

Parliament of Victoria

Inquiry by Legal and Social Issues Committee into end of life care

Submission from Health Issues Centre (HIC), Melbourne

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31 July 2015

Background

Health Issues Centre welcomes the opportunity to inform the work of the Legislative Council's Legal and Social Issues Committee in relation to end of life choices.

Using the valuable and unique insights of consumers as health service users, carers and citizens, Health Issues Centre works towards a health system with better health outcomes and experiences for all. HIC actively supports the involvement of consumers and the community in shaping policy and practice around end of life care.

Advance care planning is one mechanism that has been created to assist people to exercise their preferences for the way they want to manage their end of life. In the first half of 2015 Health Issues Centre conducted a series of consumer focus groups to gauge community awareness, attitudes and experience in relation to advance care planning.* Members of the community targeted were –

- People aged 60 or over
- People living with a chronic or serious illness
- People caring for someone with a chronic or serious illness (other than dementia)
- People caring for someone living with dementia
- People with ageing parents

Eight in-depth, semi-structured discussions were conducted with a total of fifty participants in metropolitan Melbourne.** With participant permission, discussions were recorded and transcribed. Transcripts were reviewed to identify key themes which were analysed in the context of the existing literature on consumer experience of advance care planning. Conclusions have been tested and refined in discussion with key informants from the health service and community sectors.

Introduction

Victorians are fortunate to live in a country where most of us now die at an older age. Due in part to advances in medical treatment and technology, about two-thirds of Australians now die between seventy-five and ninety-five years of age. (1) We are in the enviable

*We are grateful to the Department of Health and Human Services for their funding and support of this work.

**We acknowledge and thank Clare O'Callaghan and Associate Professor Natasha Michael at Cabrini Health, for acting as our research partners in co-facilitating the focus groups and identifying themes.

position of having an older population who aspire to be actively involved in the social, cultural, and economic activities in their local communities. This aspiration is not always well-supported by attitudes and structures that associate ageing with decline and dependency. This includes the health system, where older people have been referred to as “bed stoppers”; in danger of being seen as “cast-offs” who’ve “snuck (in) for a bit of inappropriate, grudgingly given treatment”. (2)

At the same time, it is a reality that with longer life comes the increased likelihood of chronic disease and disability. The end of life trajectory will depend on the condition(s), but for at least some Victorians this will mean slower decline with sporadic episodes of serious illness, or a long period of comparatively low quality of life. (3)

The older Victorians we spoke with did not want to be ‘written off’; nor did they want to be ‘kept alive’ by medication or technological intervention with little or no quality of life. Conversations need to be led within both the community and the health professions that address fears regarding technology-driven ‘overtreatment’ and ageism-driven ‘undertreatment’. The common use of battle metaphors and the lauding of people who are ‘fighters’ can help keep fear at bay, but also drown out a much-needed conversation around dying and the use of intervention at the end of life.

Advance care directives (ACD) have been heralded by some as the solution, with people able to give instructions for their future health care, stating what medical treatment they would like (or not like) in the event they are unable to make decisions for themselves. For the purposes of this submission, an advance care directive is defined as a written document recognised by common law or authorised by legislation that records a person’s directions about medical care and treatment refusals.

The ACD concept is appealing in its apparent simplicity but like most complex issues, end of life care is shaped by multiple and interlinking factors. In this paper, we argue for the value of end of life and advance care planning conversations whilst cautioning against the overpromise of advance care directives as a bioethical “magic bullet”. (4) Community attitudes, health and legal literacy, professional cultures, communication skills and service availability are all factors that need to be addressed. A summary of key findings can be found at [Appendix A](#).

A note about euthanasia

The basis for fears of burdensome, disrespectful or inadequate care at the end of life requires further investigation. This includes cases where symptom management, sometimes referred to as “comfort” care, is not able to achieve comfort. Policymakers need to be clear on the scale and nature of intractable cases and the capacity of law to help or hinder their management. The choice to die should not be driven by a perceived need to avoid poor or inadequate care. (5) Investment in a multi-pronged approach to service improvement should be prioritised.

Discussion

The challenge of getting the care you want at the end of life

By definition, an advance care directive relates to future health care in circumstances of incapacity. A person can indicate his/her consent or refusal to particular medical treatments. The usual legal (and ethical) standard that applies regarding patient involvement in medical decision making is that of informed consent. (6) This requires that the person be informed of –

- The diagnosis and likely outcome (prognosis) of the condition
- An explanation of the recommended treatment
- The risks of the procedure and common side effects
- Possible complications
- Any other options for treatment and their probability of success.

Clearly there are inherent limitations in applying this standard in relation to future decisions. If, as some commentators suggest, a person ideally completes an ACD at a time prior to a serious health threat, the specific diagnosis is not yet known. More common end of life trajectories can be anticipated in general terms but remain hypothetical and lack context. Human beings are typically not good at assessing what it would be like to experience different hypothetical states of health. People are often wrong when they try to conceive their future feelings; we tend to focus on our current feelings – and thus fears – about it. (7) Thus people are likely to need support picturing their future ‘nearing end of life’ self.

End of life intervention options can be anticipated and these are frequently listed on ACDs (e.g., CPR, ventilation, feeding tube). However, to meaningfully consent or refuse such procedures the person needs to understand the nature of the intervention, the risks, common side effects, the probability of success, the consequences of not intervening and any other options. Some treatment interventions have low rates of success and sometimes the burdens may outweigh the attempt at benefit. Providing a realistic picture of the pros and cons of available treatment and intervention ‘choices’ can trigger insight that sometimes the ‘best’ care may be to stop intervening. The ethical nature of the choice needs to be clear - it’s not a choice between dying and the restoration of health; it’s the choice between a ‘better’ or ‘worse’ death. For the person the question will be - how is the treatment/intervention going to support the aspects of life that I value? (8)

For a person with little or no knowledge regarding the nature or impact of common end of life treatments/interventions, informed decision making is not possible. It cannot be assumed that a person completing an ACD is able to source that information or knows what questions to ask to elicit the information they need. Thus, two opportunities to improve

health literacy in the community are clear – people need accessible information regarding common end of life treatments and their success rates; they also need to be supported to ask questions regarding any choices that are available and the pros and cons of each choice. Just grasping the two ideas that you have a choice and that not all treatment is beneficial may be new for some. (9)

Those who recognise that not planning may lead to increased future discomfort are more receptive to information. (10) For example, the daughter who starts to notice functional decline in her parent; the man who witnesses the suffering of his brother, who he believes had “a bad death”. Given an opening, these are people who may welcome a conversation.

Community members won't engage in advance care planning conversations unless they understand why it's important. Increased knowledge regarding medical intervention during the dying process, the right to ask questions and discuss options is key to this understanding.

In an advance care directive, meaningful instructions regarding treatment options are dependent on both the options available and your understanding of those options. If there are options you don't know you have or options you think you have that aren't actually available, your directive is of limited value. If you think that care stops when acute intervention stops, you may continue for fear of abandonment, not because intervention is your 'choice'. If you want to die in the community, but the services required to support that choice aren't available, then that's not a real option. Just as we want to avoid costly interventionist treatment of no benefit, if people elect the palliative care alternative, we have to be able to deliver it or the 'choice' implied by the advance care directive is rendered a false promise. Recent reviews report that sufficient palliative care is often not available. The 2009 report from The National Health and Hospitals Reform Commission concluded – *“we cannot in good faith promise patients at the end of their life access to care that is customised to preferences and reliably delivers good symptom control. Our health system can do better”*. (11)

Investment in palliative care services is required if the promise of choice is to be made real.

The capacity to choose palliative care over acute or intensive intervention relies in part on access to services. Appropriate investment in patient-centred palliative care needs to be prioritised.

Following a specific diagnosis, a person with capacity has more of a context in which to consider intervention options. If the clinical team are aware of the likely trajectory, and can recognise symptoms of decline, they are in position to discuss goals of treatment. What aspects of life does the person value most? Why do they value them? What are they prepared to sacrifice in a trade off? (12) Clinicians have a key role to play in assisting a person

to translate their values and priorities into specific treatment decisions. For example, if independence is valued, is this treatment likely to have an impact on my capacity to look after myself? If it means I'll need assistance, is it support at a level my carer or home services can provide or will 24-hour care be required? What will be the costs associated with that care?

For this to happen effectively, again assumptions by the health professional need to be avoided:

'If I discuss goals of treatment with the patient, they will become upset and lose hope'.

The patient may become emotional but that is not a reason, in and of itself, not to have the conversation. People may move back and forth between acceptance and denial, both strategies to cope with illness, without losing hope. (13) Emotion is normal and to be expected. Acknowledging emotion may be a helpful step in establishing the trust needed to engage in shared decision-making. (14) As trust goes up, fear may go down. Given the amount of fear that exists around the end of life experience, the importance of trust should not be underestimated.

'This person is over 'X' years, they wouldn't want 'Y' intervention to extend their life'.

As noted earlier, whilst older people may be concerned about being "kept alive" with no quality of life, they may be equally concerned about being "written off" as an older person of no value. A person's attitude will be affected by their previous medical history and life experience, or that of their close family. Someone with a long term chronic illness who has survived numerous acute episodes may identify as a survivor whose life has depended on a philosophy of 'never giving up'. Another person may have accommodated limitations by redeploying their attention to think about domains of life other than health, such as personal relationships. (15) Definitions of 'life worth living' are subjective, are shaped by health status and life experience, and may change over time. Finding themselves in the actual situation, patients may rate their health status more positively than they did in the hypothetical. If a person has capacity, why assume an answer when you can ask?

Patients should be asked about their goals for treatment. Health professionals need to assist the person to translate their values and priorities into specific treatment decisions. Definitions of a 'life not worth living' need to be explored, not assumed. The value of efforts to build trust cannot be overestimated.

These conversations may be less confronting in the context of prior 'priming'. In fifty to seventy per cent of deaths, death is predictable and expected. (16) Most patients do not move from 'capacity' to 'no capacity' overnight. Changes in condition and treatment response throughout the illness course may cause treatment intent to shift from curative to symptom management. As clinical teams shift their goals, they need to take patients and families with them; it may be a process of adjusting and readjusting expectations, one needing to be underpinned by information and support. Progressive conversations mean that even when it gets to the stage that the doctor can no longer ask the patient what s/he

wants, prior conversations with the person regarding their values and priorities may provide useful guidance.

These conversations may be challenging for professionals and require a sense of self-efficacy. A clinician's sense of self-efficacy is impacted by their education, training and experience. It is also influenced by the cultural climates within which the person operates and the sense of security (or not) those climates provide. In end of life care, clinicians are often handicapped by professional cultures that avoid talk of dying or climates overly focused on liability.

The skill and experience of palliative care, intensive care and geriatric specialists needs to be recognised and shared. Leadership is required to promote intra- and inter- professional reflection and dialogue regarding the limits of medicine. End of life education should be included throughout medical training curricula. Communication skills need to be modelled by experienced clinicians.

Care that appropriately addresses pain, agitation and distress should not be denied for fear of the law. If the liability fears of health professionals are impacting practice, this needs to be addressed through clarification of their position. If a lack of legal knowledge is an issue, this should also be addressed in medical training curricula.

Clinical leaders need to drive conversations within the professions regarding the limits of medicine. End of life education should be included throughout medical training curricula. If perceived legal vulnerability of health professionals is preventing the provision of effective palliative care, their legal position requires clarification. The law should support the delivery of effective palliative care.

The role of the “person responsible” and the challenges of substitute decision-making

As discussed earlier, there are difficulties in relation to informed consent for future decisions. It could be argued that a better way to deal with this scenario is via a substitute decision maker. The current law allows the appointment of an enduring power of attorney to act as your substitute in the event that you're unable to make decisions for yourself.

Identification of a substitute decision maker is prompted by an understanding that there may be a period of incapacity before death. It cannot be assumed that people are aware of this possibility or the process followed by health professionals when it occurs. A person may not have considered that near the end of life they may need another person to make decisions on their behalf.

If a patient cannot consent to their own treatment, the medical practitioner may obtain consent from the 'person responsible'. Someone formally appointed by the person or VCAT will be considered the 'person responsible'. If no formal appointment has been made, the

'person responsible' is deemed to be the person's spouse or partner, primary carer or nearest relative over the age of 18 (starting with the eldest child). (16)

It cannot be assumed that people understand the law in relation to capacity and consent to medical treatment. This lack of legal literacy may be of particular consequence to the person who does not have a spouse/partner, primary carer or near relative; or in circumstances where that relationship feels unsafe or lacks trust. Advance care planning and power of attorney conversations provide an important opportunity to identify any potential for inappropriate or unwanted influence. Particular effort needs to be made to connect people in these circumstances with information as to how to protect their best interests.

Key to understanding the value of advance care planning is knowledge regarding the law on capacity and consent. A strategy is required to increase community literacy regarding the definition of "person responsible". The value of appointing a medical enduring power of attorney (MEPOA) should be widely publicised.

Even if a person's preference is consistent with the legal default, it is unlikely that the person or their spouse, primary carer or eldest child is fully cognisant of the ethical demands of the role. Most people placed in this position want to be a "good" substitute decision maker (SDM) who makes the "right" decisions. Some would say that is clearly defined for them by the principle of substituted judgement – that is, a "good" substitute decision maker makes the same decision the person would have made. This assumes the SDM knows what decision the person would have made. It also sets a standard that makes little if any allowance for the other ways an SDM may wish to be "good". S/he may wish to be a "good family member" who tries to keep family harmony by taking account of all of the different views and the family's capacity to provide or afford care. S/he may also try to be a "good client" who cooperates with service staff and aligns with their preferences. S/he may also strive to be a "good community member" who is mindful of finite resources and pressures on the healthcare system. (17)

The complex reality of substitute decision making means SDMs are likely to need considerable support to identify and advocate for the person's wishes. It is common for people to assume that those close to them 'will just know'. This is challenged by experienced SDMs who report that when the time comes you don't "just know" and would feel more confident if you had prior communication with the person regarding their preferences. (18) This underscores the value of prompting and supporting end of life conversations in communities and households.

The power of attorney appointment process presents an opportunity to discuss beliefs and expectations. Do views differ regarding "quality of life" and life-prolonging treatment? 'Do you have strong views which you expect me to adhere to or are you happy for me to do the

best I can in the circumstances, weighing up all the factors?’ The discussion may also point to other factors that influence capability. For older people with spouses/partners of a similar age, does their own health status impact on their capacity to perform the SDM role? ‘Does the connection between us run so long and so deep that even when you’ve had enough I still may not be ready to let go?’

Again, health literacy cannot be assumed. Information should be provided regarding the kind of life-prolonging treatment options a SDM might be asked to consider, including which ones require an instant decision and which ones may be thought about for longer.

Advance care planning conversations and the MEPOA appointment process clearly present educational opportunities to better prepare SDMs for in-the-moment decision making. (Consider whether this could be strengthened by a requirement to sign a statement of acceptance, as is the case for an EPOA financial.) We would suggest a strong word of caution against viewing advance care directives as the magic bullet. Whilst advance discussion and preparation is helpful and should be strongly supported, the in-the-moment strains of making decisions and caring for a dying loved one cannot be eliminated by planning. Advance care directives should not be seen as removing the need for conversations and SDM supports at the pointy end, both during the dying phase and beyond death.

Identification of the dying phase is a medical judgement. Clinicians are responsible for presenting options in that frame. A person may need help putting a particular episode in the context of the broader trajectory of the dying process. Again, the ethical nature of the choice needs to be clear - it’s not a choice between ‘killing’ the person and ‘restoring health’; the reversal of illness is not possible. When a treatment cannot be effective, that needs to be made clear – this is not a judgement against the clinician (not skilled enough), the patient (life not valuable enough) or the SDM (doesn’t care enough). (19) An ACD cannot and should not take away the responsibility of medical teams to make a clinical assessment and guide people through any treatment decisions. Training in completing advance care directives should not take the place of training on how to discuss prognosis and goals of treatment. It’s important that the ethical demands on the SDM are acknowledged. Clinicians can lead supportive conversations with carers/families that shift away from a notion of one ‘right’ course of action. For the SDM it’s not a case of ‘the right decision’; but rather finding peace through engaging in a good decision-making process.

Substitute decision-making is ethically complex and can be a difficult process. Carers and family members are not medical experts and need information and guidance throughout the process, in particular regarding the pros and cons of end of life interventions. They may need support to identify and act in accordance with the person’s values or best interests. More attention and resources need to be directed to supporting carers and family members through the entire end of life trajectory.

Conclusion

There are concerns in both the community and the professions regarding end of life care, in particular the possibility of keeping people alive with little or no quality of life. In Australia, we are in one sense privileged to have access to life saving treatment and technology. But with that privilege comes responsibility, and the ethical dilemma of when “enough is enough”. The government needs to support conversations within the professions and community regarding dying and the role of medical intervention. Community members need to understand why advance care planning conversations are important. This requires an understanding that 1) you may lose capacity before dying 2) treatment isn’t always successful or beneficial and 3) there could be decisions to be made on your behalf that are difficult for those who care about you. Education to increase literacy in the community regarding loss of capacity, the role of the “person responsible” and medical enduring power of attorney needs to be prioritised.

The inclusion of end of life care throughout medical training curricula needs to also be a priority. The capacity of health professionals to talk about prognosis, treatment intent, and what matters to the patient is crucial. Goals and values need to be identified and reviewed at key moments in the end of life trajectory.

If the person is no longer able to speak for themselves, these goals and values need to be discussed with the carers/family. Making a decision on behalf of someone nearing end of life can be ethically complex. Prior knowledge of what’s most important to the person assists both the family and the care team at a difficult time. As the then Victorian Department of Health clearly identified in 2014, it’s important to “have the conversation”.
(20)

A single solution to a complex problem can be neat and plausible but insufficient. (21)
However useful an advance care directive may be, it is not a magic bullet. In many ways more significant are the conversations that precede the document. Even then, prior conversations cannot entirely eliminate the ethical demands of end of life decision-making. Clinicians and carers/families need to be better prepared for in-the-moment conversations and decisions. Professionals and substitute decision-makers need to be supported to make respectful, compassionate decisions that keep the patient at the centre.

Appendix A

Summary of key findings

- Conversations need to be led within both the community and the health professions that address fears regarding technology-driven ‘overtreatment’ and ageism-driven ‘undertreatment’.
- Community members won’t engage in advance care planning conversations unless they understand why it’s important. Increased knowledge regarding medical intervention during the dying process, the right to ask questions and discuss options is key to this understanding.
- The capacity to choose palliative care over acute or intensive intervention relies in part on access to services. Appropriate investment in patient-centred palliative care needs to be prioritised.
- Patients should be asked about their goals for treatment. Health professionals need to assist the person to translate their values and priorities into specific treatment decisions. Definitions of a ‘life not worth living’ need to be explored, not assumed. The value of efforts to build trust cannot be overestimated.
- Clinical leaders need to drive conversations within the professions regarding the limits of medicine. End of life education should be included throughout medical training curricula. If perceived legal vulnerability of health professionals is preventing the provision of effective palliative care, their legal position requires clarification. The law should support the delivery of effective palliative care.
- Key to understanding the value of advance care planning is knowledge regarding the law on capacity and consent. A strategy is required to increase community literacy regarding the definition of “person responsible”. The value of appointing an enduring power of attorney (medical treatment) should be widely publicised.
- When a treatment cannot be effective, that needs to be made clear – this is not a judgement against the clinician (not skilled enough), the patient (life not valuable enough) or the substitute decision-maker (doesn’t care enough).
- Substitute decision-making is ethically complex and can be a difficult process. Carers and family members are not medical experts and need information and guidance throughout the process, in particular regarding the pros and cons of end of life interventions. They may need support to identify and act in accordance with the person’s values or best interests. More attention and resources need to be directed to supporting carers and family members through the entire end of life trajectory.

Appendix B

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