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The role and significance of nurses in managing transitions to palliative care: A qualitative study

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3 **The role and significance of nurses in managing transitions to palliative care: A**
4 **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 semi-structured interviews.

Setting: Three hospitals in a major metropolitan area of Australia, including two public and one private.

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: a) professional dynamics and the roles played by nurses in initiating the transition to palliative care; b) the value of nurses' informal 'bedside' interactions in timely and effective transitions; c) the emerging challenge of managing task-oriented nursing versus intense emotional nursing work at the point of medical futility, and; d) 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 eventual transition to palliative care. They reported experiencing significant emotional burden in balancing interpersonal and inter-professional 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, patients and families is required to provide a broader interdisciplinary understanding of futility and contributions to the negotiation of palliative care.

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.

INTRODUCTION

Transitioning patients to palliative care from life-prolonging interventions can be a difficult aspect of clinical work,[1, 2] with significant patient and family distress reported in studies of negotiating futility.[3, 2] The difficulties some health professionals experience in topicalising the need for palliative care,[4, 5, 6, 2] and resistance amongst patients and their families,[7, 8, 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. [e.g. 12, 2] While the role and perspectives of doctors has been previously explored [4, 6, 13, 5] 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.[14, 12]

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 psycho-social 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.[17, 18, 8, 6, 13] 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] What roles different health professionals play in such contexts and is not well understood despite 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 palliative care.[4, 6, 5] 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 psycho-social as well as medical support,[16] and nurses are well-placed to observe and support the psycho-social wellbeing of patients and families. This type of caring work has considerable potential for emotional burden and fatigue amongst 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 which are highly valuable in effective transitions.[24,16] 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, 26, 27] Less attention, however, has been focused on how nurses' experiences 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. Ethics approval was granted by the hospital and University ethics committees (University of Queensland Human Research Ethics Committee #2011000905) prior to inviting nurses working within three hospitals to participate in the study. 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] Sampling was facilitated by Nurse Unit Managers who provided information forms to nurses who may be interested in participation. Of the 30 nurses who were approached, 20 agreed to participate. A range of areas of specialty were represented within

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3 this sample, including medical oncology, haematology, general medicine, radiation oncology,
4 and supportive/palliative care. The sample also included a range of levels of seniority, from
5 junior and newly qualified nurses to Nurse Unit Managers. Participants provided written
6 consent for the interviews to be digitally audio-recorded and transcribed verbatim and in full.
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8 The interviews lasted between 30-60 minutes, and were designed to explore the following
9 domains: the basis of nursing practice at points of transition; interacting with patients/family
10 about palliative care and the end of life; intra and inter-professional dynamics evident in the
11 transition to palliative care; and, the emotional and interpersonal impacts on nurses at this
12 point in care. We continued interviewing until the point of data saturation was reached.[31]
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20 **Analysis**

21 A systematic thematic content analysis was conducted using NVivo 9 software, into which all
22 interview transcripts were imported.. The thematic analysis of the data was driven by a
23 framework approach, which included the following steps: 1) Familiarisation - in which the
24 researchers reviewed the manuscripts; 2) Identification of framework - key themes and issues
25 identified around which the data was organised; 3) Indexing - application of themes to text;
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27 4) Charting - use of headings and sub-headings to build up a picture of the data as a whole;
28 and 5) Mapping and interpretation - in which associations were clarified and explanations
29 worked towards.[31] Independent coding of the data was provided initially by members of
30 the research team, which was then cross-checked to facilitate the development of themes,
31 moving towards an overall interpretation of the data. Analytic rigour was enhanced by
32 searching for negative, atypical and conflicting or contradicting cases in code and theme
33 development.[31, 32, 33] Inter-rater reliability was ensured by integrating a number of
34 research team members in the final analysis.[31, 34]
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45 **RESULTS**

46 Here we report on the themes emergent from our systematic analysis of the interviews. All of
47 the nurses interviewed spoke at length and in considerable detail of their experiences and
48 views on caring for patients and families approaching the end of life. It was clear from the
49 interviews that nursing work at this time had the potential to be emotionally draining, time-
50 consuming, and complex in terms of managing professional, inter-professional and nurse-
51 patient relationships. Our analysis revealed four predominant themes: a) professional
52 dynamics and the roles played by nurses in initiating the transition to palliative care; b) the
53 importance of bedside interaction and nurses roles in assisting effective transitions; c) the
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challenges of managing task-oriented nursing versus emotional work, and; d) the significant emotional work and burden experienced by nurses during these times.

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 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.

Table 1: Indicative quotations

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

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. When we have the time we'll always go and sit and talk to them. So I think they feel more comfortable with the nurses than they do the doctors because they see us a lot more often, and in a way we're a lot chattier than a doctor.
#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.

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 psycho-social 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 wellbeing. The interviews revealed the nurse-patient relationship as key to the maintenance of psycho-social wellbeing, and this was particularly pertinent given the emotionally fragile state of patients and family members at this time. In this way, nurses, particularly vis-à-vis doctors, were viewed as holding the predominant responsibility reassuring patients and their families, ensuring they were coping, 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, combined with a willingness to engage in emotional work, enabled the development of positive relationships with patients which were viewed as a crucial element of the care trajectory. The core values of nursing (i.e. alleviating suffering, maintaining dignity and comfort) shaped nurse-patient conversations which were a key element of “being there for the patient”.

Talking to patients and families: emotional support and effective transitions

Communication with patients is crucial to effective referral to palliative care.[13, 10, 9] 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.

Table 2: Indicative quotations

Talking to patients and families: emotional support and effective transitions

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 though all these kind of issues.

The significance of the nursing role was talked about in terms of the nurses' presence at the bedside of the patient. Spending time with patients and families constituted a core task in smoothing the transition, both in terms of medical and psycho-social 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 wellbeing (in both a psychological and practical sense). The nurses viewed themselves as ideally placed to talk to patients and listen to any concerns. 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. Thus, in contrast to medically driven decisions about the need for palliative care, the transition was characterised by helping the patient 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 were 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 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 that 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.

**Table 3: Indicative quotations
Managing task-oriented nursing and supporting patients in transition**

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 Unit Manager 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.

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.

Table 4: Indicative quotations
Emotional work: the burden of managing the transition to palliative care

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.

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 psycho-social wellbeing. 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,

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3 the burden of such work was clear in the majority of interviews. The maintenance of
4 emotional composure was talked about as a day-to-day skill and challenge. The majority of
5 the nurses talked about struggling with the extent to which they would (or should) get
6 emotionally involved with patients and families transitioning to palliative care. Indeed, the
7 majority of the nurses spoke at length about their own self-imposed rules and boundaries in
8 terms of interpersonal connections. Only a minority of the nurses viewed emotional work
9 with patients as straightforward or easily managed. A key element of the emotional toll of
10 this work lay in the responsibility the nurses felt to emotionally support patients and their
11 families. That is, they felt that a professional expectation to take on the vast majority of
12 emotional support work. This pressure to enact emotional work was compounded by a
13 perceived lack of emotional support for the nurses themselves.
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23 **DISCUSSION**

24 Ensuring timely and effective transitions to palliative care has significant benefits for patient
25 quality and quantity of life, and for family members' wellbeing.[12, 36] Nurses are crucial to
26 such referrals.[37, 19] This study provides a means for better understanding the significant
27 roles played by nurses in the referral and transition of patients to palliative care. The findings
28 of this study demonstrate the unique access to patients afforded to nursing staff, in both the
29 structure of their role and emerging from the core values and practice of nursing. The
30 findings also highlight the benefits of nurses who are oriented to providing psycho-social
31 support for patients and families in transition. A key process identified here was interpersonal
32 access to patients and their families. By being present at the bedside, and with a willingness
33 to talk and listen, the nurses held the advantage of uncovering crucial information on the
34 emotional and practical contexts of each patient. The benefits of such knowledge and
35 understanding (particularly when communicated to the treating physician) was viewed as
36 enabling the transition to palliative care (and planning therein) to be tailored to each
37 individual patient.
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49 The findings presented here highlight the importance of effective communication between
50 health professionals for palliative care planning.[1] While the nurses we interviewed talked
51 about being well-placed to inform treating physicians around initiating referral, around half
52 of the nurses lacked confidence in such communication. As has been shown in studies
53 elsewhere,[1, 20, 37] although nurses may be significantly involved in transitions to
54 palliative care, there may be a lack of, or variability in, opportunities for them to contribute
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3 towards decision-making around referral, which is widely considered to remain within the
4 remit of the treating physician. The self-reported data from this study highlighted nurses as
5 well situated within the ward to gain unique knowledge and understanding around patient and
6 family context. Yet, a number of practical and professional factors impeded nurse-doctor
7 communication.[38] As such, our findings support those of other studies which have
8 highlighted the benefits of inter-professional communication and team-based approaches to
9 referral, enabling nurses to have greater opportunity for input into often complex and
10 ambiguous consultant-led decisions.[39, 40, 1, 20] It is likely that such approaches would
11 improve referrals and transitions through more timely and better communicated referrals, and
12 by placing more emphasis on psycho-social factors.
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21 In addition to the potential for nurses to have significant input into decision-making around
22 initial referral, our findings also reveal the critical roles played by nurses in operationalising
23 the processes necessary for successful transitions.[41] While it was clear that the decision to
24 refer was led by the treating physician, the nurses in this study viewed tasks associated with
25 managing the transition itself as their own responsibility. A key element of this work was the
26 ability to empathise and identify with patients and families. This management of emotion is
27 an important nursing skill [42, 43, 27, 24] which is arguably under-recognised and under-
28 utilised in the context of referral and transition to palliative care. Nurses represent a
29 significant resource in this area, and their expertise could be more actively drawn on by
30 doctors and other health professionals to assist with positive professional-patient
31 communication and negotiation. In contexts where doctors frequently struggle with breaking
32 bad news to patients and their families,[1, 17, 22] nurses can and do play a pivotal role in
33 smoothing transitions and maintaining psycho-social wellbeing.[44] However, while the
34 values of nursing shape such expertise, nurses should not carry the burden of emotional work
35 with patients in isolation. Ultimately, the interviews revealed the considerable burden of
36 responsibility of nursing to maintain and manage the psycho-social wellbeing of the patient
37 and family at the point of futility and transition to palliative care. Moreover, it was clear from
38 the interviews that there was at times a perceived lack of support from other health
39 professionals and the hospital in terms of supporting them in their work. That is, this
40 important emotional work involved in helping patients transition to palliative care was
41 viewed as predominantly the responsibility of nursing staff.
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3 This study has several limitations. Although our sample of nurses including representation of
4 a range of specialty areas and levels of experience and seniority, it only captures the
5 experiences of from three hospitals in one Australian city. As such, our findings cannot be
6 generalised to other nurses in other settings despite providing indications of themes likely to
7 resonate across other settings. Furthermore, the sample of nurses was self-selected. Our
8 findings therefore may not represent the views or experiences of less experienced nurses in
9 these contexts or those with less interest in palliative care. Given the findings presented here,
10 further research focused on the experiences of doctors, social workers, patients and families
11 is required to provide a team-based understanding of negotiating referral and transition to
12 palliative care. Nurses may be utilised in a more formalised and systematic fashion in the
13 context of potential futility and the need to topicalise palliation, with the focus shifted away
14 from purely 'medical referrals' and centred on 'team-based' and 'patient-centred' timely
15 transitions. Nursing staff also require support, given the emotionally challenging nature of
16 their work. Supervision alongside a team-based approach to transitioning patients may better
17 support nurses to emotionally as well as clinically support patients during this difficult time.
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COMPETING INTERESTS

The authors declare that they have no competing interests.

AUTHOR CONTRIBUTIONS

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. All authors approved the final version of the manuscript prior to submission.

DATA SHARING STATEMENT

No additional data available

REFERENCES

1. Gott M, Ingleton C, Bennett M, et al. Transitions to palliative care in acute hospitals in England: qualitative study. *BMJ* 2011;1:42-48 doi:10.1136/bmj.d1773

2. Melvin C, Oldham L. When to refer patients to palliative care: triggers, traps and timely referrals. *J Hosp Palliat Nurs* 2009;11:291-301 doi: 10.1097/NJH.0b013e3181b543d4
3. 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 doi: 10.1191/0269216304pm921oa
4. 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 doi:10.1089/jpm.2012.0264
5. Kirby E, Broom A, Good P, et al. Medical specialists' motivations for referral to specialist palliative care: a qualitative study. *BMJ Support Palliat Care* 2012;0:1-8 doi:10.1136/bmjspcare-2012-000376
6. 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 doi: 10.1016/j.socscimed.2012.11.008
7. Quill T, Arnold R, Back A. Discussing treatment preferences with patients who want "everything." *Ann Intern Med* 2009;151:345–49
8. Kirby E, Broom A, Good P, et al. Families and the transition to specialist palliative care. *Mortality*. 2014; Published online 13/05/14 doi: 10.1080/13576275.2014.916258
9. Bowman K. Communication, negotiation, and mediation: dealing with conflict in end-of-life. *J Palliat Care* 2000;16:S17–23
10. Anderson W, Kools S, Lyndon A. Dancing around death: hospitalist-patient communication about serious illness. *Qual Health Res* 2013;23:3-13 doi: 10.1177/1049732312461728
11. 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: 474-79 doi: 10.1001/archinternmed.2008.583
12. 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 doi: 10.1056/NEJMoa1000678
13. 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 doi: 10.1177/1049732313519709
14. 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
15. Morita T, Miyashita M, Kimura R, et al. Emotional burden of nurses in palliative sedation therapy. *Palliat Med* 2004;18:550-57 doi: 10.1191/0269216304pm911oa
16. Skilbeck J, Payne S. Emotional support and the role of clinical nurse specialists in palliative care. *J Adv Nurs* 2003;43:521-30 doi: 10.1046/j.1365-2648.2003.02749.x
17. Barclay S, Maher J. Having the difficult conversations about the end of life. *BMJ* 2010; 341:c4862 doi: 10.1136/bmj.c4862
18. Oberle K, Hughes D. Doctors' and nurses' perceptions of ethical problems in end-of-life decisions. *J Adv Nurs* 2001 33:707–15 doi: 10.1046/j.1365-2648.2001.01710.x
19. Benbenishty J, Ganz F, Bulow H. Nurse involvement in end-of-life decision making: the ETHICUS study. *Intensive Care Med* 2006;32:129–32 doi:10.1007/s00134-005-2865-0
20. Marsella A. Exploring the literature surrounding the transition into palliative care: a scoping review. *Int J Palliat Nurs* 2009;15:186-89 doi: 10.1007/s00134-005-2864-1
21. Arnold B. Mapping hospice patients' perception and verbal communication of end-of-life needs. *BMC Palliat Care* 2011;10, 1 doi:10.1186/1472-684X-10-1

- 1
2
3 22. Hanratty B, Lowson E, Holmes L, et al. Breaking bad news sensitively: what is important
4 to patients in their last year of life? *BMJ Support Palliat Care* 2012;2:24-28 doi:
5 10.1136/bmjspcare-2011-000084
6
7 23. Bailey C, Murphy R, Porock, D. Professional tears: developing emotional intelligence
8 around death and dying in emergency work. *J Clin Nurs* 2011;20:3364-72.
9 doi: 10.1111/j.1365-2702.2011.03860.x
10
11 24. Broom A, Kirby E, Good P, et al. Negotiating futility, managing emotions: nursing the
12 transition to palliative care. *Qual Health Res* in press, Accepted 009/05/14.
13
14 25. Ablett J, Jones R. Resilience and well-being in palliative care staff. *Psycho-Oncology*
15 2007;16:733-40 doi: 10.1002/pon.1130
16
17 26. Fillion L, Tremblay I, Truchon M, et al. Job satisfaction and emotional distress among
18 nurses providing palliative care. *Int J Stress Manage* 2007;14:1-25 doi: 10.1037/1072-
19 5245.14.1.1
20
21 27. Sandgren A, Thulesius H, Fridlund B, et al. Striving for emotional survival in palliative
22 cancer nursing. *Qual Health Res* 2006; 16:79-96 doi: 10.1177/1049732305283930
23
24 28. Steinhauser K, Barroso J. Using qualitative methods to explore key questions in palliative
25 care. *J Palliat Med* 2009;12:723-30 doi:10.1089/jpm.2009.9580
26
27 29. Timmerman S. There is more to dying than death. In: Bourgeault I, Dingwall R, de Vries
28 R, eds. *The Sage Handbook of Qualitative Methods in Health Research*. LA: Sage
29 2010:19-33
30
31 30. Clark D, Ingleton C, Seymour J. Support and supervision in palliative care research.
32 *Palliat Med* 2000;14:441-46 doi: 10.1191/026921600701536156
33
34 31. Pope C, Ziebland S, Mays N. Analysing qualitative data. In: Pope C, Mays N, eds.
35 *Qualitative Research in Health Care*, 3rd ed. Oxford, UK: Blackwell Publishing, 2006:
36 63-81
37
38 32. Ezzy D. *Qualitative Analysis: Practice and Innovation*. London: Routledge 2002.
39
40 33. Fitzpatrick R, Boulton M. Qualitative research in health care: the scope and validity of
41 methods. *J Eval Clin Pract* 1996;2:123-30
42
43 34. Morse J. "Perfectly healthy, but dead": the myth of inter-rater reliability. *Qual Health Res*
44 1997;7:445-47 doi: 10.1177/104973239700700401
45
46 35. Clayton J, Hancock K, Parker S, et al. Sustaining hope when communicating with
47 terminally ill patients and their families: a systematic review. *Psycho-Oncology* 2009;17:
48 641-59 doi: 10.1002/pon.1288
49
50 36. Haines I. Managing patients with advanced cancer: the benefits of early referral for
51 palliative care. *Med J Aust* 2011;194:107-8
52
53 37. Bach V, Ploeg J, Black M. Nursing roles in end-of-life decision making in critical care
54 settings. *West J Nurs Res* 2009;31:496-512 doi: 10.1177/0193945908331178
55
56 38. Puntillo K, McAdam J. Communication between physicians and nurses as a target for
57 improving end-of-life care in the intensive care unit: challenges and opportunities for
58 moving forward. *Crit Care Med* 2006;34(11 Suppl.):S332-340 doi:
59 10.1097/01.CCM.0000237047.31376.28
60
61 39. Coombs M, Addington-Hall J, Long-Sutell T. Challenges in transition from
62 intervention to end of life care in intensive care: a qualitative study. *Int J Nurs Stud*
63 2012;49:519-527 doi: 10.1016/j.ijnurstu.2011.10.019
64
65 40. Ronaldson S, Devery K. The experience of transition to palliative care services:
66 perspectives of patients and nurses. *Int J Pall Nurs* 2001;7:171-77 doi:
67 10.12968/ijpn.2001.7.4.9033
68
69 41. Long-Sutell T, Willis H, Palmer R, et al. Negotiated dying: a grounded theory of how
70 nurses shape withdrawal of treatment in hospital critical care units. *Int J Nurs Stud*
71 2011;48:1466-74 doi: 10.1016/j.ijnurstu.2011.06.003

- 1
2
3 42. Bolton S. Changing faces: nurses as emotional jugglers. *Sociol Health Illn* 2001; 23:85-
4 100 doi: 10.1111/1467-9566.00242
5 43. Froggatt K. The place of metaphor and language in exploring nurses' emotional work. *J*
6 *Adv Nurs* 1998; 28:332-38 doi: 10.1046/j.1365-2648.1998.00688.x
7 44. Henderson A. Emotional labor and nursing: an under-appreciated aspect of caring work.
8 *Nurs Inq* 2001; 8:130-38 doi: 10.1046/j.1440-1800.2001.00097.x
9
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The role and significance of nurses in managing transitions to palliative care: A qualitative study

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3 **The role and significance of nurses in managing transitions to palliative care: A**
4 **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 semi-structured interviews.

Setting: Two health services with both public and 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: a) professional dynamics and the roles played by nurses in initiating the transition to palliative care; b) the value of nurses' informal interactions in timely and effective transitions; c) the emerging challenge of managing task-oriented nursing versus intense emotional nursing work at the point of medical futility, and; d) 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 inter-professional 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, patients and families is required to provide a broader interdisciplinary understanding of futility and contributions to the negotiation of palliative care.

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.

INTRODUCTION

Transitioning patients to palliative care from life-prolonging interventions can be a difficult aspect of clinical work,[1, 2] with significant patient and family distress reported in studies of negotiating futility.[3, 2] The difficulties some health professionals experience in topicalising the need for palliative care,[4, 5, 6, 2] and resistance amongst patients and their families,[7, 8, 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. [e.g. 12, 2] While the role and perspectives of doctors has been previously explored [4, 6, 13, 5] 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.[14, 12]

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 psycho-social 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.[17, 18, 8, 6, 13] 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] What roles different health professionals play in such contexts and is not well understood despite 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 palliative care.[4, 6, 5] 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 psycho-social as well as medical support,[16] and nurses are well-placed to observe and support the psycho-social wellbeing of patients and families. This type of caring work has considerable potential for emotional burden and fatigue amongst 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 which are highly valuable in effective transitions.[24,16] 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, 26, 27] Less attention, however, has been focused on how nurses' experiences 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. Ethics approval was granted by the hospital and University ethics committees (University of Queensland Human Research Ethics Committee #2011000905) prior to inviting nurses working within two hospital health services to participate in the study. 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-

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3 face interviews have been shown historically to be a feasible and effective means of
4 documenting experiences and perceptions of care in the last few weeks of life.[28, 29]
5 Furthermore, a qualitative design allows documentation of complex personal and
6 interpersonal challenges, conflicts and successes.[30] The purposive sampling strategy was
7 facilitated by Nurse Unit Managers who provided information forms to nurses who may be
8 interested in participation. The information form outlined the aims and objectives of the
9 project and described the background of the researchers, then invited potential participants to
10 voluntarily contact the researchers directly if willing to participate. The information form also
11 outlined that potential participants' would be in no way disadvantaged by electing not to
12 participate in the study, and could withdraw their participation at any time, for any reason,
13 without penalty. Of the 30 nurses who were approached, 20 agreed to participate. A range of
14 areas of specialty were represented within this sample, including medical oncology,
15 haematology, general medicine, radiation oncology, and supportive/palliative care. The
16 sample also included a range of levels of seniority, from junior and newly qualified nurses
17 (n=4) and clinical nurses (n=10), to more senior coordinators and Nurse Unit Managers
18 (n=6). There were 18 female and 2 male participants, aged from early 20s to late 50s.
19 Participants provided written consent for the interviews to be digitally audio-recorded and
20 transcribed verbatim and in full. The interviews took place in private office spaces within the
21 hospitals, lasted between 30-60 minutes, and were designed to explore the following
22 domains: the basis of nursing practice at points of transition; interacting with patients/family
23 about palliative care and the end of life; intra and inter-professional dynamics evident in the
24 transition to palliative care; and, the emotional and interpersonal impacts on nurses at this
25 point in care. We continued interviewing until the point of data saturation was reached.[31]
26 The researchers conducted member checking during the interviews by frequently
27 summarising and restating participants' views and experiences to enhance reliability through
28 allowing the participant to confirm or query the researcher's understanding.
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48 **Analysis**

49 A systematic thematic content analysis was conducted using NVivo 9 software, into which all
50 interview transcripts were imported. The thematic analysis of the data was driven by a
51 framework approach, which included the following steps: 1) Familiarisation - in which the
52 researchers reviewed the manuscripts; 2) Identification of framework - key themes and issues
53 identified around which the data was organised; 3) Indexing - application of themes to text;
54 4) Charting - use of headings and sub-headings to build up a picture of the data as a whole;
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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, 32, 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

Here 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 and families approaching the end of life. 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: a) in the nursing role in the transition to palliative care; b) emotional support and effective transitions; c) managing task-oriented nursing and supporting patients in transition, and; d) 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 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.

Table 1: Indicative quotations

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

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.

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 psycho-social 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 wellbeing. The interviews revealed the nurse-patient relationship as key to the maintenance of psycho-social wellbeing, and this was particularly pertinent given the emotionally fragile state of patients and family members at this time. In this way, nurses, particularly compared to doctors, were viewed as holding the predominant responsibility for reassuring patients and their families, ensuring they were coping, 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 (i.e. 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.[13, 10, 9] 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.

**Table 2: Indicative quotations
Talking to patients and families: emotional support and effective transitions**

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.

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 psycho-social needs. All of the nurses indicated the significance of dual considerations when considering referral to palliative care, incorporating

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3 considerations of pain and symptom management and broader wellbeing (in both a
4 psychological and practical sense). The nurses viewed themselves as ideally placed to talk to
5 patients and listen to any concerns during this transitional period. These included
6 conversations about mortality and futility, as well as talk about family members' capacity to
7 provide care at home, or ongoing practical care needs. Effective transitions were facilitated
8 by opportunities for the nurses to talk (and listen) to patients and their families beyond the
9 initial point of referral and throughout the transitional period (often a number of days at
10 least). Thus, in contrast to medically driven decisions about the need for palliative care, the
11 transition was characterised by helping the patient to understand their situation. In addition,
12 the provision of emotional support was positioned as vital for family members, and the nurses
13 were ideally located (and motivated) to offer such support. However, as discussed in the
14 following section, there were a range of factors which impeded the nurses in providing
15 sufficient support in their daily work.
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26 **Managing task-oriented nursing and supporting patients in transition**

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

**Table 3: Indicative quotations
Managing task-oriented nursing and supporting patients in transition**

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.

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.

**Table 4: Indicative quotations
Emotional work: the burden of managing the transition to palliative care**

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.

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3 #4 But when it starts to you know, sometimes even the best of palliative care, some doctors are
4 okay with it, but other doctors you know, some people are crying all through their consultation,
5 it takes its toll on them too. Because they don't have anyone to debrief with either.
6
7 #16 At the time on the ward, you don't have time to think about it because you've got to go to your
8 next patient who might be having curative intent treatment, so you've got to be positive. You've
9 got to learn how to respond to things, and be emotional at the appropriate times. If you're happy,
10 you're a happy person, you're in a good mood and you're upbeat, you can't go into that room
11 with a patient who's dying and be smiling "hey how are you all going? Is everyone okay?"
12 because to them it's not. But then you go into the next room, you can't go in there sombre, you
13 need to be positive for that patient without being unrealistic. So it's like you just put on a
14 different mask.
15 #6 I find it really difficult. I'm getting better. I guess the more, in this role I've had more exposure
16 to it so. But you never feel comfortable about having those discussions. I've got siblings that are
17 the age of people, or they're my age that are having treatments. So it's a bit, I'm pretty raw, like
18 if I get upset I'll get upset in front of them. It doesn't worry me, and it doesn't worry them. It
19 shows you care, I think.
20 #20 I've seen a couple of young nurses become quite unhinged at an event and I just don't know...I
21 don't feel there's that support for the younger girls anymore, or older girls, or anyone really. And
22 from my perspective yes I do get very upset, but I realise that things come to an end. And the
23 positive is that if I can do everything I can, then that's great. Because you spend time with the
24 families...It's quite you know, you've got to have a bit of downtime.
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26 It was clear that the nurses empathised and identified with many of their patients, and
27 experienced a range of emotions including sadness, grief, frustration and fatigue. Indeed,
28 much energy was put into emotionally supporting patients and families, and in maintaining
29 their own psycho-social wellbeing. The nurses talked about the challenges of managing their
30 own mood and demeanour around patients. Displays of emotion needed to be constantly
31 reassessed when working with patients within the same unit who may be approaching the end
32 of life alongside those undergoing curative treatment. Balancing hope and futility and the
33 according expressions of emotion required considerable thought and attention.[35] Indeed,
34 the burden of such work was clear throughout the interviews. The maintenance of emotional
35 composure was talked about as a day-to-day skill and challenge. The majority of the nurses
36 talked about struggling with the extent to which they would (or should) get emotionally
37 involved with patients and families transitioning to palliative care. Indeed, the majority of the
38 nurses spoke at length about their own self-imposed rules and boundaries in terms of
39 interpersonal connections, particularly in terms of managing the potential for compassion
40 fatigue and/or burnout.[36,37] Only a minority of the nurses viewed emotional work with
41 patients as straightforward or easily managed. A key element of the emotional toll of this
42 work lay in the responsibility the nurses felt to emotionally support patients and their
43 families. That is, they felt that a professional expectation to take on the vast majority of
44 emotional support work. This pressure to enact emotional work was compounded by a
45 perceived lack of emotional support for the nurses themselves.
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DISCUSSION

Ensuring timely and effective transitions to palliative care has significant benefits for patient quality and quantity of life, and for family members' wellbeing.[12, 38] Nurses are crucial to such referrals.[39, 19] 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 both the structure of their role and emerging from the core values and practice of nursing. The findings also highlight the benefits of nurses who are oriented to providing psycho-social 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 which have highlighted the benefits of inter-professional communication and team-based approaches to referral, enabling nurses to have greater opportunity for input into often complex and ambiguous consultant-led decisions.[41, 42, 1, 20] It is likely that such approaches would improve referrals and transitions through more timely and better communicated referrals, and by placing more emphasis on psycho-social factors.

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3 In addition to the potential for nurses to have significant input into decision-making around
4 initial referral, our findings also reveal the critical roles played by nurses in operationalising
5 the processes necessary for successful transitions.[43] While it was clear that the decision to
6 refer was led by the treating physician, the nurses in this study viewed tasks associated with
7 managing the transition itself as primarily their own responsibility. A key element of this
8 work was the ability to empathise and identify with patients and families. This management
9 of emotion is an important nursing skill [44, 45, 27, 24] which is arguably under-recognised
10 and under-utilised in the context of referral and transition to palliative care. Nurses represent
11 a significant resource in this area, and their expertise could be more actively drawn on by
12 doctors and other health professionals to assist with positive professional-patient
13 communication and negotiation. In contexts where doctors frequently struggle with breaking
14 bad news to patients and their families,[1, 17, 22] nurses can and do play a pivotal role in
15 smoothing transitions and maintaining psycho-social wellbeing.[46] However, while the
16 values of nursing shape such expertise, nurses should not carry the burden of emotional work
17 with patients in isolation. Ultimately, the interviews revealed the considerable burden of
18 responsibility of nursing to maintain and manage the psycho-social wellbeing of the patient
19 and family at the point of futility and transition to palliative care. Moreover, it was clear from
20 the interviews that there was at times a perceived lack of support from other health
21 professionals and the hospital in terms of supporting them in their work. That is, this
22 important emotional work involved in helping patients transition to palliative care was
23 viewed as predominantly the responsibility of nursing staff.

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40 This study has several limitations. Although our sample of nurses including representation of
41 a range of specialty areas and levels of experience and seniority, it only captures the
42 experiences of from two health services with both public and private clinical environments in
43 one Australian city. As such, our findings cannot be generalised to other nurses in other
44 settings despite providing indications of themes and theoretical insights likely to resonate
45 across other settings. Furthermore, the sample of nurses was self-selected. Our findings
46 therefore may not represent the views or experiences of less experienced nurses in these
47 contexts or those with less interest in palliative care. Given the findings presented here,
48 further research focused on the experiences of doctors, social workers, patients and families
49 is required to provide a team-based understanding of negotiating referral and transition to
50 palliative care. In practice, nurses can be utilised in a more formalised and systematic fashion
51 in the context of potential futility and the need to topicalise palliation by shifting the focus
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3 away from purely ‘medical referrals’ and focusing on ‘team-based’ and ‘patient-centred’
4 timely transitions. Nursing staff also require support, given the emotionally challenging
5 nature of their work, particularly in managing the potential for professional compassion
6 fatigue and burnout.[36,37] Supervision alongside a team-based approach to transitioning
7 patients may better support nurses to emotionally as well as clinically support patients during
8 this difficult time.
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25 26 **COMPETING INTERESTS**

27 The authors declare that they have no competing interests.
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30 31 **AUTHOR CONTRIBUTIONS**

32 The project was designed and developed by all authors. Data was collected by AB and EK.
33 Data analysis was led by EK and AB, with input from all authors. All authors contributed to
34 the drafting and revising of the manuscript. All authors approved the final version of the
35 manuscript prior to submission.
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39 40 41 **DATA SHARING STATEMENT**

42 No additional data available
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REFERENCES

1. Gott M, Ingleton C, Bennett M, et al. Transitions to palliative care in acute hospitals in England: qualitative study. *BMJ* 2011;1:42-48 doi:10.1136/bmj.d1773
2. Melvin C, Oldham L. When to refer patients to palliative care: triggers, traps and timely referrals. *J Hosp Palliat Nurs* 2009;11:291-301 doi: 10.1097/NJH.0b013e3181b543d4
3. 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 doi: 10.1191/0269216304pm921oa
4. 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 doi:10.1089/jpm.2012.0264
5. Kirby E, Broom A, Good P, et al. Medical specialists' motivations for referral to specialist palliative care: a qualitative study. *BMJ Support Palliat Care* 2012;0:1-8 doi:10.1136/bmjspcare-2012-000376
6. 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 doi: 10.1016/j.socscimed.2012.11.008
7. Quill T, Arnold R, Back A. Discussing treatment preferences with patients who want "everything." *Ann Intern Med* 2009;151:345–49
8. Kirby E, Broom A, Good P, et al. Families and the transition to specialist palliative care. *Mortality*. 2014; Published online 13/05/14 doi: 10.1080/13576275.2014.916258
9. Bowman K. Communication, negotiation, and mediation: dealing with conflict in end-of-life. *J Palliat Care* 2000;16:S17–23
10. Anderson W, Kools S, Lyndon A. Dancing around death: hospitalist-patient communication about serious illness. *Qual Health Res* 2013;23:3-13 doi: 10.1177/1049732312461728
11. 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: 474-79 doi: 10.1001/archinternmed.2008.583
12. 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 doi: 10.1056/NEJMoa1000678
13. 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 doi: 10.1177/1049732313519709
14. 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

15. Morita T, Miyashita M, Kimura R, et al. Emotional burden of nurses in palliative sedation therapy. *Palliat Med* 2004;18:550-57 doi: 10.1191/0269216304pm9110a
16. Skilbeck J, Payne S. Emotional support and the role of clinical nurse specialists in palliative care. *J Adv Nurs* 2003;43:521-30 doi: 10.1046/j.1365-2648.2003.02749.x
17. Barclay S, Maher J. Having the difficult conversations about the end of life. *BMJ* 2010; 341:c4862 doi: 10.1136/bmj.c4862
18. Oberle K, Hughes D. Doctors' and nurses' perceptions of ethical problems in end-of-life decisions. *J Adv Nurs* 2001 33:707-15 doi: 10.1046/j.1365-2648.2001.01710.x
19. Benbenishty J, Ganz F, Bulow H. Nurse involvement in end-of-life decision making: the ETHICUS study. *Intensive Care Med* 2006;32:129-32 doi:10.1007/s00134-005-2865-0
20. Marsella A. Exploring the literature surrounding the transition into palliative care: a scoping review. *Int J Palliat Nurs* 2009;15:186-89 doi: 10.1007/s00134-005-2864-1
21. Arnold B. Mapping hospice patients' perception and verbal communication of end-of-life needs. *BMC Palliat Care* 2011;10, 1 doi:10.1186/1472-684X-10-1
22. Hanratty B, Lawson 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;2:24-28 doi: 10.1136/bmjspcare-2011-000084
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. doi: 10.1111/j.1365-2702.2011.03860.x
24. Broom A, Kirby E, Good P, et al. Negotiating futility, managing emotions: nursing the transition to palliative care. *Qual Health Res* in press, Accepted 09/05/14.
25. Ablett J, Jones R. Resilience and well-being in palliative care staff. *Psycho-Oncology* 2007;16:733-40 doi: 10.1002/pon.1130
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 doi: 10.1037/1072-5245.14.1.1
27. Sandgren A, Thulesius H, Fridlund B, et al. Striving for emotional survival in palliative cancer nursing. *Qual Health Res* 2006; 16:79-96 doi: 10.1177/1049732305283930
28. Steinhauser K, Barroso J. Using qualitative methods to explore key questions in palliative care. *J Palliat Med* 2009;12:723-30 doi:10.1089/jpm.2009.9580
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;14:441-46 doi: 10.1191/026921600701536156
31. Pope C, Ziebland S, Mays N. Analysing qualitative data. In: Pope C, Mays N, eds. *Qualitative Research in Health Care*, 3rd ed. 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;7:445-47 doi: 10.1177/104973239700700401
35. Clayton J, Hancock K, Parker S, et al. Sustaining hope when communicating with terminally ill patients and their families: a systematic review. *Psycho-Oncology* 2009;17: 641-59 doi: 10.1002/pon.1288
36. Potter P, Deshields T, Divanbeigi J, et al. Compassion fatigue and burnout: Prevalence among oncology nurses. *Clin J Oncol Nurs* 2010;14(5): E56-62.

- 1
2
3 37. Najjar N, Davis LW, Beck-Coon K, et al. Compassion fatigue: A review of the research
4 to date and relevance to cancer care providers. *J Health Psychol* 2009; 14(2):267-277.
5 38. Haines I. Managing patients with advanced cancer: the benefits of early referral for
6 palliative care. *Med J Aust* 2011;194:107-8
7 39. Bach V, Ploeg J, Black M. Nursing roles in end-of-life decision making in critical care
8 settings. *West J Nurs Res* 2009;31:496-512 doi: 10.1177/0193945908331178
9 40. Puntillo K, McAdam J. Communication between physicians and nurses as a target for
10 improving end-of-life care in the intensive care unit: challenges and opportunities for
11 moving forward. *Crit Care Med* 2006;34(11 Suppl.):S332-340 doi:
12 10.1097/01.CCM.0000237047.31376.28
13 41. Coombs M, Addington-Hall J, Long-Suthehall T. Challenges in transition from
14 intervention to end of life care in intensive care: a qualitative study. *Int J Nurs Stud*
15 2012;49:519-527 doi: 10.1016/j.ijnurstu.2011.10.019
16 42. Ronaldson S, Devery K. The experience of transition to palliative care services:
17 perspectives of patients and nurses. *Int J Pall Nurs* 2001;7:171-77 doi:
18 10.12968/ijpn.2001.7.4.9033
19 43. Long-Suthehall T, Willis H, Palmer R, et al. Negotiated dying: a grounded theory of how
20 nurses shape withdrawal of treatment in hospital critical care units. *Int J Nurs Stud*
21 2011;48:1466-74 doi: 10.1016/j.ijnurstu.2011.06.003
22 44. Bolton S. Changing faces: nurses as emotional jugglers. *Sociol Health Illn* 2001; 23:85-
23 100 doi: 10.1111/1467-9566.00242
24 45. Froggatt K. The place of metaphor and language in exploring nurses' emotional work. *J*
25 *Adv Nurs* 1998; 28:332-38 doi: 10.1046/j.1365-2648.1998.00688.x
26 46. Henderson A. Emotional labor and nursing: an under-appreciated aspect of caring work.
27 *Nurs Inq* 2001; 8:130-38 doi: 10.1046/j.1440-1800.2001.00097.x
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3 **The role and significance of nurses in managing transitions to palliative care: A**
4 **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 semi-structured interviews.

Setting: ~~Three~~ Two health services with both public and private clinical environments hospitals in a major metropolitan area of Australia, including two public and one private.

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: a) professional dynamics and the roles played by nurses in initiating the transition to palliative care; b) the value of nurses' informal 'bedside' interactions in timely and effective transitions; c) the emerging challenge of managing task-oriented nursing versus intense emotional nursing work at the point of medical futility, and; d) 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 eventual transition to palliative care. They reported experiencing significant emotional burden in balancing interpersonal and inter-professional 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, patients and families is required to provide a broader interdisciplinary understanding of futility and contributions to the negotiation of palliative care.

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.

INTRODUCTION

Transitioning patients to palliative care from life-prolonging interventions can be a difficult aspect of clinical work,[1, 2] with significant patient and family distress reported in studies of negotiating futility.[3, 2] The difficulties some health professionals experience in topicalising the need for palliative care,[4, 5, 6, 2] and resistance amongst patients and their families,[7, 8, 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. [e.g. 12, 2] While the role and perspectives of doctors has been previously explored [4, 6, 13, 5] 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.[14, 12]

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 psycho-social 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.[17, 18, 8, 6, 13] 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] What roles different health professionals play in such contexts and is not well understood despite 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 palliative care.[4, 6, 5] 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 psycho-social as well as medical support,[16] and nurses are well-placed to observe and support the psycho-social wellbeing of patients and families. This type of caring work has considerable potential for emotional burden and fatigue amongst 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 which are highly valuable in effective transitions.[24,16] 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, 26, 27] Less attention, however, has been focused on how nurses' experiences 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. Ethics approval was granted by the hospital and University ethics committees (University of Queensland Human Research Ethics Committee #2011000905) prior to inviting nurses working within three-two hospital health services hospitals to participate in the study. 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

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3 semi-structured interview to discuss their experiences and perspectives. The transition to
4 palliative care is a particularly emotional, sensitive and difficult period for all stakeholders
5 and face-to-face interviews have been shown historically to be a feasible and effective means
6 of documenting experiences and perceptions of care in the last few weeks of life.[28, 29]
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8 Furthermore, a qualitative design allows documentation of complex personal and
9 interpersonal challenges, conflicts and successes.[30] The purposive sSampling strategy was
10 facilitated by Nurse Unit Managers who provided information forms to nurses who may be
11 interested in participation. The information form outlined the aims and objectives of the
12 project and described the background of the researchers, then invited potential participants to
13 voluntarily contact the researchers directly if willing to participate. The information form also
14 outlined that potential participants' would be in no way disadvantaged by electing not to
15 participate in the study, and could withdraw their participation at any time, for any reason,
16 without penalty. Of the 30 nurses who were approached, 20 agreed to participate. A range of
17 areas of specialty were represented within this sample, including medical oncology,
18 haematology, general medicine, radiation oncology, and supportive/palliative care. The
19 sample also included a range of levels of seniority, from junior and newly qualified nurses
20 (n=4) and clinical nurses (n=10), to more senior coordinators and Nurse Unit Managers
21 (n=6). There were 18 female and 2 male participants, aged from early 20s to late 50s.
22 Participants provided written consent for the interviews to be digitally audio-recorded and
23 transcribed verbatim and in full. The interviews took place in private office spaces within the
24 hospitals, lasted between 30-60 minutes, and were designed to explore the following
25 domains: the basis of nursing practice at points of transition; interacting with patients/family
26 about palliative care and the end of life; intra and inter-professional dynamics evident in the
27 transition to palliative care; and, the emotional and interpersonal impacts on nurses at this
28 point in care. We continued interviewing until the point of data saturation was reached.[31]
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30 The researchers conducted member checking during the interviews by frequently
31 summarising and restating participants' views and experiences to enhance reliability through
32 allowing the participant to confirm or query the researcher's understanding.
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51 Analysis

52 A systematic thematic content analysis was conducted using NVivo 9 software, into which all
53 interview transcripts were imported.- The thematic analysis of the data was driven by a
54 framework approach, which included the following steps: 1) Familiarisation - in which the
55 researchers reviewed the manuscripts; 2) Identification of framework - key themes and issues
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3 identified around which the data was organised; 3) Indexing - application of themes to text;
4 4) Charting - use of headings and sub-headings to build up a picture of the data as a whole;
5 and 5) Mapping and interpretation - in which associations were clarified and explanations
6 worked towards.[31] Independent coding of the data was provided initially by members of
7 the research team, which was then cross-checked to facilitate the development of themes,
8 moving towards an overall interpretation of the data. Analytic rigour was enhanced by
9 searching for negative, atypical and conflicting or contradicting cases in coding and theme
10 development.[31, 32, 33] Inter-rater reliability was ensured by integrating a number of
11 research team members in the final analysis.[31, 34] All audio recordings, transcripts, coding
12 reports and notes were retained and added to documentation of research aims, design and
13 sampling and recruitment processes and practices to form an audit trail.

23 RESULTS

24 Here we report on the themes emergent from our systematic analysis of the interviews. All of
25 the nurses interviewed spoke at length and in considerable detail of their experiences and
26 views on caring for patients and families approaching the end of life. It was clear from the
27 interviews that nursing work at this time had the potential to be emotionally draining, time-
28 consuming, and complex in terms of managing professional, inter-professional and nurse-
29 patient relationships. Our analysis revealed four predominant themes: a) professional
30 dynamics and the roles played by nurses in the nursing role in initiating the transition to
31 palliative care; b) emotional support and effective transition ~~the importance of bedside~~
32 interaction and nurses roles in assisting effective transitions; c) managing task-oriented
33 nursing and supporting patients in transition ~~the challenges of managing task-oriented nursing~~
34 versus emotional work, and; d) the emotional -burden of managing the transition to palliative
35 care ~~significant emotional work and burden experienced by nurses during these times.~~

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

47 The nurses offered detailed accounts of their perspectives on the nursing role and experiences
48 therein during transition to palliative care. This included the self-reported skills and
49 approaches most valuable in caring for patients and families at this difficult time. Examples
50 of indicative quotes related to participants' views on the role of nursing in the transition to
51 palliative care are provided in Table 1.
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Table 1: Indicative quotations
Professional roles and relationships: the nursing role in the transition to palliative care

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. When we have the time we'll always go and sit and talk to them. So I think they feel more comfortable with the nurses than they do the doctors because they see us a lot more often, and in a way we're a lot chattier than a doctor.
#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.

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 psycho-social 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 wellbeing. The interviews revealed the nurse-patient relationship as key to the maintenance of psycho-social wellbeing, and this was particularly pertinent given the emotionally fragile state of patients and family members at this time. In this way, nurses, particularly ~~vis-à-vis~~ ~~viscompared to~~ doctors, were viewed as holding the predominant responsibility ~~for~~ reassuring patients and their families, ensuring they were coping, 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 ~~, combined with a willingness to engage in emotional work,~~ enabled the development of positive relationships with patients which were viewed as a crucial element of the care trajectory. The core values

of nursing (i.e. 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.[13, 10, 9] 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.

Table 2: Indicative quotations

Talking to patients and families: emotional support and effective transitions

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.

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6 Having a physical presence at the bedside was talked about as crucial to supporting the
7 patient and family through the transition, particularly in terms of effective communication.
8 ~~The significance of the nursing role was talked about in terms of the nurses' presence at the~~
9 ~~bedside of the patient.~~ Spending time with patients and families constituted a core task in
10 smoothing the transition, both in terms of medical and psycho-social needs. All of the nurses
11 indicated the significance of dual considerations when considering referral to palliative care,
12 incorporating considerations of pain and symptom management and broader wellbeing (in
13 both a psychological and practical sense). The nurses viewed themselves as ideally placed to
14 talk to patients and listen to any concerns during this transitional period. These included
15 conversations about mortality and futility, as well as talk about family members' capacity to
16 provide care at home, or ongoing practical care needs. Effective transitions were facilitated
17 by opportunities for the nurses to talk (and listen) to patients and their families beyond the
18 initial point of referral and throughout the transitional period (often a number of days at
19 least). Thus, in contrast to medically driven decisions about the need for palliative care, the
20 transition was characterised by helping the patient to understand their situation. In addition,
21 the provision of emotional support was positioned as vital for family members, and the nurses
22 were ideally located (and motivated) to offer such support. However, as discussed in the
23 following section, there were a range of factors which impeded the nurses in providing
24 sufficient support in their daily work.
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39 **Managing task-oriented nursing and supporting patients in transition**

40 Being present for patients and their families through communication and emotional support
41 was central to the nurses' descriptions of effective transitions to palliative care. However, the
42 majority of nurses also talked about the challenges of providing such assistance within their
43 day-to-day nursing work. Time constraints were frequently discussed, with the majority of
44 nurses noting that the difficulties of providing emotional support for patients in addition to
45 their other clinical and bureaucratic daily tasks. As shown in the indicative quotations in
46 Table 3, there was a common view that regular interactions with patients and families
47 enabled "better" transitions, yet this was undermined by workload. Moreover, daily tasks also
48 impeded the nurses from actively working alongside doctors. This issue was talked about as
49 critical, as a team approach to communication and supporting patients transitioning to
50 palliative care was considered ideal. Daily tasks and patient loads constrained nurses from
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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.

**Table 3: Indicative quotations
Managing task-oriented nursing and supporting patients in transition**

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 Unit Manager [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.

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.

Table 4: Indicative quotations
Emotional work: the burden of managing the transition to palliative care

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.

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 psycho-social wellbeing. 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~~in the majority of 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

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3 palliative care. Indeed, the majority of the nurses spoke at length about their own self-
4 imposed rules and boundaries in terms of interpersonal connections, particularly in terms of
5 managing the potential for compassion fatigue and/or burnout.[36,37] Only a minority of the
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8 nurses viewed emotional work with patients as straightforward or easily managed. A key
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10 element of the emotional toll of this work lay in the responsibility the nurses felt to
11 emotionally support patients and their families. That is, they felt that a professional
12 expectation to take on the vast majority of emotional support work. This pressure to enact
13 emotional work was compounded by a perceived lack of emotional support for the nurses
14 themselves.
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20 DISCUSSION

21 Ensuring timely and effective transitions to palliative care has significant benefits for patient
22 quality and quantity of life, and for family members' wellbeing.[12, 386] Nurses are crucial
23 to such referrals.[397, 19] This study provides a means for better understanding the
24 significant roles played by nurses in the referral and transition of patients to palliative care.
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26 The findings of this study demonstrate the unique access to patients afforded to nursing staff,
27 in both the structure of their role and emerging from the core values and practice of nursing.
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29 The findings also highlight the benefits of nurses who are oriented to providing psycho-social
30 support for patients and families in transition. A key process identified here was interpersonal
31 access to patients and their families. By being present at the bedside, and with a willingness
32 to talk and listen, the nurses held the advantage of uncovering crucial information on the
33 emotional and practical contexts of each patient. The benefits of such knowledge and
34 understanding (particularly when communicated to the treating physician) was viewed as
35 enabling the transition to palliative care (and planning therein) to be tailored to each
36 individual patient.
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46 The findings presented here highlight the importance of effective communication between
47 health professionals for palliative care planning.[1] While the nurses we interviewed talked
48 about being well-placed to inform treating physicians around initiating referral, around half
49 of the nurses lacked confidence in such communication. As has been shown in studies
50 elsewhere,[1, 20, 397]— although nurses may be significantly involved in transitions to
51 palliative care, there may be a lack of, or variability in, opportunities for them to contribute
52 towards decision-making around referral, which is widely considered to remain within the
53 remit of the treating physician. The self-reported data from this study highlighted nurses as
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3 well situated within the ward to gain unique knowledge and understanding around patient and
4 family context. Yet, a number of practical and professional factors impeded nurse-doctor
5 communication.[4038] As such, our findings support those of other studies which have
6 highlighted the benefits of inter-professional communication and team-based approaches to
7 referral, enabling nurses to have greater opportunity for input into often complex and
8 ambiguous consultant-led decisions.[4139, 420, 1, 20] It is likely that such approaches would
9 improve referrals and transitions through more timely and better communicated referrals, and
10 by placing more emphasis on psycho-social factors.

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12 In addition to the potential for nurses to have significant input into decision-making around
13 initial referral, our findings also reveal the critical roles played by nurses in operationalising
14 the processes necessary for successful transitions.[434] While it was clear that the decision to
15 refer was led by the treating physician, the nurses in this study viewed tasks associated with
16 managing the transition itself as primarily their own responsibility. A key element of this
17 work was the ability to empathise and identify with patients and families. This management
18 of emotion is an important nursing skill [442, 453, 27, 24] which is arguably under-
19 recognised and under-utilised in the context of referral and transition to palliative care.
20 Nurses represent a significant resource in this area, and their expertise could be more actively
21 drawn on by doctors and other health professionals to assist with positive professional-patient
22 communication and negotiation. In contexts where doctors frequently struggle with breaking
23 bad news to patients and their families,[1, 17, 22] nurses can and do play a pivotal role in
24 smoothing transitions and maintaining psycho-social wellbeing.[464] However, while the
25 values of nursing shape such expertise, nurses should not carry the burden of emotional work
26 with patients in isolation. Ultimately, the interviews revealed the considerable burden of
27 responsibility of nursing to maintain and manage the psycho-social wellbeing of the patient
28 and family at the point of futility and transition to palliative care. Moreover, it was clear from
29 the interviews that there was at times a perceived lack of support from other health
30 professionals and the hospital in terms of supporting them in their work. That is, this
31 important emotional work involved in helping patients transition to palliative care was
32 viewed as predominantly the responsibility of nursing staff.

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34 This study has several limitations. Although our sample of nurses including representation of
35 a range of specialty areas and levels of experience and seniority, it only captures the
36 experiences of from three—two health services with both public and private clinical

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3 environments ~~hospitals~~ in one Australian city. As such, our findings cannot be generalised to
4 other nurses in other settings despite providing indications of themes and theoretical insights
5 likely to resonate across other settings. Furthermore, the sample of nurses was self-selected.
6 Our findings therefore may not represent the views or experiences of less experienced nurses
7 in these contexts or those with less interest in palliative care. Given the findings presented
8 here, further research focused on the experiences of doctors, social workers, patients and
9 families is required to provide a team-based understanding of negotiating referral and
10 transition to palliative care. In practice, nurses ~~may~~ can be utilised in a more formalised and
11 systematic fashion in the context of potential futility and the need to topicalise palliation,
12 ~~with the focus shifted~~ by shifting the focus away from purely ‘medical referrals’ and ~~centred~~
13 focusing on ‘team-based’ and ‘patient-centred’ timely transitions. Nursing staff also require
14 support, given the emotionally challenging nature of their work, particularly in managing the
15 potential for professional compassion fatigue and burnout.[36,37]- Supervision alongside a
16 team-based approach to transitioning patients may better support nurses to emotionally as
17 well as clinically support patients during this difficult time.
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48

49 **COMPETING INTERESTS**

50 The authors declare that they have no competing interests.
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53 **AUTHOR CONTRIBUTIONS**

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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. All authors approved the final version of the manuscript prior to submission.

REFERENCES

1. Gott M, Ingleton C, Bennett M, et al. Transitions to palliative care in acute hospitals in England: qualitative study. *BMJ* 2011;1:42-48 doi:10.1136/bmj.d1773
2. Melvin C, Oldham L. When to refer patients to palliative care: triggers, traps and timely referrals. *J Hosp Palliat Nurs* 2009;11:291-301 doi: 10.1097/NJH.0b013e3181b543d4
3. 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 doi: 10.1191/0269216304pm921oa
4. 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 doi:10.1089/jpm.2012.0264
5. Kirby E, Broom A, Good P, et al. Medical specialists' motivations for referral to specialist palliative care: a qualitative study. *BMJ Support Palliat Care* 2012;0:1-8 doi:10.1136/bmjspcare-2012-000376
6. 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 doi: 10.1016/j.socscimed.2012.11.008
7. Quill T, Arnold R, Back A. Discussing treatment preferences with patients who want "everything." *Ann Intern Med* 2009;151:345-49
8. Kirby E, Broom A, Good P, et al. Families and the transition to specialist palliative care. *Mortality*. 2014; Published online 13/05/14 doi: 10.1080/13576275.2014.916258
9. Bowman K. Communication, negotiation, and mediation: dealing with conflict in end-of-life. *J Palliat Care* 2000;16:S17-23
10. Anderson W, Kools S, Lyndon A. Dancing around death: hospitalist-patient communication about serious illness. *Qual Health Res* 2013;23:3-13 doi: 10.1177/1049732312461728
11. 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: 474-79 doi: 10.1001/archinternmed.2008.583
12. 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 doi: 10.1056/NEJMoa1000678
13. 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 doi: 10.1177/1049732313519709
14. 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
15. Morita T, Miyashita M, Kimura R, et al. Emotional burden of nurses in palliative sedation therapy. *Palliat Med* 2004;18:550-57 doi: 10.1191/0269216304pm911oa
16. Skilbeck J, Payne S. Emotional support and the role of clinical nurse specialists in palliative care. *J Adv Nurs* 2003;43:521-30 doi: 10.1046/j.1365-2648.2003.02749.x

17. Barclay S, Maher J. Having the difficult conversations about the end of life. *BMJ* 2010; 341:c4862 doi: 10.1136/bmj.c4862
18. Oberle K, Hughes D. Doctors' and nurses' perceptions of ethical problems in end-of-life decisions. *J Adv Nurs* 2001 33:707–15 doi: 10.1046/j.1365-2648.2001.01710.x
19. Benbenishty J, Ganz F, Bulow H. Nurse involvement in end-of-life decision making: the ETHICUS study. *Intensive Care Med* 2006;32:129–32 doi:10.1007/s00134-005-2865-0
20. Marsella A. Exploring the literature surrounding the transition into palliative care: a scoping review. *Int J Palliat Nurs* 2009;15:186-89 doi: 10.1007/s00134-005-2864-1
21. Arnold B. Mapping hospice patients' perception and verbal communication of end-of-life needs. *BMC Palliat Care* 2011;10, 1 doi:10.1186/1472-684X-10-1
22. Hanratty B, Lawson 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;2:24-28 doi: 10.1136/bmjspcare-2011-000084
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. doi: 10.1111/j.1365-2702.2011.03860.x
24. Broom A, Kirby E, Good P, et al. Negotiating futility, managing emotions: nursing the transition to palliative care. *Qual Health Res* in press, Accepted 09/05/14.
25. Ablett J, Jones R. Resilience and well-being in palliative care staff. *Psycho-Oncology* 2007;16:733-40 doi: 10.1002/pon.1130
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 doi: 10.1037/1072-5245.14.1.1
27. Sandgren A, Thulesius H, Fridlund B, et al. Striving for emotional survival in palliative cancer nursing. *Qual Health Res* 2006; 16:79-96 doi: 10.1177/1049732305283930
28. Steinhauser K, Barroso J. Using qualitative methods to explore key questions in palliative care. *J Palliat Med* 2009;12:723–30 doi:10.1089/jpm.2009.9580
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;14:441-46 doi: 10.1191/026921600701536156
31. Pope C, Ziebland S, Mays N. Analysing qualitative data. In: Pope C, Mays N, eds. *Qualitative Research in Health Care*, 3rd ed. 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;7:445-47 doi: 10.1177/104973239700700401
35. Clayton J, Hancock K, Parker S, et al. Sustaining hope when communicating with terminally ill patients and their families: a systematic review. *Psycho-Oncology* 2009;17: 641–59 doi: 10.1002/pon.1288
36. [Potter P, Deshields T, Divanbeigi J, Berger J, Cipriano D, Norris L, Olsen S. Compassion fatigue and burnout: Prevalence among oncology nurses. *Clin J Oncol Nurs* 2010;14\(5\): E56-62.](#)
37. [Najjar N, Davis LW, Beck-Coon K, Carney Doebbeling C. Compassion fatigue: A review of the research to date and relevance to cancer care providers. *J Health Psychol* 2009; 14\(2\):267-277.](#)

- 1
2
3 | 36-38. Haines I. Managing patients with advanced cancer: the benefits of early referral for
4 palliative care. *Med J Aust* 2011;194:107-8
- 5 | 37-39. Bach V, Ploeg J, Black M. Nursing roles in end-of-life decision making in critical
6 care settings. *West J Nurs Res* 2009;31:496-512 doi: 10.1177/0193945908331178
- 7 | 38-40. Puntillo K, McAdam J. Communication between physicians and nurses as a target for
8 improving end-of-life care in the intensive care unit: challenges and opportunities for
9 moving forward. *Crit Care Med* 2006;34(11 Suppl.):S332-340 doi:
10 | 10.1097/01.CCM.0000237047.31376.28
- 11 | 39-41. Coombs M, Addington-Hall J, Long-Sutehall T. Challenges in transition from
12 intervention to end of life care in intensive care: a qualitative study. *Int J Nurs Stud*
13 2012;49:519-527 doi: 10.1016/j.ijnurstu.2011.10.019
- 14 | 40-42. Ronaldson S, Devery K. The experience of transition to palliative care services:
15 perspectives of patients and nurses. *Int J Pall Nurs* 2001;7:171-77 doi:
16 10.12968/ijpn.2001.7.4.9033
- 17 | 41-43. Long-Sutehall T, Willis H, Palmer R, et al. Negotiated dying: a grounded theory of
18 how nurses shape withdrawal of treatment in hospital critical care units. *Int J Nurs Stud*
19 2011;48:1466-74 doi: 10.1016/j.ijnurstu.2011.06.003
- 20 | 42-44. Bolton S. Changing faces: nurses as emotional jugglers. *Sociol Health Illn* 2001;
21 23:85-100 doi: 10.1111/1467-9566.00242
- 22 | 43-45. Froggatt K. The place of metaphor and language in exploring nurses' emotional work.
23 *J Adv Nurs* 1998; 28:332-38 doi: 10.1046/j.1365-2648.1998.00688.x
- 24 | 44-46. Henderson A. Emotional labor and nursing: an under-appreciated aspect of caring
25 work. *Nurs Inq* 2001; 8:130-38 doi: 10.1046/j.1440-1800.2001.00097.x
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