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3 Defining ‘specialist palliative care’

#### 4 **Defining ‘specialist palliative care’: findings from a Delphi study of clinicians**

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16 **Objective** This study aimed to achieve consensus regarding what distinguishes specialist from non-specialist  
17 palliative care to inform service organisation and delivery to patients with life-limiting conditions.

18 **Methods** A three-phase Delphi study was undertaken, involving qualitative interviews and two questionnaire  
19 cycles. Thirty-one clinicians (nurses, doctors and social workers) working with a wide range of patients  
20 participated in interviews, of whom 27 completed two questionnaire cycles.

21 **Results** Consensus was gained on 75 items that define specialist palliative care and distinguish it from non-  
22 specialist palliative care. Consensus was gained that specialist palliative care clinicians have advanced  
23 knowledge of identifying dying, skills to assess and manage complex symptoms to improve quality of life, have  
24 advanced communication skills and perform distinct clinical practices (e.g. working with the whole family as  
25 the unit of care and providing support in complex bereavement). Non-specialist palliative care involves  
26 discussions around futile or burdensome treatments and care for people who are dying.

27 **Conclusions** Areas of connection were identified: clinicians from disease-specific specialties should be more  
28 involved in leading discussions on futile or burdensome treatment and providing care to people in their last  
29 months and days of life, in collaboration with specialists in palliative care when required.

30 **What is known about the topic?** At present there is no evidence-based definition or agreement about what  
31 constitutes specialist palliative care (as opposed to palliative care delivered by non-specialists) in the Australian  
32 Capital Territory. An agreed definition is needed to effectively determine the workforce required and its clinical

1 skill mix, and to clarify roles and expectations to mitigate risks in not adequately providing services to patients  
2 with life-limiting conditions.

3 **What does this paper add?** This paper offers, for the first time, an evidence-based definition that  
4 distinguishes specialist palliative care from non-specialist palliative care. End-of-life care and bereavement  
5 support are not just the remit of specialist palliative care clinicians. Clinicians from beyond specialist palliative  
6 care should lead discussions about futile or burdensome treatment.

7 **What are the implications for practitioners?** The findings of this study can facilitate implementation of  
8 palliative care strategies by enabling practitioners and patients to distinguish who should be delivering what  
9 care.

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## 11 **Introduction**

12 Despite palliative care being recognised as an ‘essential component of quality care in advanced  
13 illness’,<sup>1</sup> a clear, universally accepted definition of what constitutes specialist palliative care hampers  
14 the conceptualisation, commissioning and delivery of such care. Without an agreed definition and  
15 model of care, there are substantial and important implications for determining the workforce required  
16 and its clinical skill mix, the result of which may be that services risk failing to offer suitable care to  
17 patients likely to die in the next 6 months.<sup>2,3</sup> Consequently, patients may not receive care from the  
18 most appropriate clinicians, and opportunities to recognise the patient is dying, discuss goals of care  
19 and ensure optimal quality of life may be lost.<sup>4,5</sup> The lack of clarity of the definition of specialist  
20 palliative care compounds the challenge of determining who provides what care for people who are  
21 dying.

22 Across nations, terms are used interchangeably or without clear demarcation to describe specialist  
23 palliative care. Further complexity is added when examining labels applied to palliative care that is  
24 delivered by non-specialists (including terms such as ‘palliative care’, ‘palliative approach’, ‘primary  
25 palliative care’ and ‘generalist palliative care’). Each nomenclature is intended to indicate that all  
26 clinicians should be able to provide a basic level of palliative care. In this paper we use the term  
27 ‘palliative care’ to underline the idea that all clinicians should have the skill to deliver core care to  
28 people with life-limiting illness. The language in this paper (‘specialist palliative care’ and ‘palliative  
29 care’) mirrors the terms used in the Australian National Strategy for Palliative Care.<sup>6</sup>

30 Policy directives rarely make clear distinctions between specialist palliative care and palliative  
31 care, which further complicates service organisation and delivery. Although some organisations have  
32 offered definitions that distinguish between these categories,<sup>7</sup> they have not been widely adopted.  
33 Other definitions have been developed informally comparing ‘basic’ skills of ‘primary palliative care’

1 with specialist palliative care.<sup>8</sup> Such informally derived definitions consequently lack the authority of  
2 evidence-based definitions, yet still inform funding and service commissioning.

3 Some of the definitional difficulties may be due to the relatively recent emergence of palliative care  
4 as a discipline. The field initially focused on end-of-life care for people with malignant disease,<sup>9</sup> but  
5 has moved towards early referral as best practice.<sup>10</sup> Confusion abounds however, because the  
6 literature suggests that referrals for people with a life-limiting illness should be linked not necessarily  
7 with symptom burden, or prognosis, but on the basis of ‘need’,<sup>11</sup> using a term that is itself left  
8 underdefined. How specialist palliative care should be commissioned, delivered or financed alongside  
9 other specialities is unclear, as are the boundaries and connections between specialist palliative care  
10 and palliative care delivered by other clinicians.

### 11 *Aim*

12 The aim of this study was to achieve consensus regarding what constitutes specialist palliative care,  
13 compared with palliative care, in the Australian Capital Territory (ACT).

### 14 **Methods**

15 The study used the Delphi technique as a recognised consensus method for establishing the views  
16 and opinions of participants on practice-related problems.<sup>12</sup> The methodology and reporting were  
17 informed by recent guidance on the use and reporting of Delphi studies in palliative care research.<sup>13</sup>

18 Participants in Delphi studies must be considered experts. The definition of ‘expert’ is varied, but  
19 relies on an understanding of recognised depth understanding of the phenomenon under  
20 investigation.<sup>14</sup> The sample should also be heterogeneous, to preclude data becoming skewed. In order  
21 to recruit a heterogeneous group, the study sought participants from a range of healthcare professional  
22 roles (registered nurses, nurse practitioners, advanced trainees, medical consultants, allied health  
23 practitioners, social workers and service managers) and across clinical specialities (medical oncology,  
24 radiation oncology, haematology, intensive care, emergency care, urology/renal, cardiovascular,  
25 neurology, geriatric, paediatrics, respiratory, gastroenterology, chronic diseases, endocrinology,  
26 general practice, community nursing, nursing homes, rehabilitation services and specialist palliative  
27 care).

### 28 *Inclusion criteria*

29 To be eligible for inclusion in the study, participants had to: (1) be a clinician or manager (with  
30 relevant clinical background) in the ACT in one of the clinical specialities specified above; (2) be  
31 involved for  $\geq 5$  years in providing care to people with a life expectancy of  $< 12$  months; (3) be willing  
32 to provide informed consent to participate; and (4) have endorsed a commitment to participate in  
33 multiple rounds of data collection.

1 The study sought two participants from each clinical speciality named above. Recruitment  
2 proceeded initially by identifying experts in the project investigators' professional networks.  
3 Snowball sampling was then undertaken, with participants asked to nominate colleagues in  
4 specialities where recruitment had stalled. A total of 69 invitation letters and information sheets were  
5 emailed to prospective participants.

#### 6 *Data collection*

7 The study used three iterative data collection rounds (interviews and two rounds of questionnaires).  
8 To combat the limitations of face-to-face data collection and to accommodate experts from diverse  
9 clinical specialities, the study used telephone interviews and online questionnaires.

10 Round 1 data collection was conducted via individual semistructured interviews. Consenting  
11 participants were interviewed about their perspectives on the care of people in their last 6 months of  
12 life. The purpose of interviews was to generate statements on which to garner consensus in  
13 subsequent questionnaire rounds. Interview questions were derived from discussions raised in the  
14 local palliative care clinical network regarding how care should be delivered to patients with life-  
15 limiting conditions. Interviewees were asked to describe their perspective on what constitutes  
16 specialist palliative care, who should support people with life-limiting conditions, how specialist  
17 palliative care should interact with other clinical teams, what constitutes an appropriate referral to  
18 specialist palliative care, which clinicians should provide end-of-life care and who should address  
19 questions of futile or burdensome treatment. Interviewees were also asked to nominate any statement  
20 that they wanted to gain consensus on. Interviews were audio recorded and transcribed verbatim.

21 Interviewees from Round 1 were invited to take part in the two subsequent Delphi questionnaires  
22 (Rounds 2 and 3 of data collection). A small number participated in Rounds 1 and 3, but not Round 2.  
23 The Delphi questionnaires were constructed from statements derived from Round 1. Round 2  
24 consisted of 86 items, which were presented alongside a 5-point Likert scale (ranging from strongly  
25 agree to strongly disagree). Free-text spaces were provided for participants to provide qualitative  
26 comments on their responses. Such comments were used to refine questions for the subsequent round  
27 or to add new statements that the respondent felt were missing. Numerical feedback (in the form of  
28 percentage agreement) from Round 2 was provided to respondents when the Round 3 questionnaire  
29 was distributed. Round 3 consisted of 37 items. If an item achieved consensus at Round 2, it was not  
30 repeated at Round 3. Because some new items were introduced at Round 3, not all results below have  
31 a score for Round 2.

32 Round 2 and 3 questionnaires were distributed using an online survey platform (Qualtrics).  
33 Questionnaires were open for 1 month; non-responders were followed-up via email and provided a 2-  
34 week extension. Data collection commenced in September 2017 and concluded in February 2018. A  
35 maximum of two questionnaire rounds was planned to help participants understand from the outset

1 the likely burden on them consenting to participate. The addition of any further rounds was  
2 anticipated to result in attrition, and therefore be unduly burdensome on remaining respondents.

3 The study was coordinated by a full-time social science researcher with no clinical bias. The  
4 materials were not formally piloted but were robustly debated and developed within the research  
5 team. The study process is shown in **Fig. 1**.

### 6 *Data analysis*

7 Interview data were analysed thematically<sup>15</sup> to identify core elements of practice that respondents  
8 thought were central to specialist palliative care or other clinical specialities. Questionnaire responses  
9 were managed with descriptive statistics, providing a composite score for ‘strongly agree and agree’  
10 and ‘strongly disagree and disagree’. Qualitative feedback in Round 2 was used to reframe or  
11 introduce new items in Round 3. Participants in Round 3 were provided with descriptive statistics on  
12 the previous round.

13 What is considered ‘consensus’ has attracted various definitions, ranging from 51%<sup>16</sup> to 75%.<sup>17</sup>  
14 Green *et al.*<sup>18</sup> suggest that 80% agreement is the goal. Consequently, for this study, an *a priori* cut-off  
15 of 80% was used to define consensus. Where <20% of participants selected a response, this was  
16 interpreted as a rejection of that opinion (referred to as ‘dissensus’).

### 17 *Ethics permissions*

18 Ethics approval for the study was provided by human research ethics committees from ACT Health  
19 (17.154; 1 August 2017) and Calvary Public Hospital, Bruce (21-2017; 20 June 2017). All  
20 participants provided verbal and written consent. Respondents to the questionnaires were asked to  
21 provide their names to enable the research team to follow-up non-responders. Anonymity was assured  
22 by not reporting identifiable demographic or other identifiable information.

## 23 **Results**

24 There were 31 participants in the Round 1 interviews (21 doctors, nine nurses, one social worker),  
25 27 participants in Round 2 (first questionnaire; 16 doctors, six nurses, one social worker, four  
26 unknown role) and 27 participants in Round 3 (15 doctors, seven nurses, one social worker, four  
27 unknown).

28 In Round 2, 52 (of 86) items reached consensus. In Round 3, a further 23 items (of 37) reached  
29 consensus. Twelve items did not reach consensus (see XXX, available as Supplementary Material to  
30 this paper), and two items reached dissensus.

31 The 75 statements that reached consensus allowed specialist palliative care to be distinguished from  
32 palliative care. The consensus statements are conceptualised in **Fig. 2** and fall within four areas: (1)  
33 specialist palliative care (comprising skill set and knowledge, communication skill, managing

1 complexity and clinical care practices); (2) palliative care and multidisciplinary teams (comprising  
2 collaborations, discussing burdensome or futile treatments and involvement in deaths; (3)

3 triggers for collaboration with specialist palliative care; and (4) the training that specialist palliative  
4 care can provide to the wider multidisciplinary team (MDT) to support the delivery of palliative care.  
5 The latter two areas connect specialist palliative care and MDTs.

6 Each of these four areas is explored in greater detail below, summarising the key consensus items.

### 7 *Specialist palliative care*

8 Specialist palliative care clinicians were considered to hold a unique skill set and knowledge  
9 compared with the wider MDT, providing evidence-based palliative care. The skill set was considered  
10 to involve recognising and having high levels of interaction around dying, integrating physical and  
11 emotional care and navigating ethical and regulatory aspects linked with end of life. The consensus  
12 statements are listed in [Table 1](#).

13 Specialist palliative care clinicians were agreed to have specific communication skills, particularly  
14 around the ability to discuss and plan for death and dying, with compassion and empathy, having  
15 exceptional listening skills and having the ability to manage conflict ([Table 1](#)).

16 Consensus was gained that specialist palliative care clinicians managed patients deemed complex  
17 by the nature of their symptoms with the need for a different knowledge base, including specific  
18 pharmacological expertise, or managing complex family dynamics ([Table 1](#)).

19 Clinical care practices within specialist palliative care were considered to have many unique  
20 elements ([Table 1](#)), including a focus on community support for patients' and families' quality of life,  
21 psychosocial needs and dignity. Specialist palliative care was seen to occur in a timely manner, and to  
22 support decision making.

23 We propose a consensus definition as follows.

24 Specialist palliative care offers empathic, compassionate and comprehensive biopsychosocial care  
25 for patients who will die from their illness, and their families. Care is focused on quality of life and  
26 dignity, enabling people to live well until they die. Specialist palliative care clinicians have  
27 evidence-based expertise in managing pain, prognostication, diagnosing dying and recognising  
28 dying as a natural part of life, and are highly skilled in communicating about death and dying.

29 These clinicians manage conflict about decision making around benefits and burdens of treatment,  
30 complex symptom management and expert knowledge on medications and complex pharmacology  
31 while navigating the complex ethical regulatory aspects of care. Specialist palliative care clinicians  
32 support patients with high distress and complex needs and family dynamics, and are involved in  
33 complex bereavement support.

1 *Palliative care*

2 The second area of the model (Fig. 2) relates to clinicians outside of specialist palliative care (Table  
3 2). As noted in the Introduction, the term ‘palliative care’ here is used to refer to clinicians from other  
4 clinical specialities where there is an expectation that they would be able to provide basic support to  
5 people living with life-limiting illnesses. The prevailing message from the data was that collaboration  
6 between specialist palliative care and other clinicians was critical (Table 2), and that there was no  
7 discipline that should always lead provision of end-of-life care. Treating teams (the clinical team  
8 focused on specific disease management), general practitioners and specialist palliative care teams  
9 were all identified as important in caring for dying patients. Both palliative care and bereavement care  
10 were proposed to be everyone’s business rather than only the remit of specialist palliative care. The  
11 only point at which specialist palliative care was considered as the lead team was for patients  
12 receiving in-patient hospice care, or community care from the specialist palliative care team.

13 As indicated in Table 2, there was consensus that discussions about futile or burdensome treatment  
14 should be led by the treating team, with some input from specialist palliative care. Overall, specialist  
15 palliative care should not be involved in all deaths. One caveat was offered for this, which was that if  
16 patients requested specialist palliative care involvement then it should be offered.

17 *Collaboration and training*

18 Triggers for collaboration between specialist palliative care and palliative care are summarised in  
19 Table 3. Early referral to specialist palliative care was an agreed component. However, respondents  
20 reported that many clinicians did not know when to refer to specialist palliative care for chronic  
21 conditions.

22 Consensus was gained that all clinicians should be supported in their learning about palliative care,  
23 and specialist palliative care clinicians should have a role providing such training, to enable basic  
24 knowledge and principles of palliative care to be enacted by all clinicians.

25 The consensus definition of non-specialist palliative care is as follows.

26 Clinicians who are not palliative care specialists are a core part of the multidisciplinary team  
27 closely involved in looking after people who are dying in both the acute care setting and  
28 community, where there are not complex symptoms. Non-palliative care specialists collaborate  
29 with palliative care specialists. These clinicians nonetheless provide bereavement support and lead  
30 conversations about burdensome or futile treatment. These clinicians require training from  
31 specialist palliative care clinicians in basic palliative care principles.



1 **The two dissensus (rejected as having received >20% agreement) items were: (1) yes, specialist**  
2 **palliative care should be involved in all deaths (11%); and (2) specialist palliative care**  
3 **clinicians only should address questions of futile or burdensome treatment (4%). Discussion**

4 This study has, for the first time, established consensus on the difference and intersections between  
5 specialist and non-specialist palliative care. The consensus statements offer a description of specialist  
6 and non-specialist palliative care and, from these, a definition of specialist palliative care was  
7 inductively derived. The findings denote the clinical capability and workforce issues around service  
8 planning and role definition that services must navigate to provide quality care to people with  
9 incurable disease.

10 Consensus was gained via only two questionnaire rounds on 75 items, thereby challenging an  
11 established view that there is a lack of agreement about how clinicians from diverse specialities view  
12 the care and support of people who will die from their illness.

13 Specialist palliative care clinicians should have advanced skills and knowledge, advanced  
14 communication skills, manage patients with complex biopsychosocial issues and provide distinct  
15 clinical practices. The distinctive remit for pain management (93% consensus) echoes evidence  
16 regarding prevalence of pain in referred patients.<sup>19</sup> The data confirm that specialist palliative care  
17 views the family as the focus of care, not just the patient. Although this whole-family system view of  
18 specialist palliative care is commonplace, adopting the principle has implications for funding models  
19 in regions where only patient-focused contact constitutes billable clinical work.

20 Palliative care should be provided by clinicians from a range of disciplines.<sup>20,21</sup> Non-specialist  
21 palliative care clinicians will need training in order to recognise dying and provide care for people  
22 who are dying, normalise dying within their own practice<sup>22,23</sup> and lead discussions of futile or  
23 burdensome treatments.

24 A substantial finding of this study was that leading discussions of futile or burdensome treatment  
25 were not considered the sole preserve of specialist palliative care clinicians. By dispersing this  
26 responsibility to the wider clinical team there is the potential for earlier (and arguably more timely)  
27 discussions with patients and families about goals of care focused on quality of life and symptom  
28 management. The role of clinicians from other specialities in leading such conversations has  
29 substantial implications for training to do this well. Avoiding discussions about futile and burdensome  
30 treatment is a recognised obstacle to the effective provision of end-of-life care,<sup>24</sup> and thus there is a  
31 need for any devolution of futile treatments to be grounded in quality skills training. Further, the  
32 statements relating to collaborative working require different skill sets, and potentially reorganisation  
33 of services and clarity over what constitutes ‘complex’ symptoms.

34 Preparing patients and families for death and dying results in better bereavement outcomes.<sup>25</sup>  
35 Recognising dying as a natural part of life, not a medical failure, achieved full consensus and is  
36 central to endeavours to normalise dying in professional and lay communities.<sup>26,27</sup>

1 Consensus that complex grief or bereavement was the work of specialist palliative care, while all  
2 other bereavements were considered ‘everyone’s business’, aligns with guidelines on supporting  
3 bereaved individuals in contexts outside of specialist palliative care.<sup>28–30</sup>

4 Collaboration occurring early in the disease trajectory mirrors the dominant narrative from  
5 empirical research prompting early referral time frames and improved patient outcomes.<sup>21,31,32</sup>  
6 Integration models<sup>33</sup> and approaches that strengthen non-specialist palliative care<sup>34</sup> may offer fruitful  
7 mechanisms for delivering such collaboration. Indeed, consultation from specialist palliative care may  
8 drive down healthcare costs,<sup>35</sup> as well as assist in improving quality of life and symptom  
9 management.<sup>36</sup> Yet, clear integration models have not been articulated, although a recent study  
10 reported the need for both automatic referral when key criteria are triggered and physician-initiated  
11 referrals.<sup>37</sup> Many non-specialist palliative care clinicians lack adequate understanding of how  
12 palliative care specialists can support chronic condition management. Training was identified as a  
13 distinct area of consensus, which is in line with recent drives for education provision to enable other  
14 specialties to provide end-of-life care.<sup>20,38</sup>

15 The findings of this study connect with the core guiding principles of the Australian Commission  
16 on Safety and Quality in Health Care’s national consensus statement for safe and high-quality end-of-  
17 life care,<sup>39</sup> notably viewing dying as a normal part of life, ensuring that end-of-life care is needs  
18 focused, provided by interdisciplinary teams and attentive to physical, spiritual and psychosocial  
19 concerns. The data reinforce core governance requirements in national standards<sup>40</sup> regarding the need  
20 for trained and effective clinicians, and the findings could inform actions to develop guidelines on  
21 interdisciplinary care and clinicians’ scope of practice.

## 22 *Study limitations*

23 This paper has presented evidence on the distinctions between specialist and non-specialist  
24 palliative care. The findings have been endorsed by the ACT Palliative Care Clinical Network.  
25 Despite anecdotal reports, there was considerable agreement about what constitutes specialist  
26 palliative care in the initial questionnaire round. Such an accord bodes well for developing working  
27 practices that will be readily adopted across specialties.

28 The data from this study add both depth and evidence to how palliative care could be defined and  
29 adopted in strategies globally,<sup>41–43</sup> which will substantially strengthen such strategy documents  
30 because the current definitions used are not evidence based. These data can inform service design  
31 regarding the division of tasks and expertise, for example discussions of futile or burdensome  
32 treatment. These findings also have funding implications, with the potential for the consensus  
33 definition to guide which services are resourced to provide specialist and non-specialist palliative  
34 care.

1 The study's sample was drawn from the investigators' networks, which limited the breadth of  
2 participants. Data collection was focused on clinicians within the ACT in order to inform the  
3 implementation of local service reorganisation and delivery. The ACT is a small territory where there  
4 is greater likelihood of clinicians having insight into each others' expertise, skill set and experience;  
5 consequently, the findings set a precedent for a national or international study to assess the fit of the  
6 definition in other jurisdictions. Further, some clinical specialities were not represented in the sample;  
7 for example, despite multiple recruitment attempts, no participant responded from rehabilitation  
8 services, and very few clinicians who identified as from allied health participated in the study  
9 (although we note that some of the 'unspecified' respondents may have been from allied health  
10 backgrounds). The bias towards doctors may also reduce the generalisability of the results. Clinicians'  
11 views will have been informed by their varied exposure to and understanding of specialist palliative  
12 care. Participants were not asked to assess the financial implications of operationalising the definition  
13 on clinical services or the workforce.

14 The questionnaire instruments were not piloted, which may have led to important statements not  
15 being examined. Data collection ceased at Round 3, which may have precluded more items reaching  
16 consensus. Managing 'complexity' and 'patient need' are core to the definition of specialist palliative  
17 care, yet are opaque in their operationalisation and may therefore require further service-level  
18 discussion when applying the distinctions between palliative care and specialist palliative care  
19 generated through this study.

## 20 **Conclusion**

21 Specific tasks, knowledge and care practices demarcate specialist palliative care from palliative  
22 care. The findings of this study have the potential to facilitate interdisciplinary and interorganisational  
23 working across specialties, and feed into the implementation of palliative care strategies by informing  
24 service organisation and delivery. These data support a change in the model of care whereby specialist  
25 palliative care services are invited to collaborate early on, but episodically, in the care of patients and  
26 families, with other teams taking the lead on elements of care such as discussions around burdensome  
27 or futile treatments and care in the terminal phase.

## 28 **Competing interests**

29 The authors declare no competing interests.

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## References

- <jrn>1 Philip J, Collins A. Editorial: routine integration of palliative care: what will it take? *Med J Aust* 2015; 203: 385. [doi:10.5694/mja15.00994](https://doi.org/10.5694/mja15.00994)</jrn>
- <bok>2 Lynn J, Adamson DM. Living well at the end of life. Adapting health care to serious chronic illness in old age. XXX: RAND Health; 2003.</bok>
- <jrn>3 Clegg A, Young J, Iliffe S, Rikkert MO, Rockwood K. Frailty in elderly people. *Lancet* 2013; 381: 752–62. [doi:10.1016/S0140-6736\(12\)62167-9](https://doi.org/10.1016/S0140-6736(12)62167-9)</jrn>
- <jrn>4 Ellershaw J, Ward C. Care of the dying patient: the last hours or days of life. *BMJ* 2003; 326: 30–4. [doi:10.1136/bmj.326.7379.30](https://doi.org/10.1136/bmj.326.7379.30)</jrn>
- <jrn>5 Ziegler LE, Craigs CL, West RM, Carder P, Hurlow A, Millares-Martin P, *et al.* Is palliative care support associated with better quality end-of-life care indicators for patients with advanced cancer? A retrospective cohort study. *BMJ Open* 2018; 8: xxx. [doi:10.1136/bmjopen-2017-018284](https://doi.org/10.1136/bmjopen-2017-018284)</jrn>
- <bok>6 Commonwealth of Australia. Supporting Australians to live well at the end of life. National palliative care strategy. Canberra: Department of Health; 2010.</bok>
- <jrn>7 von Gunten CF. Secondary and tertiary palliative care in US hospitals. *JAMA* 2002; 287: 875–81. [doi:10.1001/jama.287.7.875](https://doi.org/10.1001/jama.287.7.875)</jrn>
- <jrn>8 Quill TE, Abernathy AP. Generalist plus specialist palliative care – creating a more sustainable model. *N Engl J Med* 2013; 368: 1173–5. [doi:10.1056/NEJMp1215620](https://doi.org/10.1056/NEJMp1215620)</jrn>
- <jrn>9 Clark D. From margins to centre: a review of the history of palliative care in cancer. *Lancet Oncol* 2007; 8: 430–8. [doi:10.1016/S1470-2045\(07\)70138-9](https://doi.org/10.1016/S1470-2045(07)70138-9)</jrn>
- <jrn>10 Murray SA, Sheikh A. Care for all at the end of life. *BMJ* 2008; 336: 958–9. [doi:10.1136/bmj.39535.491238.94](https://doi.org/10.1136/bmj.39535.491238.94)</jrn>
- <jrn>11 Zhen L, Finucane AM, Oxenholm D, McLoughlin P, McCutcheon H, Murray SA. How good is primary care at identifying patients who need palliative care? A mixed methods study. *Eur J Palliat Care* 2003; 20: 216–22.</jrn>
- <jrn>12 Powell C. The Delphi technique: myths and realities. *J Adv Nurs* 2003; 41: 376–82. [doi:10.1046/j.1365-2648.2003.02537.x](https://doi.org/10.1046/j.1365-2648.2003.02537.x)</jrn>
- <jrn>13 Jünger S, Payne SA, Brine J, Radbruch L, Brearley SG. Guidance on Conducting and REporting DELphi Studies (CREDES) in palliative care: recommendations based on a methodological systematic review. *Palliat Med* 2017; xxx: xx–xx.</jrn>
- <jrn>14 Mead D, Moseley L. The use of the Delphi as a research approach. *Nurse Res* 2001; 8: 4–23. [doi:10.7748/nr2001.07.8.4.4.c6162](https://doi.org/10.7748/nr2001.07.8.4.4.c6162)</jrn>
- <jrn>15 Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* 2006; 3: 77–101. [doi:10.1191/1478088706qp0630a](https://doi.org/10.1191/1478088706qp0630a)</jrn>

- 1 <jrn>16 Butterworth T, Bishop V. Identifying the characteristics of optimum practice: findings from a survey of  
2 practice experts in nursing, midwifery and health visiting. *J Adv Nurs* 1995; 22: 24–32. doi:10.1046/j.1365-  
3 2648.1995.22010024.x</jrn>
- 4 <jrn>17 Keeney S, Hasson F, McKenna HP. A critical review of the Delphi technique as a research  
5 methodology for nursing. *Int J Nurs Stud* 2001; 38: 195–200. doi:10.1016/S0020-7489(00)00044-4</jrn>
- 6 <jrn>18 Green B, Jones M, Hughes D, Williams A. Applying the Delphi technique in a study of GPs’  
7 information requirements. *Health Soc Care Community* 1999; 7: 198–205. doi:10.1046/j.1365-  
8 2524.1999.00176.x</jrn>
- 9 <jrn>19 Potter J, Hami F, Bryan T, Quigley C. Symptoms in 400 patients referred to palliative care services:  
10 prevalence and patterns. *Palliat Med* 2003; 17: 310–4. doi:10.1191/0269216303pm760oa</jrn>
- 11 <jrn>20 Kluger BM, Persenaire MJ, Holden SK, Palmer LT, Redwine H, Berk J, et al. Implementation issues  
12 relevant to outpatient neurology palliative care. *Ann Palliat Med* 2017.</jrn>
- 13 <jrn>21 Finn L, Green AR, Malhotra S. Oncology and palliative medicine: providing comprehensive care for  
14 patients with cancer. *Ochsner J* 2017; 17: 393–7.</jrn>
- 15 <jrn>22 Gibbins J, McCoubrie R, Alexander N, Kinzel C, Forbes K. Diagnosing dying in the acute hospital  
16 setting – are we too late? *Clin Med (Lond)* 2009; 9: 116–19. doi:10.7861/clinmedicine.9-2-116</jrn>
- 17 <jrn>23 Johnston N, Lovell C, Liu WM, Chapman M, Forbat L. Normalising and planning for death in  
18 residential care: findings from a qualitative focus group study of a specialist palliative care intervention. *BMJ*  
19 *Support Palliat Care* 2016.</jrn>
- 20 <jrn>24 Blaževičienė A, Newland JA, Čivinskiene V, Beckstrand RL. Oncology nurses’ perceptions of  
21 obstacles and role at the end-of-life care: cross sectional survey. *BMC Palliat Care* 2017; 16: 74.  
22 doi:10.1186/s12904-017-0257-1</jrn>
- 23 <jrn>25 Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health,  
24 medical care near death, and caregiver bereavement adjustment. *JAMA* 2008; 300: 1665–73.  
25 doi:10.1001/jama.300.14.1665</jrn>
- 26 <jrn>26 Tieman J, Miller-Lewis L, Rawlings D, Parker D, Sanderson C. The contribution of a MOOC to  
27 community discussions around death and dying. *BMC Palliat Care* 2018; 17: 31. doi:10.1186/s12904-018-  
28 0287-3</jrn>
- 29 <jrn>27 Grindrod A, Rumbold B. Healthy End of Life Project (HELP): a progress report on implementing  
30 community guidance on public health palliative care initiatives in Australia. *Ann Palliat Med* 2018; 7(Suppl  
31 2): S73–83. doi:10.21037/apm.2018.04.01</jrn>
- 32 <jrn>28 Hudson P, Remedios C, Zordan R, Thomas K, Clifton D, Crewdson M, Hall C, Trauer T, Bolleter  
33 A, Clarke DM, Bauld C. al. Guidelines for the psychosocial and bereavement support of family caregivers of  
34 palliative care patients. *J Palliat Med* 2012; 15: 696–702. doi:10.1089/jpm.2011.0466</jrn>

- 1 <jrn>29 Aoun SM, Breen LJ, O'Connor M, Rumbold B, Nordstrom C. A public health approach to bereavement  
2 support services in palliative care. *Aust N Z J Public Health* 2012; 36: 14–16. doi:10.1111/j.1753-  
3 6405.2012.00825.x</jrn>
- 4 <jrn>30 Kellehear A. Health-promoting palliative care: developing a social model for practice. *Mortality* 1999;  
5 4: 75–82. doi:10.1080/713685967</jrn>
- 6l. <jrn>31 Gaertner J, Siemens W, Meerpohl JJ, Antes G, Meffert C, Xander C, Stock S, Mueller M, Schwarzer  
7 G, Becker G. Effect of specialist palliative care services on quality of life in adults with advanced incurable  
8 illness in hospital, hospice, or community settings: systematic review and meta-analysis. *BMJ* 2017; 357: j2925.  
9 doi:10.1136/bmj.j2925</jrn>
- 10 <jrn>32 Rajala K, Lehto JT, Saarinen M, Sutinen E, Saarto T, Myllarniemi M. End-of-life care of patients with  
11 idiopathic pulmonary fibrosis. *BMC Palliat Care* 2016; 15: 85. doi:10.1186/s12904-016-0158-3</jrn>
- 12 <jrn>33 Siouta N, Van Beek K, van der Eerden ME, Preston N, Hasselaar JG, Hughes S, Garralda E,  
13 Centeno C, Csikos A, Groot M, Radbruch S, Payne S, Menten J. Integrated palliative care in Europe: a  
14 qualitative systematic literature review of empirically-tested models in cancer and chronic disease. *BMC*  
15 *Palliat Care* 2016; 15: 56. doi:10.1186/s12904-016-0130-7</jrn>
- 16 <jrn>34 Ewertowski H, Tetzlaff F, Stiel S, Schneider N, Junger S. Primary palliative care in general practice –  
17 study protocol of a three-stage mixed-methods organizational health services research study. *BMC Palliat*  
18 *Care* 2018; 17: 21. doi:10.1186/s12904-018-0276-6</jrn>
- 19 <jrn>35 Morrison RS, Dietrich J, Ladwig S, Quill TE, Sacco J, Tangeman J, Meier DE. Palliative care  
20 consultation teams cut hospital costs for Medicaid beneficiaries. *Health Aff (Millwood)* 2011; 30: 1–10.  
21 doi:10.1377/hlthaff.2010.0929</jrn>
- 22 <jrn>36 Hannon B, Swami N, Rodin G, Pope A, Zimmermann C. Experiences of patients and caregivers with  
23 early palliative care: a qualitative study. *Palliat Med* 2017; 31: 72–81. doi:10.1177/0269216316649126</jrn>
- 24 <jrn>37 Hui D, Mori M, Meng YC, Watanabe SM, Caraceni A, Strasser F, Saarto T, Cherny N, Glare P, Kaasa  
25 S, Bruera E. Automatic referral to standardize palliative care access: an international Delphi survey. *Support*  
26 *Care Cancer* 2018; 26: 175–80. doi:10.1007/s00520-017-3830-5</jrn>
- 27 <jrn>38 Visser M, Deliens L, Houttekier D. Physician-related barriers to communication and patient- and  
28 family-centred decision-making towards the end of life in intensive care: a systematic review. *Crit Care*  
29 2014; 18: 604. doi:10.1186/s13054-014-0604-z</jrn>
- 30 <bok>39 Australian Commission on Safety and Quality in Health Care (ACSQHC). National consensus  
31 statement essential elements for safe and high-quality end of life care. Sydney: ACSQHC; 2015.</bok>
- 32 <bok>40 Australian Commission on Safety and Quality in Health Care (ACSQHC). National safety and quality  
33 health service standards. Sydney: ACSQHC; 2012.</bok>
- 34 <bok>41 Palliative Care Australia. National palliative care standards. Canberra: Palliative Care Australia;  
35 2018.</bok>

1 <jrn>42 Morrison RS. A national palliative care strategy for Canada. *J Palliat Med* 2017; 20(Suppl 1): S63–  
2 75.</jrn>

3 <bok>43 Department of Health. End of life care strategy promoting high quality care for all adults at the end of  
4 life. London: Department of Health; 2008.</bok>

5 **Fig. 1.** Delphi process flow chart.

6 **Fig. 2.** Consensus definition of specialist palliative care.

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2

**Table 1. Specialist palliative care**

Changes made to items in Round 2 are indicated in parentheses (new or reworded items). GP, general practitioner

	% Agreement	
	Round 1	Round 2
Specialist palliative care incorporates the following skills or knowledge		
Supportive emotional and clinical care by a group of people with expertise and specialised skills for working with patients who have a condition that will lead to their death	96	
Provided by clinicians with expertise in choosing and prescribing medicines, including less commonly used medicines, in the last months of life	93	
Provided by clinicians who have experience and expertise in managing pain	93	
Has staff who are able to recognise dying (new item)		96
Recognises dying as a natural part of life, and not a medical failure (new item)		100
Experience and expertise in managing pain, delirium, nausea and vomiting	93	
Specialist palliative care clinicians have a better knowledge of the dying process to be able to help patients or families understand likely deterioration or prognostication	85	
Specialist palliative care's expertise involves having a continual high level of interaction around death and dying	81	
Specialist palliative care has knowledge and skills that are safe, effective and evidence based to help ensure access to appropriate medicines for people with life-limiting conditions (item reworded)	67	81
A holistic approach, integrating understanding of physical and emotional suffering in all of its dimensions	100	
A higher understanding of the psychological and spiritual need of patients and their families	96	
Navigating the maze around ethical and regulatory aspects	96	
Ability to provide education to other clinicians about palliative care and end-of-life care	100	
Specialist palliative care clinicians should have the following communication skills		
Have skills to talk to patients and families about death and dying (new item)		96
Have the ability to show a lot of empathy and compassion	96	
Have effective communication, including exceptional listening skills	100	
Manage conflict about end-of-life decision making within the family, if the treating team has failed to resolve it (item reworded)	55	85
Specialist palliative care clinicians should be able to manage clinical complexity such as:		
Providing an advanced level of care to patients who have symptoms that were unable to be met or hard to manage by more generalist care	89	
Management of complex symptoms	100	
Having expert knowledge on systemic effects of medications and complex pharmacology	100	
Offering care based on the patient's complex needs, not a specific diagnosis (new item)		100
Being significantly above average at pain management	88	
Managing complex scenarios regarding family dynamics	89	
Being more comprehensive and multidisciplinary, attending to physical symptoms beyond pain, alongside spiritual and psychological aspects of the patient managing their disease	85	
Complex bereavement or grief processing problems (item reworded)	78	96



Supporting patients who have particularly high distress or complex needs and symptoms	89	
Being able to cater for populations whose care needs provide unique challenges (i.e. paediatric palliative care)	100	
When care needs to focus on quality of life, instead of comorbidities	93	
Clinical care practices provided by specialist palliative care clinicians		
Offers ongoing support in the community (i.e. beyond in-patient and GP settings)	96	
Are able to act in a timely manner	100	
Incorporates consideration of quality of life and dignity	96	
Is very patient and family focused centred care, and a very individualised process helping families understand what's happening	96	
Helps people live well until they die (new item)		96
Is person-centred holistic care where the family is the unit of care, not just the person with a life-limiting illness (new item)		100
Helps patients and families make decisions about the benefits and burdens of treatments (new item)		93
Supports alternative decision makers to be engaged in care decisions, for patients who don't have competency (new item)		96
Leads to better decision making at end of life (item reworded)	78	92

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### Table 2. Palliative care working

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Changes made to items in Round 2 are indicated in parentheses (new or reworded items). GP, general practitioner

	% Agreement	
	Round 1	Round 2
Collaborations and cross-speciality working		
There should be collaborative working, with information sharing and avoidance of silos	100	
It's a two way relationship	88	
Collaboration between specialist palliative care and non-specialist palliative care leads to better decision making at end of life (new item)		92
The treating team, specialist palliative care and the GP need to communicate and collaborate on the treatment plan and decision making	100	
Patients should have access to social workers, clinical nurse specialists, allied health and psychologists	100	
The treating team should look after people who are dying, and should have some palliative care skills, but have a clear threshold for when they refer out to specialist palliative care	80	
Specialist palliative care is the lead service when the person is an in-patient at the hospice or being seen by the community palliative care team (item reworded)	36	81
There should be a lead clinician (e.g. GP, specialist palliative care or treating team) with services working collaboratively (new item)		100
Specialist palliative care clinicians should feed back to the referring team as soon as possible their assessment of the patient, and their expectations regarding ongoing involvement	96	
For hospitalised patients, the treating team and specialist palliative care team should have adequate resources to conduct joint rounds at least twice a week (item reworded)	62	81
Palliative care is something all clinicians should be doing	88	
The GP should take a key role in enabling people to write advance care plans	92	
Bereavement support should be everyone's job (item reworded)	29	89

Discussions of burdensome or futile treatments should be conducted by...		
The lead clinician from the treating team	93	
Both the patient or family and treating team	93	
The patient themselves, and they would need advice from appropriate health professionals who understand the illness process and the treatment options	96	
Both specialists and palliative care team	85	
Nurses, who can have these discussions if they are empowered and educated to do so	78	85
Should specialist palliative care be involved in all deaths?		
No, absolutely not. They will not have the capacity to provide specialist palliative care to every single person who will die from their illness	81	
No, because with some deaths there is no need for complex symptom control	82	
It is possible to offer good end-of-life care without the involvement of specialist palliative care services	96	
They don't have to be involved in all deaths. Dying is a natural process, it needs to be part of every doctor or nurse's repertoire, as does pain control and managing a degree of mental distress. Often people don't need specialists	93	
It depends on the timing of the patient's dying; if they are dying quickly and are comfortable, then specialist palliative care may not add very much (item reworded)	74	85
Yes, if that's what the patient wants	66	85

**Table 3. Triggers for collaboration and training**

Changes made to items in Round 2 are indicated in parentheses (reworded items). COPD, chronic obstructive pulmonary disease

	% Agreement	
	Round 1	Round 2
<b>Collaboration</b>		
Specialist palliative care should be integrated with the treating team early on, rather than late referral out	100	
It is important that specialist palliative care get involved earlier rather than later	81	
Collaboration is needed when the palliative care needs of a patient are not being met by the existing services or the usual services that are engaged or for those patients who have reached end of available treatment	96	
Collaboration is needed when someone with a life-threatening disease may benefit from palliative care services	96	
Collaboration is needed when the patient or family are specifically requesting specialist palliative care	93	
Some patient groups, such as paediatrics, should always have a specialist palliative care team involved (item reworded)	68	81
Palliative care is not just for people affected by cancer	100	
Many non-specialist palliative care clinicians don't understand when palliative care specialists can get involved in chronic condition management, (e.g. COPD, chronic kidney disease etc.) (item reworded)	37	81
The whole aim of palliative care is that the patient has a very comfortable end of life	93	
A palliative approach should be adopted by all clinicians involved with patients who have little or no hope of cure	88	
<b>Training requirements are such that...</b>		
All clinicians should have knowledge of some of the basic principles of palliative care and be involved because it's going to increasingly be a part of every speciality	96	

There should be obligatory training in end-of-life discussions for every medical officer who works in hospital	96	
If clinicians in the community were better trained, then they'd have more confidence and knowledge base to provide palliative care	78	85
Specialist palliative care clinicians should focus on providing clinicians from other specialties with advice, education and on capability building	81	

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