

Hospital patients' perspectives on what is essential to enable optimal palliative care: a qualitative study

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Abstract (255 words)

Background

The majority of expected deaths in high income countries occur in hospital where optimal palliative care cannot be assured. In addition, a large number of patients with palliative care needs receive inpatient care in their last year of life. International research has identified domains of inpatient care that patients and carers perceive to be important, but concrete examples of how these might be operationalised are scarce, and few studies conducted in the southern hemisphere.

Aim

To seek the perspectives of Australian patients living with palliative care needs about their recent hospitalisation experiences to determine the relevance of domains noted internationally to be important for optimal inpatient palliative care and how these can be operationalised.

Design

An exploratory qualitative study using semi-structured interviews.

Setting/participants

Participants were recruited through five hospitals in New South Wales, Australia.

Results

Twenty-one participants took part. Results confirmed and added depth of understanding to domains previously identified as important for optimal hospital palliative care, including: Effective communication and shared decision making; Expert care; Adequate environment for care; Family involvement in care provision; Financial affairs; Maintenance of sense of self / identity; Minimising burden; Respectful and compassionate care; Trust and confidence in clinicians and Maintenance of patient safety. Two additional domains were noted to be important: Nutritional needs; and Access to medical and nursing specialists.

Conclusions

Taking a person-centred focus has provided a deeper understanding of how to strengthen inpatient palliative care practices. Future work is needed to translate the body of evidence on patient priorities into policy reforms and practice points.

Key words

Palliative care, hospital, terminal care, consumer participation, qualitative research, patient-centred care

Key statements required by Palliative Medicine

What is already known about the topic?

- There is a large number of people with palliative care needs receiving care within the hospital setting;
- International research has documented what inpatients perceive to be most important in enabling optimal palliative care in the hospital setting;

No studies to date have replicated these results in Australian inpatients with palliative care needs. What this paper adds?

- Confirmation of key domains of importance for optimal palliative care in the Australian hospital setting;
- Increased depth of understanding about previously stated domains of importance, and how these might be operationalised in practice;
- Two newer areas of importance described in relation to nutrition and easy access to clinical specialists.

Implications for practice, theory or policy?

- Synthesising identified care priorities into a series of key practice points will enable clinicians and managers to implement care in line with what matters most to people with palliative care needs in the hospital setting;
- Translating identified care priorities into a series of feasible and actionable strategies is critical to inform policy reforms at local, regional and national levels.

Introduction

The majority of expected deaths in high income countries occur in hospitals,¹⁻⁷ where optimal palliative care cannot be assured.^{6, 8-12} People with palliative care needs are also often hospitalised within the last year of life, even if they don't die in this setting,¹³⁻¹⁶ so hospital clinicians provide care intermittently to this population from diagnosis through to death.^{4, 17, 18} Hospitals can and do provide excellent palliative care.^{6, 17, 19, 20} however, there is persisting evidence that optimal inpatient palliative care is not always provided.^{10, 21-25} The reasons for this are both varied and complex,²¹ but largely relate to ineffective communication, too little input into decision making and poor symptom management.^{6, 10, 26-28}

A recent systematic review and metasynthesis identified 15 key domains of importance ('domains') for optimal hospital-based palliative care, from the perspectives of inpatients and carers^{8, 9} including: expert care (inclusive of physical care, symptom management and integrated care), optimal communication, respectful and compassionate care, valued family involvement in care planning and delivery, maintenance of self-identity for patients, environmental privacy for families, ensuring patient safety, supporting patient choices, preparing families for death and providing contact for families after a patient has died.^{8, 9} However, it is unclear how these domains might be operationalised in clinical practice. For example, inpatients describe the importance of being treated with care, respect and dignity, but there is little evidence on which hospital procedures and clinician behaviours best communicate this to patients. Furthermore, data informing recent systematic review work are predominantly derived from the northern hemisphere^{8, 9}.

Therefore, more research is needed to build on the previously reported domains of importance for optimal hospital-based palliative care, with a particular focus on how to enable such care in practice, as well as to build the evidence base from a country outside of the northern hemisphere.

Aim

To seek the perspectives of Australian patients living with palliative care needs about their recent hospitalisation experiences to determine the relevance of domains noted internationally to be important for optimal inpatient palliative care and how these can be operationalised.

Method

Design

An exploratory qualitative study using semi-structured interviews was used. Open-ended interview questions were adopted to encourage a depth of understanding from each

participant and to allow points of interest to be followed as they arose.²⁹ This exploratory design allowed for the systematic collection, ordering, description and interpretation³⁰ of narratives generated from each interview. The philosophical worldview of pragmatism, whereby researchers focus on the defined research problem and how best to understand this using practical, outcome-oriented processes and embracing multiple viewpoints, was used.³¹⁻³³

Participants

Participants were eligible if they met the criteria noted within Table 1:

Table 1 – Inclusion and exclusion criteria for participant eligibility

Inclusion criteria	<ol style="list-style-type: none"> 1. Adult with palliative care needs, as defined by: <ul style="list-style-type: none"> ▪ Clinical indicators of one or multiple life-limiting conditions in accordance with the Supportive and Palliative Care Indicators Tool (SPICT™³⁴) ▪ Australia-modified Karnofsky Performance Status (AKPS)³⁵ score between 30 and 70 ▪ 1 or more admissions to hospital within the previous 12 months 2. Aware they have a serious chronic illness 3. Comfortable talking about their serious chronic illness and related care needs 4. Willing to give verbal informed consent to participate in the study
Exclusion criteria	<ol style="list-style-type: none"> 1. Unable to converse in English 2. Cognitive impairment that impairs ability to describe prior hospitalisations and care experiences

Setting

Recruitment occurred through five hospitals (4 metropolitan and 1 remote) in New South Wales, Australia.

Research team

The team consisted of experienced researchers with oncology, palliative care and mixed methods research expertise (JLP and TL) and a palliative care nursing doctoral candidate (CV), who completed all the interviews. Rigour was supported by: (1) preferencing the 'consumer voice' throughout data collection and analysis through open questioning and coding in accordance with consumer identified domains of importance^{8, 9}; and (2) investigator (CV) reflections captured in a reflexive journal after each interview informing discussions with the research team when uncertainties arose.^{36, 37}

Recruitment

The recruitment process was co-designed with consumer representatives (n=11) within five panel meetings held over an 18-month period.³⁸ These panel meetings focused on co-designing optimal strategies for identifying, approaching and recruiting people with palliative care needs, and their families, and supporting their participation throughout the proposed research. This co-design process informed changes to terminology used throughout study paperwork, the screening and recruitment process and the process for enabling support for participants, as needed. Details about this work are published elsewhere.³⁸

Purposive sampling by senior clinicians known to each patient, informed by the study's inclusion criteria, identified eligible participants at participating sites. If eligible, clinicians provided study information to the potential participant and gained verbal consent to provide their details to the research team. Once received, the researcher (CV) contacted the potential participant to discuss study details. CV had no prior relationship with participants.

Data collection

Telephone interviews were completed over 12-months, October 2018 - 2019. Telephone interviews were chosen so as to limit burden for this population given high levels of symptoms and disability (patients), as well as frequent medical and treatment appointments (patients and families) and to facilitate recruitment of a diverse inpatient population reflecting different demographic characteristics. Families / carers are often preoccupied with caring for patients and under considerable stress. Therefore, it was hoped offering phone interviews enabled less impact on time, energy levels (feeling one needed to be up and dressed) and facilitated changes as needed by patients or families on a day to day basis. That is, a quick call or text to cancel or reschedule the interview could occur (and frequently did) if the participant felt unwell or had other priorities to attend to. Acknowledging phone interviews can be considered to generate less data depth than face to face,^{39, 40} careful planning of the interview guide was completed to facilitate comfort, ease and depth of conversation. An interview guide based on areas of importance for optimal hospital palliative care^{8, 9} was used in addition to open-ended questions (table 2).

Table 2 Semi-structured interview question route

Open questions with no prompting provided:

1. My first question is really to understand a little about your illness - could you tell me a little about the serious chronic illness you live with?
-

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2. Now I am keen to learn about the care you received the last time you were in hospital. I am wondering if you can think back and tell me what was most important for you about the way your care was provided?

Prompting in relation to previously noted areas of importance:

3. Other studies that have talked to patients about this, have suggested (name one of the domains of care from previous work) is important – can you tell me what you think about that?

Focusing and extending understanding of key elements of importance described to inform practice:

4. You mentioned the importance of XXX a number of times and I am keen to understand that in a little more detail – what things made or make XXX feel like good XXX for you? Could you also discuss what you perceive could have been better in relation to XXX?
 5. Overall, if you had to think of 1 or 2 questions you wish you were regularly asked about your care when you were an inpatient, what would these be?
 - It can be hard to think about key questions perhaps, but if not questions – is there anything you think would have made a big difference to the quality of your care?
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Interviews were audio-recorded, transcribed verbatim and field notes taken. When no new information emerged, data saturation was considered reached.

Demographic data including: age; gender; highest level of education; nationality; metropolitan or rural location and diagnosis, were collected to describe the study sample.

Data analysis

Transcripts were checked against audio-files and entered into NVivo 12 for management. Analysis used principles of inductive reasoning alongside a predetermined coding structure⁴¹ using the following steps:

1. Data immersion:⁴¹ Each interview was listened to and read twice before line-by-line analysis. Field notes were integrated onto the transcripts, to inform analysis.
2. Coding: An integrated approach⁴¹ was used allowing for both inductive and deductive analysis:
 - Initial inductive coding of question 2 (Table 2) was completed independently by CV and a research assistant, before review and consensus discussions were held;
 - Deductive coding involved structuring the parent codes with domains identified in the international literature,^{8,9} with reference to confirmatory data, deeper insights and new knowledge. Emerging knowledge that did not fit domains was coded inductively. Coding was led by CV, with review by TL to gain clarity and resolve areas where consensus was needed.

Given the deductive coding was informed by prior research,^{8,9} the results reflect such domains and are described as such.

Ethical considerations

Ethical approval was granted by St Vincent's Hospital Sydney, Human Research Ethics Committee Ref. No. 2019/ETH03307, October 2018. Participants provided informed verbal consent to participate.

Reporting of the data

Reporting was guided by the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.³⁷ Analysis is reported alongside illustrative participant quotes to enhance transparency and trustworthiness of data presentation.³⁷ A broader representation of illustrative quotes for both confirmatory and new data is available in Appendix 1.

Results

Thirty-nine participants were eligible for interview with 21 (54%) completing interviews (Figure 1). Sample characteristics are provided in Table 3. Interview lengths ranged from 17 to 118 minutes with the average being 51 minutes.

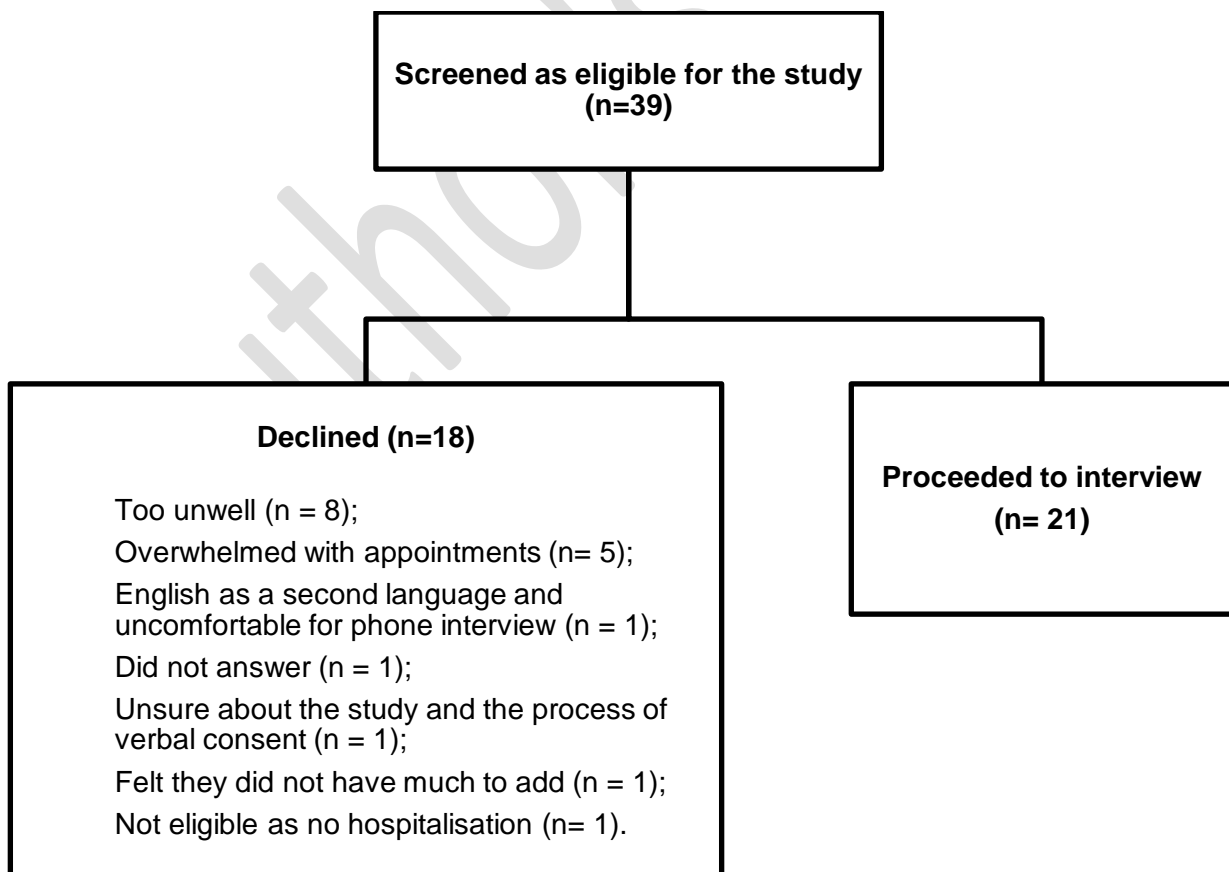


Figure 1: Overview of participation for those screened as eligible for this study

Table 3 – Sample characteristics (n=21)

Age (Yrs)	Gender	Highest level of education	Nationality	Metropolitan or rural	Diagnosis
Median: 69	Male: n=9	Post school education: n=8	Australian: n=13 Indigenous Australian: n=1	Metropolitan: n=18	Malignant n=10
Range: 45-82	Female: n=12	Yr 12 schooling: n=9 Yr 9 schooling: n=4	New Zealander: n=1 Sri Lankan: n=1 Filipino: n=1 South African: n=1 Austrian: n=1 Maltese: n=1 Italian: n=1	Rural: n=3	Non-malignant n=11

Participants both confirmed and added depth of understanding to what has been reported in the international literature,^{8,9} summarised below:

Effective communication and shared decision making

Participants unanimously confirmed the importance of effective communication and shared decision making. They desired compassionate communication that was honest, clear and used layman’s language. They stressed the importance of active listening, adequate information provision provided in an unhurried manner and the need for engaging both patients and families in care planning. Consistency of messaging, accurate documentation across teams and departments and pulling together complex information is important. Participants also highlighted the importance of clinicians being fully present and focused on the current situation. Connection was considered critical:

Well, I think it's somebody looking at you, speaking to you. Not appearing thinking about something else or thinking about the next thing they have to do. But, they're absolutely focused on what we're talking about. They're mindful. In the moment, and that they had done their homework and know what they're talking about (Patient 3, 80yr female with non-malignant illness).

Participants described the importance of acknowledging and tapping into the patient’s own knowledge in relation to their health condition:

They think well they've done the training, they know what they're talking about and whatnot. They don't ask the patient "How are you managing and what you're doing yourself" (Patient 22, 75yr female with non-malignant illness)

Participants spoke about wanting clinicians to be positive and maintain hope within the context of living with a serious illness stressing they want to understand the reality of their situation but then focus on how to live as well as they can:

Well, don't just give me the bad news, now I'll give you the good news about what I can do that is positive...what we can do, in the meantime, is make sure that you live in the best possible manner to reduce... to keep this at the slowest rate of progression possible, and enjoy as much quality of life as you can (Patient 16, 60yr male with non-malignant illness)

Finally, the importance of cross-cultural awareness to prevent misunderstanding and negativity amongst both patients and clinicians was described:

in many cases the language doesn't transfer well, in other cases then that creates confusion and possibly I think a cross cultural component, just making people aware that cultures are very different and people react very differently in different cultures, not necessarily meaning offense, which could be taken by offence. And that it definitely, that triggers a reaction, which is a negative reaction and that creates its own another negative reaction (Patient 11, 72yr female with malignancy)

Expert care (good physical care, symptom management and integrated care)

Physical care

Participants confirmed the importance of personal care needs being met with a compassionate, empathetic and willing approach appreciated:

When I, like, I had trouble with my bowels also, because I'm on special medication and I get embarrassed. They said, "Patient 8, don't worry about it," you know? They're very, yes, they made me feel at ease (Patient 8, 77yr female with malignancy)

Participants understood the multiple competing priorities for nurses and appreciated open communication and responsive attention accordingly:

I understood if I needed my diaper changed they couldn't come immediately because they were doing other things, so that was the reason. Like they'd say "We'll be back in five minutes," or something like that, and they were (Patient 17, 66yr female with malignancy)

Symptom management

Participants confirmed the importance of effective symptom management as well as the need for prompt, individualised assessment and management of pain and breathlessness in particular. Patients also spoke of the importance of effective communication with regard to symptom assessment and management in relation to three areas:

1) Clinicians to be mindful of clarity of message as multiple drug names can be confusing for people who are unwell and may have cognitive effects from illness or pharmacology:

They say it's anti-nausea that's fine. It's for the pain, that's fine. But if they say always MS-contin and then they say oxytocin and then they say, I don't know all these different names, then you get confused... One form, one function. The function is pain, you're giving a pain killer. The function is stomach, you give whatever (Patient 11, 72yr female with malignancy)

2) Patients understanding that asking for medication assists the clinical team to optimise their analgesia:

At first, I thought asking for more pain relief it seemed a little bit wussy on my part, but that was my head space. And they just kept reassuring me and saying, "Don't be afraid to ask. You need to ask because that's how we're going to measure your dosage"... So I thought that was really good (Patient 4, 54yr female with malignancy)

3) Exploring why patients may be reluctant to take analgesia:

When I was younger I had two really good mates and they started taking tablets and pills and stuff like that, and then their lives just changed and they ended up getting all the other drugs and one of them died and the other one, I don't know what happened to him. And it was through just taking... I just hate taking tablets (Patient 1, 48yr male with malignancy)

Accurate assessment and responsive attention was emphasised as crucial with adequacy of nursing staffing noted to enable this:

Look, the important thing, I think is to know there's somebody there. And very often, they're not. Not because they don't want to be, but there's not enough staff. We know that. The nurses are absolutely run off their feet. They are so good, but they can't do everything..... And I mean if you are in the toilet and you press the button, they do come eventually, but if you're not breathing or something like that, it's not fun (Patient 10, 82yr female with non-malignant illness)

Patients described the challenges of managing breathlessness in the hospital when fans, fresh air or cooling aren't easy to access:

Because what happens when you can't breathe... You sort of hit a panic button. And you get all hot, very very hot and flustered. You want cooling blowing on you. You start to wheeze because you've got no control because you're panicking... And they can't always find a fan for me (Patient 23, 69yr female with non-malignant illness)

Integrated care

Participants confirmed the importance of clinicians being knowledgeable about their specific condition and working as a team both within and across departments:

So they knew what Professor XXXX was doing as her treatment, and the oncology team were checking in with that. So they all knew. Everybody was talking to each other... Which was great. If you don't have your staff talking to each other, you can get a gap in the hole (Patient 4, 54yr female with malignancy)

Frustration was expressed at the fact that access to advice from departments outside of their admitted location could be difficult to manage. For example, a participant wanted to arrange a dental review whilst an inpatient, as arranging this from home with related transport, care and oxygen needs was difficult. However, this was not enabled across her admission.

Once you're in hospital, getting anybody in another department is ... forget it. It's impossible. Communication between departments is not on. It is one of the worst things to try in the hospital... You know, that's annoying because you can't get hold of the people you want to get hold of (Patient 10, 82yr female with non-malignant illness)

Patients confirmed the importance of effective discharge planning and noted concerns with discharge summaries and management of medication changes with general practitioners:

The only thing is, when you're discharged from hospital, only once have I had a sheet given to me on the discharge summary. And, my GP has never got summaries from them. She's always complaining. I have to take my list of medication in and explain what medication I'm on (Patient 3, 80yr female with non-malignant illness)

Participants described that nursing handover is problematic, with complex needs not always translated between shifts:

"It's changeover time." ... I don't want to listen to that, because it's hard. Because they've got to change over, and then they don't know who you are. And then we're back to square one (Patient 10, 82yr female with non-malignant illness)

A patient with a cognitive impairment also noted the difficulties she experiences as her medical history and care plan were not accessible within the Emergency Department:

... in the emergency, they... Isn't it, our profile, is in the system already, in the computer? So, why is it that they need to repeat all over and over again... the interview before they go in to cure you? (Patient 21, 50yr female with malignancy)

Technical competence

Participants also described the importance of competence, with particular examples provided in relation to intravenous cannulation and pleural effusion drainage where the patients felt junior staff were practising, required multiple attempts and in doing so, caused distress

The cannulisation. Took them six pricks. Six, yeah, because they are all juniors. They are all practicing. And I was like a mannequin who, yeah, you know? No, it's so unfair (Patient 21, 50yr female with malignancy)

Adequate environment for care

The concept of space was personal with a variance in preferences in relation to private and shared rooms noted. Some participants described a preference to enable company and helpfulness of fellow patients:

As a matter of fact, it's better, because if you're in a shared room, first of all you can help somebody else if they need it. And secondly, they can help you if you need it. It is much better that you are in a shared room. I'm not really that keen on being in a private room, because you are stuck like a shag on a rock, like I am here at home (Patient 10, 82yr female with non-malignant illness)

However, difficulties in sharing included being disturbed by noise, having to tolerate different smells and feeling confronted by other people's illnesses:

...the lady next to me ... she used to bring in her own food and the smell was not the best. And also her visitors used our toilet, which is a big no, no ... I'm very sensitive to smells (Patient 19, 69yr female with malignancy)

Participants described their bed being moved as disorientating and distressing:

The point is, I want to be left alone. I want to say, "This is my bed. This is where I belong." Once you're there, you want to belong somewhere not feel, "This is where I belong until they think of something else this afternoon at four o'clock." (Patient 10, 82yr female with non-malignant illness)

Participants described the importance of a restful environment that was quiet and enabled sleep:

To be in a place where you can be in a room or something without much disturbance (Patient 5, 72yr male with malignancy)

Cleanliness was valued by participants noting the relevance of this for infection control:

everything was cleaned every morning...So I knew if I got out and I had my bare feet, I could walk on the floor and I knew that I wasn't going to get... they talk about the hospital bugs and that you can get? Staph and all that. I don't think I had any chance of getting any of that (Patient 1, 48yr male with malignancy)

Patients with breathlessness spoke about their need for adequate ventilation, particularly in the bathroom, to assist with showering:

... there's no exhaust fans in hospital toilets, all that, in the showers. They're that small ... Yeah, you can't leave the door open. You can't shut the door, because of the steam, and you can't breathe in there. There's no windows to open. If there is a window, it only opens about three or four inches at the most anyway (Patient 23, 69yr female with non-malignant illness)

Window access was described as important to: enable a connection to the day/night cycle; feel connected to the world; feel warmth from sunlight; and prevent feeling claustrophobic:

Light and sky, is correct. Probably the only thing I always look for. I grew up on a farm...the sky is be all, and end all really. It gives you time, tells you what time it is (Patient 12, 65yr male with non-malignant illness)

Patients spoke about their need for comfort whilst waiting in the Emergency department and also their need to be appropriately triaged and quarantined if immunosuppressed. They are aware of how busy it is, but found being left in a chair for long periods, distressing:

not have to sit and wait. Which has happened every single time. I have not had to wait. They got me through straight away, which is brilliant....It's just that I'm so sick that I need to go and lie down basically (Patient 19, 69yr female with malignancy)

Two practical concerns were described by patients: (1) The practicality of the hand held TV audio-control:

The worst part of being in hospital is having to hold the thing to listen to television. That's a nuisance, because you can't eat and hold that at the same time. So you can't watch the news in the evening, while you're eating your dinner (Patient 10, 82yr female with non-malignant illness)

(2) Arriving at hospital without basic toiletry items:

I understand now that they don't supply you with shampoo and proper soap and deodorant... but it is very difficult when a person has an emergency situation, you're going to the hospital, and you need that stuff, and you haven't got it (Patient 18, 71yr male with non-malignant illness)

Family involvement in providing care

Participants confirmed that company and family connection is vital in providing comfort and emotional healing for patients and the importance of carers feeling respected as partners in the care of their loved one when in hospital. Participants added to this, describing family involvement as supportive for understanding as a patient's cognition may be affected by illness or medications:

It's easier to remember it all because when you're bombed out on drugs, well not bombed out, but you know what I mean you sort of got so many tablets in you for your pain and it's hard to sort of take everything fast (Patient 1, 48yr male with malignancy)

Participants valued flexible visiting hours. Simple comforts to support carers when staying overnight would be appreciated:

Well, it is very important for him to sleep well so that he will kind of care for me... You can just imagine the whole day, the whole week, he's looking after me. He's assisting me... Even going to the toilet because I'm so weak (Patient 21, 50yr female with malignancy)

Participants expressed frustration with being unable to find out when medical ward rounds occurred:

I think it would help if when the doctors doing their rounds...if they could give you some sort of indication of when they'd be in the ward so that you're family member wouldn't have to get there at eight and stay until midday, and the doctor comes at 11:30. It's a strange world the hospital world... it's like working on another planet. Everything else in the outside world just gets turned off. People don't have appointments, everything that happens in the hospital is the most important. Which it probably is, but you still need to realize that people need to go to work and have that appointment to talk about their mother (Patient 13, 61yr female with non-malignant illness)

Financial affairs

Participants noted the supportive health system in Australia where a lot of healthcare is provided at little or no cost: However, they noted the need for improved processes and supports in relation to hospital parking costs, supported accommodation and subsidies for relevant clinical equipment or services enabling transition home:

It would be helpful for us especially if I'm confined because the fee, the parking fee is so expensive. And if you're not working like us, both of us are not working...It's very too much for us, and where we will get the money to pay for it? (Patient 21, 50yr female with malignancy)

Maintenance of sense of self / identity

Patients confirmed research that outlined the profound impact of living with a terminal illness and the need to live as well as possible within the context of life limiting illness. Patients spoke about wanting to maintain wellness, within the context of their illness and wanting to isolate their illness from their full life – not to *become* their diagnosis:

I like to be treated as a normal well individual. Because that's where I keep my consciousness, my self-view of myself. Is that I am well, all is well, in terms of keeping myself positive...I've found a way to be very... to live very well, in the state that I'm in. Which is now fairly rapidly deteriorating (Patient 16, 60yr male with non-malignant illness)

Patients talked about wanting to maintain independence through exercise and support their sense of self through connections with others:

I may go through emails and the telephone and all the connections I've got... Sometimes it just too tiring, but I try, I try not to let it go, because it is myself.....It helps me still feel Patient 11 with my interests, with my friends, with what I have always done (Patient 11, 72yr female with malignancy)

Taking control of the daily routine was important to patients, with a focus on physical activity:

As soon as I'm in a hospital, whatever time I wake up, I get out of bed and I'll sit in the chair or go for a walk up and down the passage. The nursing staff will say "You think you're well enough to do that?". I was like "Yes I'm doing it to get well". And a lot of them can't understand that (Patient 22, 75yr female with non-malignant illness)

The notion of becoming institutionalised was discussed by patients as something to be avoided:

I think it would be easy... it would be very easy to just relax and buy into it, and be the helpless renal patient who everyone has to look after. It terrifies me. It absolutely terrifies me that that could happen to me (Patient 3, 80yr female with non-malignant illness)

The importance of humour and having a laugh was discussed in relation to coping:

Oh, man, if you stop laughing, you might as well give up (Patient 16, 60yr male with non-malignant illness)

Patients talked about their need to engage in meaningful activity describing their days as long and their need to occupy themselves to assist in wellbeing:

It allowed me to be me too, because I could go and get those things to them, because I was making a nappy baby for one lady, and I bought a present in the chemist for her, and I bought another present. So I was able to sort of, yeah, be a little bit of me. And that was good (Patient 4, 54yr female with malignancy)

Patients provided suggestions of how to enable meaningful activity centering around reading materials or puzzles/games, access to information about what is available across the hospital, visits from pastoral care workers and encouragement to get out of bed and engage in an activity:

There used to be a library that a volunteer would bring around a trolley and it had games on it like Checkers or things like that... To do stuff like that...if they had a thing on the TV ... like an information pack that didn't get too into the nitty gritty of it. It just said do you know that you can ... there's a podiatrist service and this is the number. There's a hand clinic, this is their number... Just listed the things that are available (Patient 13, 61yr female with non-malignant illness)

Finally, patients talked about their spirituality, noting the support their beliefs provide, that they wanted to maintain positivity and hope in line with such beliefs and pray to support their clinical team to provide optimal care:

... I mean I am a Christian, I always believe that there is always hope and we have gone through that – we want to overcome this problem (Patient 5, 72yr male with malignancy)

Minimising burden

Previous research found patients noted minimising physical or emotional burden as important. When discussing this with participants, several noted feelings of being burdensome on family members or friends but did not talk about needing to minimise this *per se*, rather describing the fact they felt burdensome due to their care needs:

I think most people feel that way...That's a personal thing within yourself and it's just thoughts. I mean, I feel that way and it will eventually it will get worse. So, you can't help feeling that way (Patient 19, 69yr female with malignancy)

One patient described working to limit the time required to care for him and actively trying to delineate between 'carer' time and time being husband and wife:

She owns her time, and I own my time, but we share time together. But, she shouldn't be sharing my illness time, right, we should be sharing good time. That's how I feel about it (Patient 12, 65yr male with non-malignant illness)

Respectful and compassionate care

Participants unanimously confirmed the importance of respectful and compassionate care with specific reference to people feeling welcomed; being treated with care, respect and dignity; clinicians anticipating patient/family needs, being responsive and demonstrating cheerfulness and care for their work; and clinicians being compassionate and supportive. Participants noted the tone of communication as being important, the need for clinicians to connect with each patient and the need for simple acts of care and kindness:

Well, a nurse gets to know their patients, I suppose, and needs to know their needs, and I think when a new nurse comes on, the first thing she can do, besides introducing herself, which she should be doing anyway, she might just say, "Are there any things you need? Anything special that I've got to look after for you?" Just get to know your patient... And I'm not talking about having to give her a whole life story. Just maybe one minute or two minutes to find out my personal needs while I'm there. (Patient 18, 71yr male with non-malignant illness)

Participants spoke of the impact of friendliness, a nice manner and common courtesy:

Just a general attitude to the nurses on the ward. I don't have to be your best friend, but a bit of common courtesy, I suppose, would be better. (Patient 13, 61yr female with non-malignant illness)

Participant's appreciated clinicians who ensured they were comfortable before leaving the room and who listened. One patient recalled how difficult it was when she was told not to buzz as the nurses were writing reports. This same patient noted the importance of clinician friendliness particularly for those who have an extended hospital admission:

I was in there for nine weeks, in March, you're in there a long time. It's a long time to be alone. Not alone, but separate from your family and spend days with ... If you don't get a visitor, it's a long day. You would like the staff to not necessarily notice you don't have a visitor, but just be that little more pleasant on a day to day basis. (Patient 13, 61yr female with non-malignant illness)

Participants spoke of noting a 'vibe' from clinicians in relation to whether they were happy to be at work or not. The impact of being cared for by someone who appeared happy to be at work, who was engaged and deliberately made an effort to connect with patients and families, was important:

I never got that feeling if someone helped me and they're thinking "Oh look, she doesn't want to do this or he doesn't want to do this." I never got that. I never got that vibe at all with any of them (Patient 1, 48yr male with malignancy)

Participants spoke of wanting to be treated as a human, the importance of empathy and the need for care to be less mechanical and more compassionate:

Yeah, it's lack of compassion. She's just like a woman with answers- You know, you ask question and she going to answer it just like reading books... It's too mechanical. It's yes or no. And well, with a patient like me, I need more explanations and more compassions on what to do (Patient 21, 50yr female with malignancy)

A participant also described the power difference she felt when trying to provide feedback about care, and the fact it should not be that way:

Oh, it's the power. Patients feel they're at the bottom of the power-triangle. They shouldn't feel like that but I'm sure a lot do just from stuff I've done.... It changes, and I know that, but it's interesting as a patient, you do feel like that (Patient 3, 80yr female with non-malignant illness)

Trust and confidence in clinicians

Participants confirmed the importance of trust and confidence in clinicians and described that effective communication assisted them in relation to this:

I get confidence from the medical staff when they talk to me and they tell me exactly what's going on. Obviously, I have to trust what they say because they're the doctors ... But it's good that the doctors don't just talk. They've got to followup (Patient 18, 71yr male with non-malignant illness)

A clinician being attentive, responsive and mindful in their care delivery also helps in the development of trust and confidence:

Isn't looking at other things or checking her mobile or something else. Just being attentive, I suppose, being in the moment. Being mindful (Patient 3, 80yr female with non-malignant illness)

A good clinical outcome (feeling better) engendered confidence as did feeling the clinician themselves is confident, competent and efficient in their care delivery:

Well, people should be sure what they're doing, and know you have to have confidence in them. Not to feel that they are doubtful and they're asking you (Patient 11, 72yr female with malignancy)

Finally, the approach to care was noted as being important to enable trust and confidence with helpful approaches being those that are strong, caring, compassionate and professional:

...being strong and caring, but not overdoing it ...Strong... definite... Yeah. And that strength follows like ... connects you know (Patient 19, 69yr female with malignancy)

Maintenance of patient safety and prevention of harm

Participants spoke of the need to feel their care is safe and well managed without needing continual oversight, given they are so unwell:

Where it lacked is that unless you were always on the ball for your own case, there could be a lot of mistakes because if... and then they are put down on computers, you don't know what is written there so you'll have to constantly be on the ball. But if somebody's very ill, or very tired or uneducated, it's not easy to be on the ball (Patient 11, 72yr female with malignancy)

They discussed the importance of their clinical team being knowledgeable about their specific health care needs within the context of their broader health issues:

I'd like to see that there is attention being given to the overall aspect of where I'm at (Patient 14, 45yr male with malignancy)

Medication management was discussed by participants with a focus on accuracy in prescription and administration, with particular concerns noted in relation to: translation of complex medication regimes in the home setting to the hospital setting (and vice versa), accuracy in timing of administration and managing an error in the computer system once entered:

And also, the hospital constantly gets the medications wrong. That is terrible. I check every tablet I take, and they get it wrong. Then they tell me I don't take this. Then we get into screaming arguments. And then they bring up pharmaceuticals again. They say, "Yes, you do, but they didn't believe you." You know things like that or it's not on the computer, because somebody forgot to put it down (Patient 10, 82yr female with non-malignant illness)

One patient noted the lack of pressure injury prevention provided and the impact this continues to have on her wellbeing:

It was just a bedsore...If I'd been rotated or my ankle would have been elevated or a couple of nurses just sort of stuck the bandage back on even though it was a bit wet ... Which the wound care for that was shocking. I have a wound on my right stump at the moment caused from the same problem... At the moment, I've got quite a problem to live the best life I can (Patient 13, 61yr female with non-malignant illness)

Optimal care was described as being adversely affected by understaffing. This meant patients could not always get assistance with simple tasks, could not communicate in any depth, and care felt mechanical, task orientated and not responsive to needs:

... you don't always get attention immediately but I totally respect and understand that because it's usually because they're busy, not because they're ignorant or don't want to do what you ask them. So, it's about lack of staff. That's what it's about and that's a huge problem (Patient 3, 80yr female with non-malignant illness)

There were two other areas described as important by participants not previously reported in the literature:

1. Nutritional needs;

Food within the hospital setting was described as important in relation to nutrition, wellbeing (including diabetic management), recovery and comfort:

My diet in the hospital is a big drama because I don't eat meat. I have to be on a dialysis diet and a diabetic diet so really getting down to not many very choices on the diet front. The food front. Then at breakfast time you might get a lukewarm cup of supposedly hot water and a tea bag, and I don't drink tea. Then you ask someone, could you have a coffee satchel. By the time they get back with the coffee satchel the hot water's cold. It just sort of ... it's a bad way to start the day.... It's just a shocker. I find that quite depressing actually (Patient 13, 61yr female with non-malignant illness)

Participants noted their need to maintain weight across an admission:

This is going to sound petty, but that the food I was given was okay... was what I normally eat and what I wanted...it's things I prefer and I don't have much appetite...And, I'm only 55 kilos, so I need to maintain my weight if I can, because you lose a lot of protein and stuff, and I've always been fairly thin. I just need to keep my weight up (Patient 3, 80yr female with non-malignant illness)

Comfort provided by good food that is at the right temperature, fresh and in line with preferences was noted:

The kitchen at the hospital is one of the most fabulous things. People do not realize what that kitchen does for the hospital. Their food is bloody good...Now, morning and afternoon tea.... They're the important things in life (Patient 10, 82yr female with non-malignant illness)

The impact of diet aides and kitchen staff was described:

even down to the women that come and take your order for your food. I think we forget about those people. Yeah. Like I might've been in the shower and they would come back. It's just those little things that, they come back to take my order. They could have just given me anything (Patient 4, 54yr female with malignancy)

The need for assistance in managing food-trays was noted as important and an area that was often missed:

The nurse stood there and opened the packet so I could... it says on my plate every time 'needs help with opening packages because of my strokes'. Yet, I think one out of every second week, one person would help me. Then you're sitting there trying to open packets with your teeth, which is very undignified (Patient 13, 61yr female with non-malignant illness)

2. Access to medical and nursing specialists.

Participants described the comfort and reassurance felt by having easy access to clinical specialists. They specifically described the positive impact of having access to a nurse specialist given their prompt attention to noted concerns, answers to questions, time for support and planning, ongoing support on discharge home, continuity in care and high levels of expertise:

... because the nurses from the PD clinic, the peritoneal dialysis clinic there, come and see you every day as well. They're so... across your particular case, because I see them at least monthly. They are like angels. They're just absolutely tops in terms of nurses. So, they would come up daily and they'd always check with the staff on the ward. I don't know that that's so in all chronic disease but certainly renal dialysis at Hospital XX, we are incredibly lucky (Patient 3, 80yr female with non-malignant illness)

Discussion

This qualitative study confirms and adds depth to understanding of domains previously identified as important for optimal hospital inpatient palliative care, namely: Effective communication and shared decision making; Expert care; Adequate environment for care; Family involvement in providing care; Financial affairs; Maintenance of sense of self / identity; Minimising burden; Respectful and compassionate care; Trust and confidence in clinicians and Maintenance of patient safety and prevention of harm.^{6, 8, 9, 17} Two additional domains were noted to be important by the Australian informants in our study: Nutritional needs; and Access to medical and nursing specialists. Our study also provides new insights on how the above domains can be operationalised in inpatient palliative care. Integrating data from this study with prior published work is important to inform progress in supporting acute care clinicians in their efforts to improve on and deliver optimal palliative care.

The emergence of two new domains within our results is notable. The importance of food and nutrition to enable optimal inpatient palliative care was not identified in previous international literature.^{8,9} This may reflect cultural differences or be explained by the fact palliative care provision is gaining greater prominence for people with chronic and complex illness, seeking to live as well as they can despite their diagnosis. The role and meaning of food and nutrition for people with palliative care needs is an under-reported area with current literature focused mostly on cancer cachexia.⁴² This study reports the importance of nutrition for physiological reasons such as to maintain wellness, strength and weight in addition to the psychosocial aspects of food in relation to comfort and pleasure. How to enable this uniformly within hospitals warrants further investigation. Working with dieticians to design optimal models to address this for inpatients would be a valuable first step.⁴²

The importance of access to clinical specialists is also described as a new domain in this study. Two Canadian studies previously reported the importance of the availability of medical clinicians who can communicate in a way the patient understands.^{43,44} Participants in this study extended this further describing the importance of both accessibility and effective communication as important and distinct elements of optimal care. Participants spoke of the value of accessing nurse specialists in addition to medical clinicians. The emergence of the nurse specialist role^{45,46} is highly valued by those with advanced chronic and complex illness and therefore a priority to further investigate in relation to future improvements in models of care and patient outcomes. It is noted that uniform access to nurse specialist support is not available across Australia and highlighted as a ready solution for system-level healthcare improvement.⁴⁶

Work focused on enabling optimal inpatient palliative care has commenced with one recent study outlining the need to consider a compassionate model to inform care provision.¹⁷ Our study suggests that a more comprehensive approach to enabling optimal palliative care within hospitals is required, whilst not disputing the noted importance of compassionate care provision to enhance patient and carer experience. Another recent study⁶ has provided an example of how to use data from bereaved carers to inform improvement efforts within a hospital environment, complemented by structured committees with noted executive and quality improvement staff involvement. Whilst not disputing the value of this approach, maintaining an ability for the patient voice in addition to carer experience is both possible and important.

There are many examples of excellent palliative care within the hospital setting.^{6,17,19} To enable this experience to be possible across all wards, irrespective of location or population is the challenge. An initiative involving ward based palliative care champions was tested without improved experience for bereaved carers.⁴⁷ Similarly, the implementation of a

framework to support clinicians in their care provision (the AMBER care bundle) has shown mixed results specifically noting challenges in relation to identification of patients,⁴⁸ enabling improved experiences once implemented particularly in relation to effective communication,⁴⁹ and the complexities inherent in a standardised package across such varied clinical contexts where some wards may engage with this work regularly and others infrequently.⁵⁰ Given the complexity both in relation to the care of those with palliative care needs, and the hospital environments such care is delivered in (ranging from intensive, critical and high-dependency care units through to all ward areas and emergency departments) it could be argued that a standardised approach to care provision cannot succeed.

Recommendations for future practice

Patients' voices provide clear direction for practice that enables a positive experience of inpatient palliative care. Recommendations for future practice lie within testing how this can be achieved within each ward/unit and once implemented, how we would know this enabled improved experiences of care for those who need it.

Strengths and limitations

The strength of this study lies within the engagement of consumers in the co-design process for research protocol development³⁸, defining the sampling approach, interviewing and data analysis. The integrated data analysis enabled the voices of this study's participants to be compared and contrasted with the voices of other patients,^{8,9} adding a richness and depth that could not have otherwise been achieved. The major limitation of this study is that the sample is not representative of the broader Australian population, with the views of people from culturally and linguistically diverse backgrounds, and Indigenous Australians underrepresented. Recruiting through clinicians also raises the potential for sampling bias through 'gatekeeping'. In an attempt to limit such bias, clinicians were encouraged to refer people with a full range of experiences. Of note, participants were often critical of their hospital care, suggesting that selection was not biased towards encouraging a favourable report. Finally, given participants were describing past care experiences (within 12 months), it is possible some recall bias may have occurred. On the other hand, participants had an opportunity during the intervening time to reflect on and distil the personal meaning of their hospital experiences, lending weight to the importance of issues they identified as most salient.

Conclusions

These findings provide a starting point to building more person-centered care models for palliative care in hospitals. Translating the care priorities defined by patients and carers into a series of feasible and actionable strategies will be critical to: driving the policy reforms

required at a national and local level; and enabling clinicians and managers to implement practice points in each ward. Research to date suggests a fairly substantial level of reform is required to improve care and outcomes for inpatients with palliative care needs. Developing a framework for involving palliative care consumers in informing ongoing improvement work across the sector will be critical to ensuring this reform process remains aligned with patient and family priorities.

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Data management and sharing

Raw data are contained within this manuscript in the form of participant quotes and also available within attached Appendices. The corresponding author is available to contact for further information. However, further data about each specific quote cannot be provided due to the risk of re-identifying the participants involved.

References

1. Broad J, Gott M, Kim H, et al. Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. *International Journal of Public Health* 2013; 58: 257-267.
2. Australian Institute of Health and Welfare. Trends in palliative care in Australian hospitals. 2011.
3. Sarmiento VP, Higginson IJ, Ferreira PL, et al. Past trends and projections of hospital deaths to inform the integration of palliative care in one of the most ageing countries in the world. *Palliative Medicine* 2016; 30: 363-373.
4. Tung J, Chadder J, Dudgeon D, et al. Palliative care for cancer patients near end of life in acute-care hospitals across Canada: a look at the inpatient palliative care code. *Current Oncology* 2019; 26: 43.
5. Pivodic L, Pardon K, Morin L, et al. Place of death in the population dying from diseases indicative of palliative care need: a cross-national population-level study in 14 countries. *Journal of Epidemiology and Community Health* 2016; 70: 17-24.
6. Coimín DÓ, Prizeman G, Korn B, et al. Dying in acute hospitals: voices of bereaved relatives. *BMC Palliative Care* 2019; 18: 91.
7. Palliative Care Australia and KPMG. *Investing to save. The economics of increased investment in palliative care in Australia.* 2020. Canberra, Australia: <https://palliativecare.org.au/kpmg-palliativecare-economic-report>.
8. Virdun C, Lockett T, Lorenz K, et al. Dying in the hospital setting: A meta-synthesis identifying the elements of end-of-life care that patients and their families describe as being important. *Palliative Medicine* 2016; 31: 587-601.
9. Virdun C, Lockett T, Davidson PM, et al. Dying in the hospital setting: A systematic review of quantitative studies identifying the elements of end-of-life care that patients and their families rank as being most important. *Palliative Medicine* 2015; 29: 774-796.
10. Hillman KM. End-of-life care in acute hospitals. *Australian Health Review* 2011; 35: 176-177.
11. Black A, McGlinchey T, Gambles M, et al. The 'lived experience' of palliative care patients in one acute hospital setting—a qualitative study. *BMC Palliative Care* 2018; 17: 91.
12. Noble C, Grealish L, Teodorczuk A, et al. How can end of life care excellence be normalized in hospitals? Lessons from a qualitative framework study. *BMC Palliative Care* 2018; 17: 100.
13. Tanuseputro P, Budhwani S, Bai YQ, et al. Palliative care delivery across health sectors: a population-level observational study. *Palliative Medicine* 2017; 31: 247-257.
14. To T, Greene A, Agar M, et al. A point prevalence survey of hospital inpatients to define the proportion with palliation as the primary goal of care and the need for specialist palliative care. *Internal Medicine Journal* 2011; 41: 430-433.
15. Rosenwax LK, McNamara BA, Murray K, et al. Hospital and emergency department use in the last year of life: a baseline for future modifications to end-of-life care. *Medical Journal of Australia* 2011; 194: 570-573.
16. Clark D, Armstrong M, Allan A, et al. Imminence of death among hospital inpatients: Prevalent cohort study. *Palliative Medicine* 2014; 28: 474-479.
17. Gott M, Robinson J, Moeke-Maxwell T, et al. 'It was peaceful, it was beautiful': A qualitative study of family understandings of good end-of-life care in hospital for people dying in advanced age. *Palliative Medicine* 2019; 7: 793-801.
18. Gott M and Robinson J. Are we getting it wrong? Perspectives on the future of palliative care in hospitals. *Palliative Medicine* 2018; 1: 2.
19. Robinson J, Gott M, Gardiner C, et al. A qualitative study exploring the benefits of hospital admissions from the perspectives of patients with palliative care needs. *Palliative Medicine* 2015; 29: 703-710.

20. Vidal M, Rodriguez-Nunez A, Hui D, et al. Place-of-death preferences among patients with cancer and family caregivers in inpatient and outpatient palliative care. *BMJ Supportive & Palliative Care* 2020.
21. Nevin M, Hynes G and Smith V. Healthcare providers' views and experiences of non-specialist palliative care in hospitals: A qualitative systematic review and thematic synthesis. *Palliative Medicine* 2020; 34: 605-618.
22. Bloomer MJ, Hutchinson AM and Botti M. End-of-life care in hospital: an audit of care against Australian national guidelines. *Australian Health Review* 2019.
23. Milnes S, Orford NR, Berkeley L, et al. A prospective observational study of prevalence and outcomes of patients with Gold Standard Framework criteria in a tertiary regional Australian Hospital. *BMJ Supportive & Palliative Care* 2019; 9: 92-99.
24. Al-Qurainy R, Collis E and Feuer D. Dying in an acute hospital setting: the challenges and solutions. *International Journal of Clinical Practice* 2009; 63: 508-515.
25. Heckel M, Vogt AR, Stiel S, et al. The quality of care of the dying in hospital—next-of-kin perspectives. *Supportive Care in Cancer* 2020: 1-11.
26. Le B and Watt J. Care of the Dying in Australia's Busiest Hospital: Benefits of Palliative Care Consultation and Methods To Enhance Access. *Journal of Palliative Medicine* 2010; 13: 855-860.
27. Gott M, Seymour J, Ingleton C, et al. 'That's part of everybody's job': The perspectives of health care staff in England and New Zealand on the meaning and remit of palliative care. *Palliative Medicine* 2012; 26: 232-241.
28. Garner KK, Goodwin JA, McSweeney JC, et al. Nurse Executives' Perceptions of End-of-Life Care Provided in Hospitals. *Journal of Pain & Symptom Management* 2013; 45: 235-243. Article. DOI: 10.1016/j.jpainsymman.2012.02.021.
29. Minichiello V and Sullivan G. *Handbook for research methods in health sciences*. Pearson Education, 2004.
30. Kitto SC, Chesters J and Grbich C. Quality in qualitative research. *Medical Journal of Australia* 2008; 188: 243.
31. Creswell, J and Creswell J,. *Research Design. Qualitative, Quantitative, and Mixed Method approaches (5th Ed)*. California, United States: SAGE publications, Inc, 2018.
32. Johnson RB and Onwuegbuzie AJ. Mixed methods research: A research paradigm whose time has come. *Educational Researcher* 2004; 33: 14-26.
33. Andrew S and Halcomb EJ. *Mixed Methods Research for Nursing and the Health Sciences*. West Sussex, United Kingdom: Blackwell Publishing Ltd, 2009.
34. The University of Edinburgh. SPiCT, <https://www.spict.org.uk/> (accessed August 16 2018).
35. Abernethy AP, Shelby-James T, Fazekas BS, et al. The Australia-modified Karnofsky Performance Status (AKPS) scale: a revised scale for contemporary palliative care clinical practice [ISRCTN81117481]. *BMC Palliative Care* 2005; 4: 7.
36. Malterud K. Qualitative research: standards, challenges, and guidelines. *The Lancet* 2001; 358: 483-488.
37. Tong A, Sainsbury P and Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care* 2007; 19: 349-357.
38. Viridun C, Lockett T, Gilmore I, et al. Involving consumers with palliative care needs and their families in research: A case study. *Collegian* 2019; 26: 645-650.
39. Irvine A. Duration, dominance and depth in telephone and face-to-face interviews: A comparative exploration. *International Journal of Qualitative Methods* 2011; 10: 202-220.
40. Novick G. Is there a bias against telephone interviews in qualitative research? *Research in Nursing & Health* 2008; 31: 391-398.
41. Bradley EH, Curry LA and Devers KJ. Qualitative data analysis for health services research: developing taxonomy, themes, and theory. *Health Services Research* 2007; 42: 1758-1772.

42. Ellis J. The Psychosocial impact of food and nutrition on hospitalised oncological palliative care patients and their carers. 2017.
43. Heyland D, Dodek P, Rocker G, et al. What matters most in end-of-life care: perceptions of seriously ill patients and their family members. *Canadian Medical Association Journal* 2006; 174: 627-633.
44. Heyland DK, Cook DJ, Rocker GM, et al. Defining priorities for improving end-of-life care in Canada. *CMAJ: Canadian Medical Association Journal* 2010; 182: E747-752.
45. Brandis S, McPhail, R., Fitzgerald, A., Avery, M., Fisher, R., & Booth, J. The emergence of new kinds of professional work within the health sector. In: A. Wilkinson, D. Hislop & C. Coupland, (ed) *Perspectives on Contemporary Professional Work: Challenges and Experiences*. Elgar, Cheltenham, 2015.
46. Australian College of Nursing (ACN). *A New Horizon for Health Services: Optimising Advanced Practice Nursing—A White Paper by ACN 2019*. 2019. ACN, Canberra.
47. Witkamp FE, van Zuynen L, van der Rijt CC, et al. Effect of palliative care nurse champions on the quality of dying in the hospital according to bereaved relatives: a controlled before-and-after study. *Palliative Medicine* 2016; 30: 180-188.
48. Etkind SN, Karno J, Edmonds PM, et al. Supporting patients with uncertain recovery: the use of the AMBER care bundle in an acute hospital. *BMJ Supportive & Palliative Care* 2015; 5: 95-98.
49. Bristowe K, Carey I, Hopper A, et al. Patient and carer experiences of clinical uncertainty and deterioration, in the face of limited reversibility: a comparative observational study of the AMBER care bundle. *Palliative Medicine* 2015; 29: 797-807.
50. Bristowe K, Carey I, Hopper A, et al. Seeing is believing—healthcare professionals' perceptions of a complex intervention to improve care towards the end of life: A qualitative interview study. *Palliative Medicine* 2018; 32: 525-532.