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## The role of hospice care at the end of life for people with cancer

--Manuscript Draft--

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<b>Abstract:</b>	<p>Patient-defined factors that are important at the end of life include being physically independent for as long as possible, good symptom control and spending quality time with friends and family. Hospice care adds to the quality of care and these patient-centered priorities for people with cancer and their families in the last weeks and days of life. Evidence from large observational studies demonstrate that hospice care can directly improve outcomes, and support better and more appropriate health care utilization for people in the last stages of cancer.</p> <p>Team-based community hospice care has measurable benefits for patients, their family caregivers and health services. In addition to improved symptom control for patients and greater likelihood of time spent at home, caregiver outcomes are also better when hospice care is accessed: informational needs are better met and caregivers have an improved ability to move on with life after the patient's death when compared to people who did not have access to these services.</p> <p>Hospice care continues to evolve as its reach expands, and the needs of patients continue to broaden. This is reflected in the transition from hospice being based on excellence in nursing to teams with a broad range of health professionals to meet the complex and changing needs of patients and their families. Further integration of cancer services with hospice care will help to provide more seamless care for patients and supporting family caregivers during their caregiving and after the death of the patient.</p>
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Please enter the name of the editor who invited or solicited your submission in the space provided. as follow-up to " <b>Was your submission invited or solicited by one of JCO's editors?</b> "	Jennifer Temel
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**Funding Information:**

Dear Editor

Re: The role of hospice care at the end of life for people with cancer

JCO.18.02235R2

Thank you for the opportunity to respond to the helpful and constructive comments of Reviewer #2 for this paper. The comments are addressed in the order in which they appear on a point-by-point basis.

	Reviewers' comments	Authors' responses
Reviewer #2		
	1. Please add the citation number after Steinhauser et al. on page 4.	The citation number has been added after the first sentence.
	2. The manuscript describes treatment options for breathlessness (page 5) but not fatigue (page 5). Consider adding text briefly describing treatment options or management strategies for fatigue near the end of life.	This omission has been rectified. The most recent Cochrane review is now cited and its findings reflected in the manuscript.
	3. Please remove parentheses around the statement on page 9 beginning, "There is a current generation...".	The parentheses have been removed as suggested.
	4. Consider adding text in the manuscript on page 9 identifying the palliative care needs assessment tool that is the focus of reference 62.	Text has been added outlining the name of the tool and its overall structure.
	5. There would appear to a typo in the text in parentheses at the bottom of page 10 describing the percentages of patients with and without hospice access who used the ED.	Thank you. The sentence now reads '...used the ED while it <i>increased to 52.0%</i> of people...'
	6. Please edit for clarity the sentence on page 12 that begins, "One observational study...". There would appear to be multiple typos present.	This sentence has been rewritten to improve clarity.
	7. There would appear to be word missing after "phase III on page	The word 'studies' has been added.

Attached is a clean copy of the manuscript and a version with track changes. Thank you once again for the opportunity to respond to these questions.

If there are any issues that I can clarify, please do not hesitate to contact me.

With kind regards

David Currow

(on behalf of the authors)

**The role of hospice care at the end of life for people with cancer.**David C Currow<sup>1,2,3</sup>Meera R Agar<sup>1,3,4</sup>Jane L Phillips<sup>1,3</sup><sup>1</sup>IMPACCT, Faculty of Health, University of Technology Sydney, Ultimo, New South Wales, Australia. 2007<sup>2</sup>Wolfson Palliative Care Research Centre, University of Hull, Hull, England. HU6 7RX<sup>3</sup>Australian national Cancer Symptom Trials (CST) Group, IMPACCT, Faculty of Health, University of Technology Sydney, Ultimo, NSW, Australia.<sup>4</sup>Liverpool Hospital, Liverpool, New South Wales, Australia.**Corresponding Author:**

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## **Abstract**

Patient-defined factors that are important at the end of life include being physically independent for as long as possible, good symptom control and spending quality time with friends and family. Hospice care adds to the quality of care and these patient-centered priorities for people with cancer and their families in the last weeks and days of life. Evidence from large observational studies demonstrate that hospice care can directly improve outcomes, and support better and more appropriate health care utilization for people in the last stages of cancer.

Team-based community hospice care has measurable benefits for patients, their family caregivers and health services. In addition to improved symptom control for patients and greater likelihood of time spent at home, caregiver outcomes are also better when hospice care is accessed: informational needs are better met and caregivers have an improved ability to move on with life after the patient's death when compared to people who did not have access to these services.

Hospice care continues to evolve as its reach expands, and the needs of patients continue to broaden. This is reflected in the transition from hospice being based on excellence in nursing to teams with a broad range of health professionals to meet the complex and changing needs of patients and their families. Further integration of cancer services with hospice care will help to provide more seamless care for patients and supporting family caregivers during their caregiving and after the death of the patient.

## ***Introduction***

How can hospice care best add value to the quality of care and outcomes for patients and their families as they live with advanced cancer?

Given differences in how the terms ‘palliative care’ ‘hospice’ are used around the world, in this article the definitions reflect care provision in the United States of America where:

‘palliative care’ refers to a range of services offered through close and ongoing integration of care for anyone with a life-limiting illness, ideally from the time that a life-limiting illness is recognised. High quality evidence from randomised trials and large observational studies support early access for people with advanced cancer;<sup>1-5</sup> and

‘hospice’ refers to community-based care that is offered, ideally, by a multi-disciplinary team that supports patients with advanced diseases and their families. In the USA, this type of care is funded *per diem* by the Medicare Hospice benefit and is available to people who have less than six months to live.

Palliative care is dealt with in other articles in this issue and, although philosophically and practically palliative care and hospice have some overlap, this article focuses on hospice care. Likewise the taxonomy of ‘end of life’ differs globally and in this article it will refer to the last weeks or days of people’s lives.

Ideally, palliative care will have been introduced earlier in the disease trajectory for people with advanced cancer, as this is likely to increase the proportion of people referred earlier to hospice care.<sup>6</sup> Even if earlier referral to palliative care has not happened, congruent with emerging health services evidence,<sup>7,8</sup> hospice care at the end of life is crucial if outcomes are to be optimised for patients and for their caregivers (while caring and after the person’s death). Such care reflects the expressed wishes of communities<sup>9</sup> to prioritise care for people at the end of life in the setting of their choice wherever possible and to the highest standard that evidence-based practice enables.

### *Patient-defined priorities at the end of life*

In order to determine the benefits that hospice care can deliver, patients with advanced cancer need to determine the priorities. These voices are heard in the seminal study by Steinhauser *et al.*<sup>10</sup> The team ran focus groups with patients to define issues deemed important at the end of life which were then transformed into survey questions for random samples in the USA from: a Veteran’s population who were aware they had limited prognoses and caregivers 6-12 months after their caregiving was completed; and health professionals (not limited to Veterans Affairs): physicians who provided care for people with life-limiting illnesses as part of their practice; and nurses and allied health professionals.<sup>10</sup> Key priorities identified by all groups included: excellence in pain and other symptom control (not as an end in itself but in order to optimise wellbeing and physical independence for as long as possible); to be well enough to spend as much quality time with friends and family; deal with unfinished business; and finalise any legacy issues. These priorities have been affirmed in several other studies of people with advanced, progressive cancers.<sup>11-19</sup> In the Steinhauser study, there were also occasions where patients’ priorities differed from other respondents’. The place of care at the time of death was *not* a high priority for patients, perhaps reflecting the complexity of

decisions around this, especially if there are tensions between patients and their family caregivers.<sup>20</sup> Health professionals providing care in the last weeks of life need to constantly re-explore the patient's preferred place of care and the caregivers' willingness and capacity to provide that care, especially if symptoms worsen or as physical function declines.<sup>21</sup>

Reflecting these patient- and caregiver-defined priorities, hospice care services have grown rapidly to support families and communities to care for people at home (including in skilled nursing facilities) through excellence in physical symptom control, psychological support, spiritual care and support for caregivers.

### *Symptom burden in end-of-life care*

Hospice care improves symptom control in problems prevalent at the end of life.<sup>22</sup> Attention to physical symptoms is valued by patients and their families as a key goal of care.<sup>10</sup> There is a rapidly evolving evidence base from randomised controlled trials to improve symptom control in end of life care<sup>23-26</sup> yet many of these findings have not been embedded in practice.<sup>14</sup> The research also highlights areas where further research is necessary.

The burden of physical symptoms evolves in the last weeks of life. Two symptoms which tend to worsen as functional status predictably declines are fatigue and breathlessness.<sup>27,28</sup> Fatigue not reduced by rest is often the most overwhelming symptom experienced by people with advanced cancer. It often co-exists with cachexia in this setting.<sup>29</sup> Fatigue generates frustration for patients as they struggle to re-prioritise their activities in the limited time that they have left, while often being exhausted by relatively trivial exertion. Non-pharmacological interventions have not been well studied in people in the last weeks of life.<sup>30</sup> Other than reversing causes that can cause fatigue (severe anaemia), the evidence for pharmacological interventions for fatigue in patients with advanced cancer is limited.<sup>31</sup> Candidate medications include methylphenidate, amantadine or modafinil, but none has sufficient data to justify their use in routine clinical care.

Prevalence and intensity of chronic breathlessness<sup>32</sup> often worsen as death approaches even in people with no documented cardio-respiratory disease, especially in the last two to three weeks of life.<sup>33</sup> The proportion of people with *no breathlessness* drops rapidly in the last weeks of life and the proportion with *severe breathlessness* increases despite symptomatic treatment. The evidence base for effectively and safely treating chronic breathlessness continues to improve using non-pharmacological and pharmacological interventions reflected in systematic reviews and meta-analyses.<sup>34,35</sup> In a systematic approach to assessing and treating chronic breathlessness akin to the World Health Organisation (WHO) analgesic ladder, the most important step is to ensure that reversible causes have been adequately treated<sup>36</sup> while considering non-pharmacological and subsequently pharmacological interventions.<sup>37</sup> Uncontrolled breathlessness is frightening and exhausting for patients, and confronting for caregivers, often leaving haunting and unpleasant memories.<sup>38</sup> Minimising breathlessness is therefore imperative for patients' and families' wellbeing.

As function declines in the last weeks of life, the intensity and prevalence of pain may also decrease, perhaps reflecting how much of the pain is exacerbated with incident movement and subsequently experienced at rest.<sup>39</sup> Good analgesia is often *the* priority for patients and their families above any other symptom right through until death. Evidence supports that hospice care provides better analgesia for patients when compared to patients who did not

access hospice.<sup>22</sup> Late in life, immobility perversely also frequently causes pain and careful attention to repositioning patients regularly is a hallmark of exemplary nursing care. When patients no longer have the strength to reposition themselves, air mattresses can help to shift patients' weight but do not replace ongoing attentive nursing care.

Delirium is characterised by cognitive changes (especially poor concentration), perceptual changes (especially hallucinations) and physical changes such as disturbed sleep/wake cycles. One third of people admitted for inpatient care at the end of life will have prevalent delirium and another one third will develop incident delirium during the admission,<sup>40</sup> encompassing hypoactive and hyperactive delirium. Hypoactive delirium is under-diagnosed in people at the end of life, but can be as distressing for patients as hyperactive delirium.

In a percentage of patients, reversible causes for delirium will be found, aiding them to more rapidly regain their cognition.<sup>41,42</sup> The first aim of managing delirium is to ensure patient safety, and the safety of all those around the patient. Excellent nursing care ensures that visual and hearing aids are in place, ongoing efforts are made to orient the person, day and night are differentiated, and that hydration and nutrition are attended to with regular meals where feeding is supervised.

Benefits from anti-psychotics for delirium seem negligible in placebo controlled studies involving intensive care patients and those nearing the end of life.<sup>25,43</sup> Delirium requires excellent nursing care, treating reversible precipitants and, if there is a need for safety, consideration of a sedative short term.

#### *Symptoms in the last hours of life*

For many caregivers, the person's last hours will be remembered because of noisy respiratory secretions. This noise is because secretions are not being cleared effectively and is usually associated with the patient being deeply unconscious. The treatment of these secretions is largely, if not exclusively, for the benefit of the person's family. There is no demonstrated intervention for preventing noisy secretions at the end of life and no pharmacological or non-pharmacological intervention that has been shown to be of predictable benefit in changing the clinical course of secretions.<sup>43</sup>

#### *Patients rating of symptom control – the need to improve care*

There is international evidence that the quality of care for people with advanced, progressive illnesses must improve.<sup>15-19,45</sup> Feedback that is independent of the individual health care professional/patient interaction suggests that symptom control is not as good as we anticipate, nor as good as patient and families expect.<sup>17,19</sup> This reflects an under-detection by clinicians, clinical interventions which do not reflect best evidence, and lack of referral to interdisciplinary services that could provide more comprehensive support for people with more complex needs.

Addressing this mismatch includes critically evaluating the quality of care for people with cancer at the end of life.<sup>46-50</sup> Providing timely feedback from patients and their caregivers to their clinicians can contribute to improved symptom control.<sup>49,50</sup> For example, patients filling out a symptom assessment tool immediately before clinical consultations so that clinicians see the results improves symptom control and is associated with better survival.<sup>51</sup> Given the value placed on symptom control by patients and their caregivers, and the symptom burden



experienced by people with cancer at the end of life, health professionals need to ensure that the best available evidence underpins all clinical care.

### *Hospice care*

Given the emphasis on excellent nursing care for optimal outcomes at the end of life, it is appropriate that hospice care has arisen from nursing and been complemented with other clinical disciplines more recently. Care that can support patients to be functional for as long as possible and simultaneously provide symptom control will deliver the best outcomes. The majority of care in the last year of life occurs in the community<sup>52</sup> and relies almost exclusively on the presence, capability and willingness of family and friends to take on caregiving roles.<sup>53</sup> The way that caregivers are supported in their new roles is a fundamental of hospice care.

When people with advanced cancer start to experience rapid functional declines, it is important to ensure hospice care is in place. At this time, conversations about prognosis should occur. The speed of deterioration in the last weeks of life is surprising to many clinicians who do not frequently encounter it.<sup>54</sup> Providing realistic timeframes to patients and their caregivers is an important part of care in the last weeks of life. Patients need this information so that they are able to prioritise the things that are most important to them in the time remaining.

### *Key competencies for all health professionals in end of life care.*

Several competencies are required for good end-of-life care. *Every* health professional ought to be able to demonstrate core end-of-life competencies including: recognising the end-of-life; understanding of the principles of symptom control and inter-disciplinary care; patient-centred communication and shared decision making; clinical skills in thorough bedside assessment; and fostering personal attributes including empathy and compassion.<sup>55</sup> Good communication includes active listening, responding to emotion, communicating difficult information, and ascertaining the person's values and preferences (especially for advance care planning). These capabilities enable health professionals to help patients and their families plan their end-of-life care, manage concerns and foster good interdisciplinary care. There is a current generation of health professionals for whom hospice care was not part of their training, and for whom a specific commitment will need to be made to improve knowledge and skills<sup>56</sup> - a challenge once in busy practice.<sup>57</sup>

### *Key competencies for specialist hospice care clinicians*

To complement the general clinical workforce, there is the need to have a specialist hospice/palliative care workforce that can provide care to patients and families with more complex needs. Whilst providing this more complex care, this specialist workforce is simultaneously continuing to generate new evidence (research) and rapidly translate it into practice to improve care (education, systems change).<sup>24,25,58-61</sup> Studies demonstrate that when high quality evidence is generated, health professionals change practice.<sup>62,63</sup>

### *Team-based care*

Good support provided to patients and their families is intrinsically complex. It is unlikely that any one clinician will meet the entire hospice care needs of each patient and their family while the person is alive or the family's needs after the person's death. Using a validated

palliative care needs assessment tool helps clinicians recognise when the patients or families require additional support from other team members or services.<sup>64</sup> The Palliative Care Needs Assessment Tool (Cancer) (PC-NAT (Cancer)) has four domains: patient; caregiver willingness to provide care; caregiver ability to provide care; and any health professional issues.<sup>65</sup> The routine use of such a tool in people with advanced cancer in an interrupted time series study compared to standard practice demonstrated better met informational needs for patients and caregivers.<sup>21</sup> Evidence for the validity of this tool in primary care consultations in people with advanced cancer has been established.<sup>66</sup>

An inter-disciplinary team approach is needed to provide patients and their families with a range of health professionals with whom to interact. The ability to relate to a broader group of people allows patients and their families to choose when and what is discussed and with whom. It is likely that patients will discuss different issues with different health professionals in the time and place that suits the patient. This means that several lines of communication need to be open to people in the last weeks of life.

Given the advances that are being made in high quality evidence, it is unlikely that any one practitioner can be fully up to date, thus requiring a team-based, interdisciplinary approach. Given the breadth of patient-defined needs at the end of life, several health professionals working collaboratively will be essential to achieve the best possible patient outcomes.

#### *Interfaces between hospice and other healthcare settings*

Most people will use hospitals in the last year of life, increasing markedly in the final months of life<sup>52</sup> and in most high income countries the majority of people who die from cancer will do so as an inpatient. This requires an effective working relationship between hospice and other health services. Planning of care reduces hospitalisations and emergency department presentations.<sup>67,68</sup> In a retrospective consecutive cohort study of 91,561 people with advanced cancer in Canada, on average, people made more than two visits to the Emergency Department (ED) in the last six months of life, mostly due to poor symptom control.<sup>69</sup> In a retrospective consecutive cohort study of 746 people with advanced cancer, timely referral to hospice was associated with reduced use of the ED by people with advanced cancer (31.3% of people who had earlier access to hospice used the ED while it increased to 52.0% of people who didn't have hospice access), fewer hospital bed days and better symptom control.<sup>70</sup> These findings are reflected in a more recent retrospective study from 54,743 people with advanced cancer where access to hospice care in the last six months of life reduced high- and low-acuity ED presentations.<sup>71</sup> Reduced costs without compromising care can be demonstrated,<sup>67,68,72</sup> although this cost-benefit was less clear after the hospice benefit payment was extended to nursing homes in the USA.<sup>73</sup> Differentials in hospital utilisation and use of intensive care is a key driver in any measured cost differentials.<sup>74,75</sup>

A dynamic and timely interface between hospice providers and inpatient services is increasingly being facilitated by the use of electronic information technology clinical platforms, ensuring better currency of clinical data as people move between places of care. Ensuring that both clinical teams are aware of each other's conversations with the patient and family is a fundamental challenge that persists even in an era with improving electronic records.

Inpatient hospice care may be the preferred choice by patients and their families when:

- symptoms are complex or not responding to current therapies where a brief inpatient admission may more rapidly bring symptoms under control;<sup>76</sup>
- An unexpected change in clinical condition when the person had a reasonable level of function and wants to pursue reasonable efforts to reverse treatable pathology;
- Care needs exceed available community services especially due to caregiver fatigue;<sup>77</sup> or
- The person in the last days or hours of life does not want to die at home.<sup>20,78</sup>

A growing number of people live alone in our communities and is projected to rise in the decades ahead. The ability of someone with advanced cancer to remain at home if they live alone until the time of their death is very limited. If a person's preference is to die at home, the greatest predictor of this occurring is the presence of a willing and able caregiver.<sup>53</sup> Specific issues arise in advance care planning for people without a live-in caregiver that need to be addressed expectantly.

### *Caregiver outcomes*

Few data are available for long term caregiver outcomes with and without access to hospice. One large observational study comparing cohorts who did and did not access hospice care suggests two benefits for caregivers: informational needs were better met; and the caregiver had a greater ability to 'move on' with his/her life after the patient's death.<sup>79</sup> A cause-and-effect relationship cannot be inferred, but the study provides supportive evidence from a randomly selected community population who identified that they had provided care for someone close to them with a terminal illness in the preceding five years. Studies using propensity matched scores for caregivers who did and did not access hospice have shown associations including improved survival and lower rates of depression.<sup>80</sup> Such data complement data on patient-related measures such as improved symptom control.<sup>10,81</sup>

### *Conclusion*

Clinically, data support ensuring patients have the option to consider hospice as a clinical path when it is recognised that they have advanced cancer. Hospice provides patients with the potential for better quality of life, improved symptom control, and more time away from inpatient care.<sup>2</sup> The majority of care falls to family and friends, and any additional support for them while fulfilling their role is likely to be of substantial benefit. Observational studies suggest measurable benefits for caregivers after the patient dies.<sup>79,80,81</sup> For health services, data support that health service utilisation is more likely to be clinically appropriate with fewer hospital visits, shorter lengths of stay and less time in intensive care units if hospice is engaged.<sup>2,7,8,53,67,74</sup> The future research agenda needs to include larger health service randomised controlled trials to fully define the net effects (benefits and burdens) of hospice together with larger phase III studies in key symptoms where the therapeutic choices are still extremely limited.

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**The role of hospice care at the end of life for people with cancer.**David C Currow<sup>1,2,3</sup>Meera R Agar<sup>1,3,4</sup>Jane L Phillips<sup>1,3</sup>

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## **Abstract**

Patient-defined factors that are important at the end of life include being physically independent for as long as possible, good symptom control and spending quality time with friends and family. Hospice care adds to the quality of care and these patient-centered priorities for people with cancer and their families in the last weeks and days of life. Evidence from large observational studies demonstrate that hospice care can directly improve outcomes, and support better and more appropriate health care utilization for people in the last stages of cancer.

Team-based community hospice care has measurable benefits for patients, their family caregivers and health services. In addition to improved symptom control for patients and greater likelihood of time spent at home, caregiver outcomes are also better when hospice care is accessed: informational needs are better met and caregivers have an improved ability to move on with life after the patient's death when compared to people who did not have access to these services.

Hospice care continues to evolve as its reach expands, and the needs of patients continue to broaden. This is reflected in the transition from hospice being based on excellence in nursing to teams with a broad range of health professionals to meet the complex and changing needs of patients and their families. Further integration of cancer services with hospice care will help to provide more seamless care for patients and supporting family caregivers during their caregiving and after the death of the patient.

## ***Introduction***

How can hospice care best add value to the quality of care and outcomes for patients and their families as they live with advanced cancer?

Given differences in how the terms ‘palliative care’ ‘hospice’ are used around the world, in this article the definitions reflect care provision in the United States of America where:

‘palliative care’ refers to a range of services offered through close and ongoing integration of care for anyone with a life-limiting illness, ideally from the time that a life-limiting illness is recognised. High quality evidence from randomised trials and large observational studies support early access for people with advanced cancer;<sup>1-5</sup> and

‘hospice’ refers to community-based care that is offered, ideally, by a multi-disciplinary team that supports patients with advanced diseases and their families. In the USA, this type of care is funded *per diem* by the Medicare Hospice benefit and is available to people who have less than six months to live.

Palliative care is dealt with in other articles in this issue and, although philosophically and practically palliative care and hospice have some overlap, this article focuses on hospice care. Likewise the taxonomy of ‘end of life’ differs globally and in this article it will refer to the last weeks or days of people’s lives.

Ideally, palliative care will have been introduced earlier in the disease trajectory for people with advanced cancer, as this is likely to increase the proportion of people referred earlier to hospice care.<sup>6</sup> Even if earlier referral to palliative care has not happened, congruent with emerging health services evidence,<sup>7,8</sup> hospice care at the end of life is crucial if outcomes are to be optimised for patients and for their caregivers (while caring and after the person’s death). Such care reflects the expressed wishes of communities<sup>9</sup> to prioritise care for people at the end of life in the setting of their choice wherever possible and to the highest standard that evidence-based practice enables.

### *Patient-defined priorities at the end of life*

In order to determine the benefits that hospice care can deliver, patients with advanced cancer need to determine the priorities. These voices are heard in the seminal study by Steinhauser *et al.*<sup>10</sup> The team ran focus groups with patients to define issues deemed important at the end of life which were then transformed into survey questions for random samples in the USA from: a Veteran’s population who were aware they had limited prognoses and caregivers 6-12 months after their caregiving was completed; and health professionals (not limited to Veterans Affairs): physicians who provided care for people with life-limiting illnesses as part of their practice; and nurses and allied health professionals.<sup>10</sup> Key priorities identified by all groups included: excellence in pain and other symptom control (not as an end in itself but in order to optimise wellbeing and physical independence for as long as possible); to be well enough to spend as much quality time with friends and family; deal with unfinished business; and finalise any legacy issues. These priorities have been affirmed in several other studies of people with advanced, progressive cancers.<sup>11-19</sup> In the Steinhauser study, there were also occasions where patients’ priorities differed from other respondents’. The place of care at the time of death was *not* a high priority for patients, perhaps reflecting the complexity of

decisions around this, especially if there are tensions between patients and their family caregivers.<sup>20</sup> Health professionals providing care in the last weeks of life need to constantly re-explore the patient's preferred place of care and the caregivers' willingness and capacity to provide that care, especially if symptoms worsen or as physical function declines.<sup>21</sup>

Reflecting these patient- and caregiver-defined priorities, hospice care services have grown rapidly to support families and communities to care for people at home (including in skilled nursing facilities) through excellence in physical symptom control, psychological support, spiritual care and support for caregivers.

#### *Symptom burden in end-of-life care*

Hospice care improves symptom control in problems prevalent at the end of life.<sup>22</sup> Attention to physical symptoms is valued by patients and their families as a key goal of care.<sup>10</sup> There is a rapidly evolving evidence base from randomised controlled trials to improve symptom control in end of life care<sup>23-26</sup> yet many of these findings have not been embedded in practice.<sup>14</sup> The research also highlights areas where further research is necessary.

The burden of physical symptoms evolves in the last weeks of life. Two symptoms which tend to worsen as functional status predictably declines are fatigue and breathlessness.<sup>27,28</sup> Fatigue not reduced by rest is often the most overwhelming symptom experienced by people with advanced cancer. It often co-exists with cachexia in this setting.<sup>29</sup> Fatigue generates frustration for patients as they struggle to re-prioritise their activities in the limited time that they have left, while often being exhausted by relatively trivial exertion. [Non-pharmacological interventions have not been well studied in people in the last weeks of life.](#)<sup>30</sup> [Other than reversing causes that can cause fatigue \(severe anaemia\), the evidence for pharmacological interventions for fatigue in patients with advanced cancer is limited.](#)<sup>31</sup> [Candidate medications include methylphenidate, amantadine or modafinil, but none has sufficient data to justify their use in routine clinical care.](#)

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Prevalence and intensity of chronic breathlessness<sup>32,9</sup> often worsen as death approaches even in people with no documented cardio-respiratory disease, especially in the last two to three weeks of life.<sup>33,4</sup> The proportion of people with *no breathlessness* drops rapidly in the last weeks of life and the proportion with *severe breathlessness* increases despite symptomatic treatment. The evidence base for effectively and safely treating chronic breathlessness continues to improve using non-pharmacological and pharmacological interventions reflected in systematic reviews and meta-analyses.<sup>34,35,33</sup> In a systematic approach to assessing and treating chronic breathlessness akin to the World Health Organisation (WHO) analgesic ladder, the most important step is to ensure that reversible causes have been adequately treated<sup>36,4</sup> while considering non-pharmacological and subsequently pharmacological interventions.<sup>37,5</sup> Uncontrolled breathlessness is frightening and exhausting for patients, and confronting for caregivers, often leaving haunting and unpleasant memories.<sup>38,6</sup> Minimising breathlessness is therefore imperative for patients' and families' wellbeing.

As function declines in the last weeks of life, the intensity and prevalence of pain may also decrease, perhaps reflecting how much of the pain is exacerbated with incident movement and subsequently experienced at rest.<sup>39,7</sup> Good analgesia is often *the* priority for patients and their families above any other symptom right through until death. Evidence supports that hospice care provides better analgesia for patients when compared to patients who did not

access hospice.<sup>22</sup> Late in life, immobility perversely also frequently causes pain and careful attention to repositioning patients regularly is a hallmark of exemplary nursing care. When patients no longer have the strength to reposition themselves, air mattresses can help to shift patients' weight but do not replace ongoing attentive nursing care.

Delirium is characterised by cognitive changes (especially poor concentration), perceptual changes (especially hallucinations) and physical changes such as disturbed sleep/wake cycles. One third of people admitted for inpatient care at the end of life will have prevalent delirium and another one third will develop incident delirium during the admission.<sup>40,38</sup> encompassing hypoactive and hyperactive delirium. Hypoactive delirium is under-diagnosed in people at the end of life, but can be as distressing for patients as hyperactive delirium.

In a percentage of patients, reversible causes for delirium will be found, aiding them to more rapidly regain their cognition.<sup>41,42,39,40</sup> The first aim of managing delirium is to ensure patient safety, and the safety of all those around the patient. Excellent nursing care ensures that visual and hearing aids are in place, ongoing efforts are made to orient the person, day and night are differentiated, and that hydration and nutrition are attended to with regular meals where feeding is supervised.

Benefits from anti-psychotics for delirium seem negligible in placebo controlled studies involving intensive care patients and those nearing the end of life.<sup>25,43+</sup> Delirium requires excellent nursing care, treating reversible precipitants and, if there is a need for safety, consideration of a sedative short term.

#### *Symptoms in the last hours of life*

For many caregivers, the person's last hours will be remembered because of noisy respiratory secretions. This noise is because secretions are not being cleared effectively and is usually associated with the patient being deeply unconscious. The treatment of these secretions is largely, if not exclusively, for the benefit of the person's family. There is no demonstrated intervention for preventing noisy secretions at the end of life and no pharmacological or non-pharmacological intervention that has been shown to be of predictable benefit in changing the clinical course of secretions.<sup>43+</sup>

#### *Patients rating of symptom control – the need to improve care*

There is international evidence that the quality of care for people with advanced, progressive illnesses must improve.<sup>15-19,45,3</sup> Feedback that is independent of the individual health care professional/patient interaction suggests that symptom control is not as good as we anticipate, nor as good as patient and families expect.<sup>17,19</sup> This reflects an under-detection by clinicians, clinical interventions which do not reflect best evidence, and lack of referral to inter-disciplinary services that could provide more comprehensive support for people with more complex needs.

Addressing this mismatch includes critically evaluating the quality of care for people with cancer at the end of life.<sup>46-50,44-48</sup> Providing timely feedback from patients and their caregivers to their clinicians can contribute to improved symptom control.<sup>49,50,47,48</sup> For example, patients filling out a symptom assessment tool immediately before clinical consultations so that clinicians see the results improves symptom control and is associated with better survival.<sup>51,49</sup> Given the value placed on symptom control by patients and their caregivers, and the

symptom burden experienced by people with cancer at the end of life, health professionals need to ensure that the best available evidence underpins all clinical care.

#### *Hospice care*

Given the emphasis on excellent nursing care for optimal outcomes at the end of life, it is appropriate that hospice care has arisen from nursing and been complemented with other clinical disciplines more recently. Care that can support patients to be functional for as long as possible and simultaneously provide symptom control will deliver the best outcomes. The majority of care in the last year of life occurs in the community<sup>529</sup> and relies almost exclusively on the presence, capability and willingness of family and friends to take on caregiving roles.<sup>534</sup> The way that caregivers are supported in their new roles is a fundamental of hospice care.

When people with advanced cancer start to experience rapid functional declines, it is important to ensure hospice care is in place. At this time, conversations about prognosis should occur. The speed of deterioration in the last weeks of life is surprising to many clinicians who do not frequently encounter it.<sup>543</sup> Providing realistic timeframes to patients and their caregivers is an important part of care in the last weeks of life. Patients need this information so that they are able to prioritise the things that are most important to them in the time remaining.

#### *Key competencies for all health professionals in end of life care.*

Several competencies are required for good end-of-life care. *Every* health professional ought to be able to demonstrate core end-of-life competencies including: recognising the end-of-life; understanding of the principles of symptom control and inter-disciplinary care; patient-centred communication and shared decision making; clinical skills in thorough bedside assessment; and fostering personal attributes including empathy and compassion.<sup>553</sup> Good communication includes active listening, responding to emotion, communicating difficult information, and ascertaining the person's values and preferences (especially for advance care planning). These capabilities enable health professionals to help patients and their families plan their end-of-life care, manage concerns and foster good interdisciplinary care. (There is a current generation of health professionals for whom hospice care was not part of their training, and for whom a specific commitment will need to be made to improve knowledge and skills<sup>564</sup> - a challenge once in busy practice.<sup>575</sup>)

#### *Key competencies for specialist hospice care clinicians*

To complement the general clinical workforce, there is the need to have a specialist hospice/palliative care workforce that can provide care to patients and families with more complex needs. Whilst providing this more complex care, this specialist workforce is simultaneously continuing to generate new evidence (research) and rapidly translate it into practice to improve care (education, systems change).<sup>24,25,58-61,56-59</sup> Studies demonstrate that when high quality evidence is generated, health professionals change practice.<sup>62,639,64</sup>

#### *Team-based care*

Good support provided to patients and their families is intrinsically complex. It is unlikely that any one clinician will meet the entire hospice care needs of each patient and their family while the person is alive or the family's needs after the person's death. Using a validated

palliative care needs assessment tool helps clinicians recognise when the patients or families require additional support from other team members or services.<sup>642</sup> [The Palliative Care Needs Assessment Tool \(Cancer\) \(PC-NAT \(Cancer\)\) has four domains: patient; caregiver willingness to provide care; caregiver ability to provide care; and any health professional issues.](#)<sup>65</sup> [\[ref\]](#) The routine use of such a tool in people with advanced cancer in an interrupted time series study compared to standard practice demonstrated better met informational needs for patients and caregivers.<sup>21</sup> Evidence for the validity of this tool in primary care consultations in people with advanced cancer has been established.<sup>663</sup>

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An inter-disciplinary team approach is needed to provide patients and their families with a range of health professionals with whom to interact. The ability to relate to a broader group of people allows patients and their families to choose when and what is discussed and with whom. It is likely that patients will discuss different issues with different health professionals in the time and place that suits the patient. This means that several lines of communication need to be open to people in the last weeks of life.

Given the advances that are being made in high quality evidence, it is unlikely that any one practitioner can be fully up to date, thus requiring a team-based, interdisciplinary approach. Given the breadth of patient-defined needs at the end of life, several health professionals working collaboratively will be essential to achieve the best possible patient outcomes.

#### *Interfaces between hospice and other healthcare settings*

Most people will use hospitals in the last year of life, increasing markedly in the final months of life<sup>529</sup> and in most high income countries the majority of people who die from cancer will do so as an inpatient. This requires an effective working relationship between hospice and other health services. Planning of care reduces hospitalisations and emergency department presentations.<sup>67,684,65</sup> In a retrospective consecutive cohort study of 91,561 people with advanced cancer in Canada, on average, people made more than two visits to the Emergency Department (ED) in the last six months of life, mostly due to poor symptom control.<sup>696</sup> In a retrospective consecutive cohort study of 746 people with advanced cancer, timely referral to hospice was associated with reduced use of the ED by people with advanced cancer (31.3% of people who had earlier access to hospice used the ED while it [increased to](#) 52.0% of people who didn't have hospice access), fewer hospital bed days and better symptom control.<sup>7067</sup> These findings are reflected in a more recent retrospective study from 54,743 people with advanced cancer where access to hospice care in the last six months of life reduced high- and low-acuity ED presentations.<sup>7168</sup> Reduced costs without compromising care can be demonstrated,<sup>67,68,7264,65,69</sup> although this cost-benefit was less clear after the hospice benefit payment was extended to nursing homes in the USA.<sup>739</sup> Differentials in hospital utilisation and use of intensive care is a key driver in any measured cost differentials.<sup>74,754,72</sup>

A dynamic and timely interface between hospice providers and inpatient services is increasingly being facilitated by the use of electronic information technology clinical platforms, ensuring better currency of clinical data as people move between places of care. Ensuring that both clinical teams are aware of each other's conversations with the patient and family is a fundamental challenge that persists even in an era with improving electronic records.

Inpatient hospice care may be the preferred choice by patients and their families when:



- symptoms are complex or not responding to current therapies where a brief inpatient admission may more rapidly bring symptoms under control;<sup>763</sup>
- An unexpected change in clinical condition when the person had a reasonable level of function and wants to pursue reasonable efforts to reverse treatable pathology;
- Care needs exceed available community services especially due to caregiver fatigue;<sup>774</sup> or
- The person in the last days or hours of life does not want to die at home.<sup>20,785</sup>

A growing number of people live alone in our communities and is projected to rise in the decades ahead. The ability of someone with advanced cancer to remain at home if they live alone until the time of their death is very limited. If a person's preference is to die at home, the greatest predictor of this occurring is the presence of a willing and able caregiver.<sup>531</sup> Specific issues arise in advance care planning for people without a live-in caregiver that need to be addressed expectantly.

#### *Caregiver outcomes*

Few data are available for long term caregiver outcomes with and without access to hospice. One [large](#) observational study [comparing cohorts who did and did not access hospice care](#) suggests [two benefits for caregivers: informational needs were better met; and the caregiver had a greater ability to 'move on' with his/her life after the patient's death.](#) ~~that caregivers who have access to hospice identified their informational needs were better met and after the death of the person, they were better able to 'move on' with their lives.~~<sup>796</sup> A cause-and-effect relationship cannot be inferred, but [the study](#) provides supportive evidence from a randomly selected community population who identified that they had provided care for someone close to them with a terminal illness in the preceding five years. Studies using propensity matched scores for caregivers who did and did not access hospice have shown associations including improved survival and lower rates of depression.<sup>8077</sup> Such data complement data on patient-related measures such as improved symptom control.<sup>10,8178</sup>

#### *Conclusion*

Clinically, data support ensuring patients have the option to consider hospice as a clinical path when it is recognised that they have advanced cancer. Hospice provides patients with the potential for better quality of life, improved symptom control, and more time away from inpatient care.<sup>2</sup> The majority of care falls to family and friends, and any additional support for them while fulfilling their role is likely to be of substantial benefit. Observational studies suggest measurable benefits for caregivers after the patient dies.<sup>79,80,8176,77,78</sup> For health services, data support that health service utilisation is more likely to be clinically appropriate with fewer hospital visits, shorter lengths of stay and less time in intensive care units if hospice is engaged.<sup>2,7,8,53,67,74,64,71</sup> The future research agenda needs to include larger health service randomised controlled trials to fully define the net effects (benefits and burdens) of hospice together with larger phase III [studies](#) in key symptoms where the therapeutic choices are still extremely limited.

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