;8:130–8.