


CLINICAL PERSPECTIVES

Advance care planning in Australia during the COVID-19 outbreak: now more important than ever

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Abstract

The novel Coronavirus disease 2019 (COVID-19) outbreak has led to rapid and profound changes in healthcare system delivery and society more broadly. Older adults, and those living with chronic or life-limiting conditions, are at increased risk of experiencing severe or critical symptoms associated with COVID-19 infection and are more likely to die. They may also experience non-COVID-19 related deterioration in their health status during this period. Advance care planning (ACP) is critical for this cohort, yet there is no coordinated strategy for increasing the low rates of ACP uptake in these groups, or more broadly. This paper outlines a number of key reasons why ACP is an urgent priority, and should form a part of the health system's COVID-19 response strategy. These include reducing the need for rationing, planning for surges in healthcare demand, respecting human rights, enabling proactive care coordination and leveraging societal change. We conclude with key recommendations for policy and practice in the system-wide implementation of ACP, to enable a more ethical, coordinated and person-centred response in the COVID-19 context.

Introduction

The novel coronavirus disease 2019 (COVID-19) was first reported on 31 December 2019 and has since spread across the globe, being declared a pandemic on 11 March 2020.¹ COVID-19 is capable of causing a range of severe respiratory symptoms in a significant minority of infected individuals.² The rapid spread of COVID-19 and elevated mortality rates among older adults and those with underlying conditions have presented significant health, economic and social challenges for governments, health services and communities. While Australia has so far avoided the rampant transmission and devastating mortality rates seen in some parts of Asia, Europe and the USA, the scale of the COVID-19 outbreak, along with the extent of associated mitigation measures at a domestic level have been unprecedented.

As in other countries, Australian state and territory governments have activated emergency powers that constrain civic freedoms, including implementing travel restrictions and 'physical distancing' regulations. These measures are aimed at flattening the epidemic curve and enabling health services to manage the predicted increase in demand for acute and intensive care services.³ Health services have also been compelled to plan for worst-case scenarios in which rapid surges in severe cases overwhelm the capacity of intensive care and other healthcare settings.⁴ Measures implemented to date have included securing alternative sources for critical medical supplies, increasing acute and intensive care capacity, ceasing elective surgery, closing specialist clinics, establishing dedicated wards or spaces for confirmed or suspected COVID-19 cases, transitioning sections of the healthcare workforce to telehealth delivery, limiting hospital visitors, and limiting resident movement and family visitation in residential aged care facility (RACF) settings.⁵

In the absence of an effective vaccine or antiviral treatment, these measures are an unquestionably important public health response to COVID-19, with evidence from

Abbreviations: ACD, advance care directive; ACP, advance care planning; RACF, residential aged care facility.
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previous outbreaks indicating that they will slow infection rates and reduce overall mortality.³ However, from a broader bio-psycho-social model of health, it is also important to reflect on how these rapid changes may impact on other valued health and social outcomes, particularly for older adults and those with chronic or life-limiting conditions.⁶ These people are at increased risk of experiencing severe or critical symptoms associated with COVID-19,² but are also more likely to be regularly accessing health or aged care and may be on an end-of-life trajectory for other reasons. Advance care planning (ACP) is always important for these groups,⁷ and as we argue below, for several reasons is now more important than ever. However, it is not simply a matter of accelerating a 'business as usual' approach; several factors will impact on ACP in the current context. This paper argues there is an urgent need to include ACP as part of the health system response to COVID-19, and concludes with key recommendations on how this might be facilitated in the current context.

Advance care planning

ACP is the coordinated process of communication and planning that aims to clarify and share a person's values and preferences relating to medical treatments, in order that these can inform healthcare decision-making should the person be unable to make or communicate these decisions in the future.⁸ In addition to advance care directives (ACD) that specify a person's preferences for future medical treatments or nominate a substitute decision-maker, there may also be episodic documentation of 'goals of care' by the treating team in consultation with the person and/or family as part of a shared decision-making process.⁹ Both ACP and goals of care may include preferred place or type of care, and cultural or spiritual preferences. Importantly, ACP is a voluntary person-led approach that should not be conflated with unilateral clinical decision-making regarding 'futility' or 'rationing' of scarce healthcare resources (although it may reduce the need for such decision-making). ACP has been associated with a range of positive end-of-life care outcomes, including reduced use of life-sustaining treatments,¹⁰ increased compliance with patients' end-of-life wishes,¹¹ and reduced symptoms of depression and anxiety among bereaved relatives.¹² In Australia, the best estimates of ACD prevalence place rates at around 14% in population-based surveys,¹³ 25% among older adults accessing health or aged care settings, with relatively higher rates in the RACF setting (38%) than hospital (11%) or general practice (6%) settings.¹⁴ These later findings are significant, given the complex

circumstances of the study participants, many of whom were of advanced age, with multiple co-morbidities, resided in aged care facilities and had significant functional impairment.

There has been a growing recognition of the importance of ACP in the response to COVID-19.^{15,16} However, the Australian Health Sector Emergency Response Plan for Novel Coronavirus COVID-19 contains just one reference to ACP, stating that part of the clinical care and public health management response should include 'encourag(ing) advance (care) planning directives of aged care providers and residents'.¹⁷ We believe that a vague strategy targeted towards the aged care population alone is insufficient. The current low rate of ACD documentation among susceptible groups reflects an urgent need for increased engagement with ACP, at both a healthcare system and societal level. There are existing, evidence-based approaches that can increase ACP uptake¹² and facilitate a more ethical, coordinated and person-centred response to the COVID-19 outbreak. The justification for devoting scarce healthcare resources to ACP in the COVID-19 context includes five key benefits: reducing the need for rationing, planning for surges in healthcare demand, respecting human rights, enabling proactive care coordination and leveraging societal change.

Reducing the need for rationing

In some parts of the world, COVID-19 has resulted in an inability to provide necessary life-sustaining treatments to all who need them, requiring 'impossible' clinical decisions about who to prioritise for treatment. International experience has shown that the ethical basis for these 'rationing' decisions is contested, and at a clinical level they are extremely challenging for all involved.¹⁸ In Australia, ethical frameworks have been developed to support clinical triaging decisions and the allocation of scarce healthcare resources should this be necessary.^{19,20} We argue that an ethical response does not begin only once a rationing scenario is encountered, but instead starts with taking all sensible measures to prevent, or mitigate this scenario. These include implementing infection control measures, increasing clinical service capacity, and stockpiling necessary equipment and medications, as is occurring. However, not all patients who experience clinical deterioration will desire aggressive, life-sustaining treatment in a hospital environment. An ACP process can enable such patients to express their preferences ahead of time.¹⁶ In a situation of rapid clinical deterioration and loss of decision-making capacity, such patients would not be placed in 'competition' for scarce healthcare resources with others who do desire,

and who could benefit from, such treatment. This will also reduce healthcare professional exposure to unnecessary infection risk associated with administering unwanted life-sustaining treatments.¹⁶ In a rationing scenario it is arguably unethical to provide treatments without actively seeking to offer patients and families ACP discussions wherever possible. It is of course critical that the person-led ACP process is upheld, and not conflated with clinical or health systems-level decision-making processes regarding futile/non-beneficial treatment or rationing. It is also imperative to emphasise that ‘no intensive care’ or ‘no hospitalisation’ does not mean ‘no care’; all available resources should be used to ensure person-centred palliative care is available to all, with particular priority for those who have refused aggressive treatments.¹⁵

Planning for unexpected surges

International experience has shown how unchecked community transmission of COVID-19 can rapidly overwhelm local healthcare resources, even in high-income countries.¹⁸ While infection control measures have been effective in arresting the rate of new cases during Australia’s ‘first wave’, the threat of future outbreaks remains.³ If a surge in healthcare demand overwhelms key healthcare resources it will be too late to undertake appropriate ACP discussions with all new admissions at this point, regardless of their COVID-19 infection status.⁴ Prudent healthcare system planning should extend to resourcing programmes to encourage ACP discussions, particularly among those at risk of experiencing severe or critical symptoms if infected with COVID-19,¹⁶ ideally before infection occurs. General practitioners, hospital discharge teams, nurses and allied health practitioners, aged care facility staff, trained community volunteers and public health communication strategies may all play a role in raising community awareness and facilitating ACP discussions. Non-acute, community settings provide a more comfortable context for exploring patient views,²¹ and these preparatory discussions reduce the burden on acute health practitioners, who will be able to communicate with patients and family members who have already started an ACP process. Starting ACP prior to an acute event may also reduce the likelihood of patients misinterpreting a routine ‘goals of care’ discussion on hospital admission as a signal of poor prognosis or that further treatment is not appropriate. The risk of these perceptions is particularly acute with COVID-19 given the extensive media coverage and international experiences of overt healthcare rationing. All of these proactive measures aim to increase ACP discussions and documentation, and thus ease the ethical burden

and likely trauma that would be experienced by health practitioners associated with having to make unilateral decisions to withdraw or withhold medical treatments.^{16,18}

Respecting human rights

There are long-standing concerns about the capacity for emergency powers activated in response to public health or national security threats to compromise human rights.²² The United Nations Siracusa Principles provide a framework for public health responses, to ensure that any measures infringing on human rights are necessary, proportionate, non-discriminatory and subject to review.²³ While parliamentary processes may provide at least some scrutiny of the rapidly legislated response to the COVID-19 outbreak over coming months,²⁴ at a health service level, clinicians and managers are charged with real-time implementation in their local context, while maintaining key healthcare system functions. Part of a proportionate and non-discriminatory response to COVID-19 will include protecting patient autonomy and procedures underpinning full informed consent wherever possible (including through ACP) and taking action to promote equitable access to healthcare regardless of group membership (e.g. gender, ethnicity, disability or religious belief).

While much commentary to date has focussed on who would have access to healthcare in extreme ‘rationing’ scenarios,^{19,25} other scenarios are also relevant to a rights-based perspective. In the COVID-19 context, accessing hospital or residential aged care may come with a risk of periods of isolation from full family visitation,⁵ a possibility of dying without access to visitors,²⁶ and the potential for healthcare-associated infection if localised outbreaks occur. Given these constraints, some may choose to forego treatments, hospitalisation or admission to residential aged care.⁶ A facilitated ACP process involving health practitioners can help patients and family members discuss their concerns, with opportunities to address misinformation or unfounded fears. Practitioners can provide contextualised information about the person’s underlying conditions, available treatment and care options and the likely burdens and benefits in the unique COVID-19 context, enabling the person to express and document their preferences. Encouraging and assisting in ACP discussions explicitly demonstrates to patients and family members how health practitioners continue to value patient preferences, in spite of having to enforce strict infection control measures.^{16,26,27} Protecting core bio-ethical principles of autonomy, dignity and informed consent in healthcare decision-making, even in

constrained and extraordinary situations, may provide a sense of higher meaning and shared purpose for health practitioners and the broader community. A rights-based approach that incorporates ACP can thus enable a proportionate and person-centred approach to care provision during COVID-19.

Enabling proactive care coordination

Routine healthcare has changed dramatically in the COVID-19 context, even for those who are not themselves infected or in close contact with someone with the condition. Physical distancing measures have complicated normal visiting practices and face-to-face healthcare delivery, making telehealth the 'new normal' in some settings. The use of face masks may obscure verbal and non-verbal cues and hinder communication among those with auditory or cognitive impairments.²⁸ Family members or social support networks who normally contribute to informal care in the community may be less (or more) available to provide care in person. In this context, commonly expressed preferences for end-of-life care, such as receiving support to die at home, may be more complicated to deliver. An important benefit of ACP is that it promotes understanding of a person's preferences for future care, enabling health practitioners and the person's existing support networks proactively to address logistical challenges and coordinate formal and informal care arrangements, so the person's choices can be respected. This may include ensuring supplies of consumables, medications or personal protective equipment to a person's home, acquiring or re-purposing equipment for remote video-conferencing, organising influenza vaccinations to enable visitation in RACF settings and developing contingency plans in case care partners are infected and required to quarantine. An ongoing process of ACP discussion, with information communicated between family members, support networks and the healthcare team, may enable proactive and creative solutions to the challenges that COVID-19 infection control measures present to high-quality end-of-life care.

Leveraging societal change

The COVID-19 pandemic has presented challenges for many societies, but also opportunities to demonstrate resilience, question accepted practices and create lasting change, in healthcare systems and society more broadly. In the short term, some changes may present new opportunities to facilitate ACP. Research has indicated that individual readiness to engage in ACP is influenced

by personal experiences, particularly those that increase an individual's sense of susceptibility (e.g. health scares or experience with end-of-life care for family members).²⁹ In the COVID-19 context, intensive media coverage and confronting images from abroad have brought the limits of medical technology, and our personal vulnerability to sudden illness, into the forefront of community consciousness. Anecdotal clinical experiences suggest that patients with and without COVID-19 are more actively seeking information about ACP. Information resources to assist community members in engaging in ACP (perhaps through online or other broadcast media) may be particularly effective in the current climate, with benefits both during and beyond the COVID-19 crisis.

More broadly, the COVID-19 response provides an opportunity to accelerate health reforms that will improve patient care for all, both immediately and in the post-COVID-19 context. Electronic medical records systems with functionality in communicating ACD documentation between healthcare settings play an important role in ensuring concordance between preferred and actual care.³⁰ Telehealth approaches may help in overcoming barriers to inclusive, family based ACP discussions due to physical distancing and limitations on visitation.³¹ This rapid health system and community capacity building (particularly in the area of video-conferencing) will likely have permanent impacts on healthcare delivery, including opportunities to improve ACP for people with chronic diseases and those living in rural and remote areas.

Key recommendations for ACP in the COVID-19 context

While ACP is a routine part of healthcare,⁷ the five benefits outlined above demonstrate why it should be particularly prioritised in the current situation. We propose below several key recommendations for facilitating ACP in the COVID-19 context (Table 1). Some of these recommendations (e.g. telehealth capabilities) are for measures to overcome specific COVID-19 associated challenges. In addition to information about the ACP process, patients and families will require up-to-date information about local infection control measures (e.g. family visiting policies) to enable informed decision-making and planning. In addition to existing ACP resources,^{34,35} specific resources to assist ACP and goals of care communication in the COVID-19 context are becoming available.^{9,16,27} At a policy level we would recommend that the Australian Health Sector Emergency Response Plan for Novel Coronavirus (COVID-19) be updated to incorporate a more strategic

Table 1 Key recommendations for health and aged care organisations and health practitioners to facilitate advance care planning (ACP) as part of the COVID-19 response

For organisations

- Ensure organisational policies and procedures for ACP and goals of care are up-to-date and supported by resources and staff competencies
- Adhere to existing National Quality Standards promoting ACP, the use of ACD and quality improvement
- Ensure systems are in place to store, communicate and access ACD documentation
- Provide clear and up-to-date information regarding community-wide and local infection control policies for staff and those accessing services, to enable informed decision-making and person-centred care planning

For health practitioners

- Utilise existing staff development and clinical supervisory relationships to develop confidence and competence in facilitating and implementing ACP, ACD, goals of care and/or end-of-life care discussions, including in the context of the COVID-19 pandemic
- Validate patient and family member concerns about COVID-19, and draw on these expressed concerns to prompt further discussion about ACP, preferences and values for future care in the event of serious illness
- Become familiar with community-facing ACP information resources, including those in online formats that can be shared with patients and family members remotely
- Become familiar in using telehealth techniques to facilitate ACP discussions
- Consider incorporating visual aids and/or video materials to assist in communication during ACP discussions, particularly if personal protective equipment is a barrier to communication
- Become familiar with options for overcoming the barriers to witnessing ACD documents, such as utilising common law directives,³² and in some jurisdictions through audio-visual witnessing in combination with countersigning electronic copies³³
- Understand organisational and State/Territory-based systems for storing, sharing and accessing ACD documentation electronically, including the use of My Health Record

ACD, advance care directive.

approach to increasing system-wide ACP implementation.

Conclusion

The COVID-19 situation has emerged rapidly and will continue to evolve. In the rush to ‘ready the ship’ from a

logistical and health system perspective, it is important to also consider the significance of everyday clinical interactions, person-centred care and the opportunities for addressing ACP from a broader bio-psycho-social health perspective. This paper presents the case for prioritising a system-wide approach to ACP as part of the response to COVID-19, with immediate and longer-term benefits.

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