



Palliative Care Looking Towards 2020

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EDITORIAL

Please cite this paper as: Murray SA, Mason S. Palliative care: Looking towards 2020. AMJ, 2010, 3, 6, 318-324.
Doi 10.4066/AMJ.2010.343

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What are the key challenges facing medicine internationally in the next 10 years to maximise the quality of people's lives when they are living with progressive life-threatening illnesses? This paper flags up **5 important challenges** and areas for development which are relevant internationally, and which may also be relevant in Australasia (Figure 1). We illustrate these with examples of recent innovative research and successful developments in each of these challenges from different parts of the world.

The first challenge is to reach all people in need with any life-threatening illness, taking palliative care beyond cancer from which only 25% of people now die. The second challenge is to help people earlier rather than later: not just in the very terminal stage but from diagnosis of a life-threatening illness. The third challenge is to care for all aspects of the person, all dimensions - physical, psychological, social and spiritual, and to regain a spiritual lens that was present when palliative care was born 50 years ago. The fourth challenge is to have reliably good end-of-life care available in all settings: in the community, nursing homes and hospitals as well as in hospices. The fifth challenge is making end-of-life care available for people in all nations, especially the poorer countries.

The first challenge: caring for people with all life-threatening illnesses

Everyone dies. We are all born; we all die. It's part of the human condition, although as doctors we often deny it, and are slow to recognise it. A century ago, most people died of infectious diseases, accidents or childbirth at an average age of 46, with little disability before death. Nowadays the situation remains that way in developing countries but in economically developed countries most people die after a longish period of disability at an average age of 78 with the top three causes of death now being cancer, organ failure and frailty/dementia.¹ This can be illustrated by looking at trends in UK primary care. A family doctor in the UK, who has about 1800 patients on his or her registered list, has 20 deaths on average per year. Five of these deaths are from cancer, 6 from organ failure, (such as chronic obstructive pulmonary disease, heart failure, liver failure, renal failure, and 7 from frailty (either physical frailty or dementia). Only about 2 of the 20 are likely to die totally unexpectedly (Figure 2).

For these three main causes of death, the implications for palliative care provision are quite different. The cancer trajectory normally follows a generally predictable course with a short decline towards the end. Hospice care fits well with people dying with cancer and meets their needs.² Conversely, patients with organ failure may have a gradual decline over 2-5 years physically, but during that period there are acute declines, and sometimes hospital admissions. Patients with organ failure may die suddenly at any time, but are not expected to die in the next few months. Due largely to this prognostic uncertainty and various funding reasons such patients rarely actually benefit from a palliative care approach. The frailty trajectory is variable and may last for many years with the onset of deficiencies in activities of daily living or speech or walking. The needs of this group are for integrated clinical care and long term support at home, carer support and nursing care. In many countries support for this group is unreliable. Therefore, to reliably meet the end-of-life needs of all



patients we must design or redesign our services so that they are set up to meet the typical needs of people on the three archetypal trajectories.³

The second challenge – a palliative care approach must start early, at diagnosis of a life-threatening illness rather than at the very end

With cancer, traditionally there was a period when a cure was attempted, and then when cure was no longer possible, palliative care intervened. The new and better concept is that supportive and palliative care should start at diagnosis of a life-threatening illness and gradually increase while disease modifying care may decrease (Figure 3). This model and understanding can be applied to all people with a progressive illness including organ failure and frailty.^{4, 5} As debility increases from specific illnesses or general frailty, people can be considered for more of a palliative approach. Provision of palliative care should be triggered not by diagnosis, or even prognosis, but according to need. Another specific trigger for consideration for a holistic palliative approach might be admission to a care home, as this is generally done to increase supportive care. Alternatively, another criterion could be the need of a certain amount or hours of care in the community.

In the organ failure and frailty trajectories it has previously been more difficult to conceptualise and decide when a palliative care approach might be clinically appropriate. However, examining a typical organ failure trajectory (Figure 4) it is evident that events or triggers such as a hospital admission might be utilised to consider if a supportive approach is now appropriate for that individual patient. Alternatively, there might be clinical indicators such as grade 4 heart failure (i.e. breathlessness at rest) to trigger this approach, or even the “surprise question”. This question is where a physician asks himself or herself the question “would I be surprised if this patient were to die in the next year”? If the answer is “no” this means that the patient might die and therefore a plan should be started “just in case”. Our research has shown that patients can manage both preparation for death and hope for the future, as they tend to have dual, competing narratives in their mind.⁶

Overzealous treatment later in the course of all these types of illnesses, in the very last days of life (see Figure 3, Stage 3) can be prevented by diagnosing imminent death, and starting the patient on an end-of-life care pathway, such as the Liverpool Care Pathway.⁷ This ensures among other

things the consideration of stopping any unnecessary treatments and tests.

The third challenge - meeting all dimensions of need - physical, psychological, social and spiritual

It is now recognised in the US and increasingly in Australia and the UK that everyone has spiritual needs when faced with serious life-threatening illness; after all we are all human. There is an accepted definition of spiritual needs used internationally that states, “spiritual needs are needs that relate to the meaning and purpose of life”.⁸ People may or may not use religious vocabulary to express such needs. If the spiritual issue or need causes the person distress it becomes “spiritual distress”. If such distress is upsetting the person, such as interfering with sleep or their ability to work, then this should be identified and addressed by someone because such distress also impinges on other areas: it makes pain more painful, anxiety less bearable and leads to increasing health service utilisation.

Dying is a 4-dimensional activity, it’s more than physical. So what’s actually happening in respect to the non-physical dimensions of need? Our research team found that in lung cancer at least, that social decline runs in parallel with the physical decline: “his old friends won’t even take a cup of tea with me now I’ve got cancer” (Figure 5). And what was happening with respect to psychological trajectory in these patients with lung cancer? Our research uncovered four times when distress can routinely be expected: at the time of diagnosis, after initial treatment when the patient returned from the hospital, at recurrence or disease progression, and then again in the terminal stage. Unsurprisingly it was when someone was anxiously coming to a diagnosis that also they were thinking then about the meaning and purpose of life. So it would appear that the spiritual trajectory in these patients with lung cancer was parallel with the psychological one. It appears that the physical and social declines tend to run together as do the psychological and spiritual.⁹ We also studied patients with advanced heart failure and a typical quotation about a social issue was “I feel like I’m in prison here with him and each day is just like that” and that was the carer of one of the patients speaking.¹⁰ The psychological trajectory appeared to mirror the physical and social trajectories with one respondent recollecting “I slipped down the bed and oh panic attacks I got.” The spiritual trajectory reflected gradual loss of identity and growing dependence on others “where is God in all this, has God forsaken me”?



So is it worth thinking about trajectories because first of all we can plan 4 dimensional (4D) care according to what the needs of the patients are likely to be and we can plan timely care when these needs are likely. People may ask us *“how long have I got?”* It’s often very hard to say, but what we can say is *“well it’s hard to know how long, but let me tell you what it might be like for you”* and that can be very reassuring for people. If this is explained to patients and carers they can then understand and feel empowered, knowing what the future may hold. It was Hippocrates who said *“the physician who can foretell the course of the illness is the most highly esteemed”*.

The fourth challenge - making a difference in the community

In the UK only 19% of people die at home and that’s decreasing. However, it is believed that over 50% would prefer to die at home if possible. In the last decade Dr Keri Thomas has pioneered the development of the Gold Standards Framework of Care, which at present is used in over 80% of UK practices. It gives a structure for doctors and community nurses to organise and co-ordinate care around general practices. It highlights the “7Cs” which are vital for quality end-of-life care in the community: communication, co-ordination, control of symptoms, continuity of care, continued learning, carer support and care in the dying phase (Figure 6). For more details about how people can be identified and assessed as suitable for palliative care please see the Gold Standards Framework website and specifically the indicators for identifying people on the frailty and organ failure trajectories. (<http://www.goldstandardsframework.nhs.uk/>) A number of evaluations are revealing that this care is effective, and a specific programme for nursing care homes is also associated with positive outcomes such as less hospital admissions in the last weeks of life, and more frequent documentation of advance care plans and resuscitation status information.¹¹

The fifth challenge - reaching to all in need in economically poorer countries and learning from them about bringing death back to life

Having completed a study in Scotland of people dying with lung cancer, we took the opportunity to do a similar study with colleagues in Kenya.¹² We asked the same questions in Scotland and in Kenya *“what are the main problems that you are facing just now?”* and compared the findings.

In Scotland the main issue that people would mention first was existential, leading to spiritual distress, whereas in Kenya the main issue was that of physical suffering, especially pain. In Scotland analgesia was effective and affordable, but in Kenya it was unaffordable and largely unavailable. In Scotland people felt anger in the face of the illness whereas in Kenya there was greater expression of acceptance. In Edinburgh someone might say *“I’ll just keep it to myself”* but in Kenya there was community support and engagement which was accepted by patients. In Scotland the spiritual needs were evident but unmet while in Kenya patients were comforted and inspired by their belief in God. In Scotland diagnosis brought active treatment but in Kenya it signalled waiting for death. This comparison indicates the very different approaches that we need to take when aiming to develop palliative care but also illustrates what we can learn from each other.

This map of Africa shows that only 4 countries have any real palliative care services (Figure 7). In all the other 52 countries in Africa there is very little access to morphine or any strong analgesia, although the Africa Palliative Care Association and Hospice Uganda are addressing this vigorously.

Call for a public discourse on death and dying

In Africa there is little pain relief but the communities are vibrant and members visit people to comfort and support them practically. Economically developed countries can learn much from talking about death and dying and visiting people, and supporting our friends and neighbours in the community at the end-of-life as we read above. In Australia an exciting development known as “Health promoting palliative care” is starting to address this.¹³ This calls for community involvement in end-of-life care and encourages people and the community to generally talk and be more involved in many aspects of care at the end-of-life. Health promoting palliative care argues that if death and dying were brought more into the open it would of course be much easier to plan for a good death. Practical guidelines for this approach are available at <http://www.latrobe.edu.au/pcu/guide.htm>

Caring for all in the last year or phase of life

We suggest there are 5 key challenges that we must address. We must go beyond cancer and help people at the end-of-life no matter what the illness. We shouldn’t palliate according to diagnosis or even prognosis but according to



need, which is usually in fact a product of number of co-morbidities. The second challenge is that we should try to help earlier rather than later, when input is strategic and formative, and when emotional needs are often acute. Thirdly we should help all dimensions of need: going beyond the physical to the social, psychological and spiritual. Fourthly we should increasingly try to help more and more people spend more time in the setting they really want. Finally we should assist poorer countries in setting up and training to meet the need for analgesia, while learning from them how to promote wellbeing in the face of death.

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ACKNOWLEDGEMENTS

We thank other members of the Primary Palliative Care Research Group, University of Edinburgh for comments on this paper.

PEER REVIEW

Not commissioned. Externally peer reviewed.

CONFLICTS OF INTEREST

The authors declare that they have no competing interests.

FUNDING

Nil

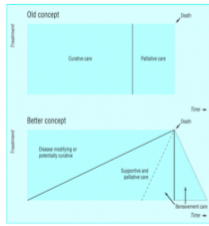


FIGURES

Figure 1

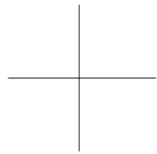


5 KEY CHALLENGES



1. All illnesses

2. Earlier than later



3. All dimensions



5. All nations



4. All settings

Figure 2.

[Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. BMJ. 2005; 330:1007-1011.](#)

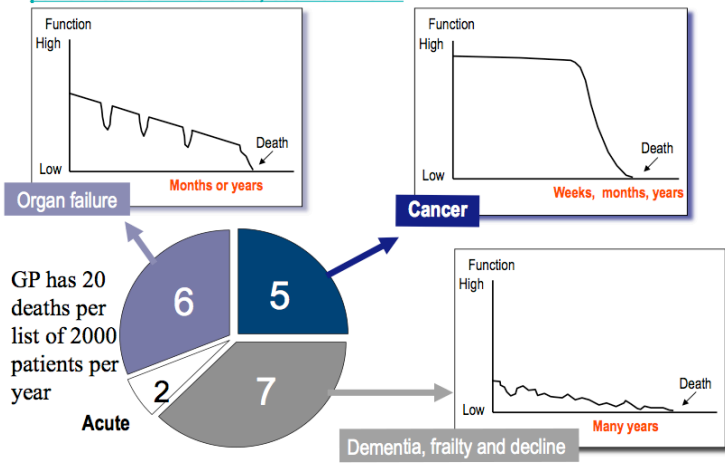
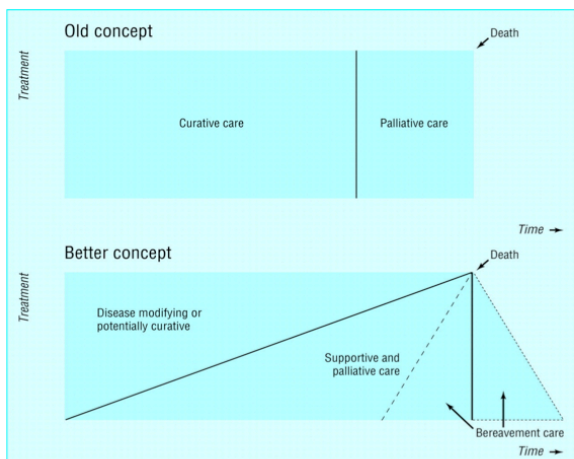


Figure 3. Appropriate care near the end-of-life: from disease modifying to active palliation.



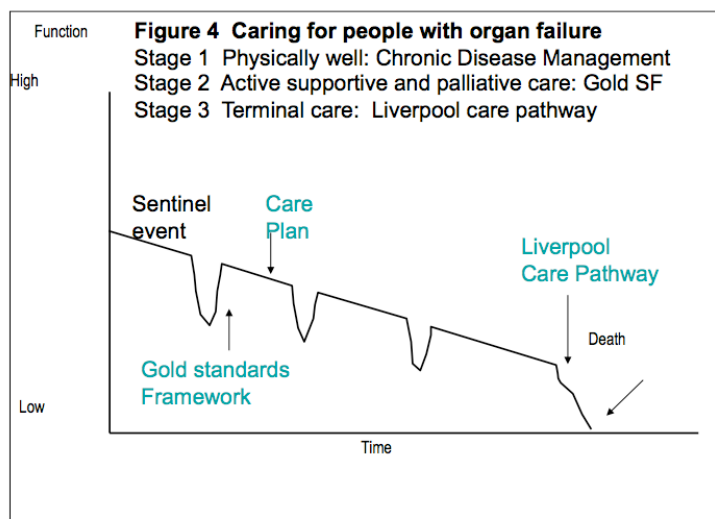


Figure 5 Lung cancer – physical, social trajectories, psychological and spiritual trajectories from diagnosis to death

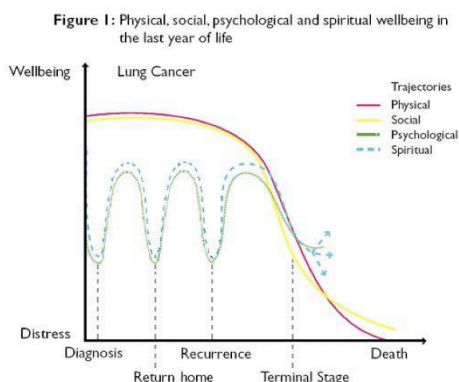


Figure 6. Key tasks in the Gold Standards Framework(7 Cs)

- C1** Communication
SC Register and PHCT Meetings, Pt info, PHR, Advanced care planning (ACP) eg PPC
- C2** Co-ordinator
Key Person, assessment tools eg PEPSI COLA
- C3** Control of Symptoms
Assessment, body chart, SPC ,ACP etc
- C4** Continuity Out of Hours
Handover form + OOH protocol
- C5** Continued Learning
Learning about conditions on patients seen
- C6** Carer Support
Practical, emotional, bereavement, National Carer's Strategy
- C7** Care in dying phase-
LCP / ICP for care in last few days



Figure 7 Provision Of palliative Care in Africa

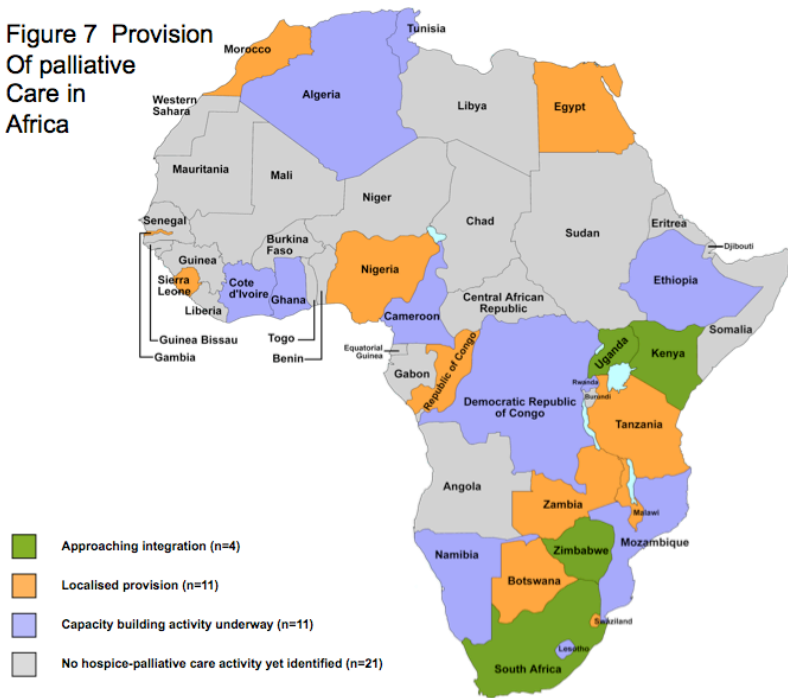


Diagram from International Observatory on End of Life Care, Lancaster University, UK