

Opening the lines of communication: towards shared decision making and improved end-of-life care in the Top End

Meeting the need for culturally appropriate discussions regarding patient values and preferences at end of life

Advance care directives are pre-emptive discussions that anticipate a future loss of ability to make or communicate decisions. There is no uniformity in advance care directives in Australia, with each state or territory having differing terminologies and requirements.¹ The Northern Territory has the lowest population density but the highest proportion of Aboriginal people of any Australian jurisdiction.² In the NT, an individual can make a common law or statutory advance care directive,³ referred to as an advance personal plan (APP).⁴ The NT APP enables documentation of legally binding directives in reference to resuscitation and life support, as well as the appointment of substitute decision maker(s).⁵ We have previously documented the utility of the NT APP for Aboriginal people but highlighted the need for a more culturally appropriate document.⁶

For patients with life-limiting diagnoses reviewed at Top End Health Service (TEHS) hospitals, the APP could previously be used in conjunction with a not-for-resuscitation form. TEHS and community-based clinicians noted clear patient care imperatives for a move away from decisions targeted solely towards cardiac arrest. Expanding capacity based on a more patient-focused goals of care (GOC) framework also aligned with expanding evidence in the literature in support of such a focus.⁷

In the NT, there has been growing recognition of the need for improved discussions regarding patient values and preferences regarding end of life, informed specifically by cultural understandings.^{6,8} An important example of this includes determination of the site of death; for many Aboriginal people from rural and remote regions, the land holds particular spiritual and cultural significance.⁸ For such patients, the need to “finish up” (a culturally appropriate term for death and dying) “on country” (ancestral lands) may be paramount and may take precedence over life-prolonging treatments in tertiary centres.⁸

Exploring cultural requirements

The TEHS GOC committee was formed in March 2017. This group had wide stakeholder engagement across three TEHS hospitals and included medical, allied health, administrative, nursing, primary health care and Aboriginal practitioner representation. Through the committee, the NT Department of the Attorney-General and Justice was enlisted to assist in updating the APP (governed under the *Advance Personal Planning Act 2013* (NT)). Officers representing the Attorney-General worked with the GOC committee to explore

the core cultural values to be reflected in an updated APP. A Palliative Care Australia document was used as reference material for these discussions.⁹ The APP is a territory-wide document (unlike the GOC) and the Attorney-General's office additionally undertook consultation in Central Australia.

An updated APP was released in June of 2018.⁴ New questions asked in the section concerning values and preferences (Section B) include: Where would you like to die/finish up? If nearing death, what is unacceptable to you? If nearing death, what are your goals/priorities? After death, what is important to you? People completing the APP are now able to specify cultural rituals such as ceremonial smoking, or to make a request for their body to be returned to their birth country. The capability to provide advance directives concerning cardiopulmonary resuscitation (CPR) if appropriate and other life-sustaining treatments, as well as to nominate substitute decision makers, was retained. The ability to nominate a substitute decision maker in the event of future impairment of capacity is of utmost importance in the NT, as unlike other Australian jurisdictions, the NT does not recognise default decision makers (next of kin or responsible person in other states and territories).³ An educational video was produced with involvement of rural Aboriginal APP champions to illustrate the method and advantages of completing an APP.

The new GOC form ([Supporting Information](#)) was progressively released throughout the TEHS in 2018. The trigger for commencing GOC discussions is if the treating clinician feels that their patient may be in their last year of life (the “surprise question”). This includes patients with advanced malignancy, end-stage organ failure, dementia or other progressive neurodegenerative conditions. It also includes specific reference to GOC in neonatal and paediatric patients. Uptake of the form in this patient population remains small but important.

The resuscitation component of the GOC form documents the appropriateness of rapid response/code blue calls as well as ceilings of care (possible options range from full intensive care unit care to supportive and palliative care). This allows staff caring for dying patients outside the hospice setting to obtain immediate clinical support as required, irrespective of whether CPR is to be performed. The GOC form also allows people to document their wish to remain in their regional hospital for end-of-life care. The implications of this and inherent ceilings of care require detailed discussion with patients and family.

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The TEHS GOC form also requires the documentation of barriers to understanding, cultural responsibility and patient wishes. For some Aboriginal people, in certain instances, the patient may not be the key decision maker (despite having decision-making capacity). The appropriate clinical information — the “right story” — needs to be provided to the appropriate person, usually referred to as the “right person”.⁶ The GOC form provides structured assistance to the completing clinician, to consider the involvement of Aboriginal liaison officers, interpreters and the culturally defined right people. Finally, it requires the completing clinician to consider whether the patient wishes to finish up on country.

The revised NT APP and the GOC form were significant steps towards improved and patient-focused end-of-life care. The working group also recognised that improved documentation required a more comprehensive strategy informed by data collection and research, and enriched by communications training for clinicians in order to be robust and capable of developing over time.

Data collection and research

In February 2019, Royal Darwin Hospital participated in a Commonwealth-funded national study, led by Advance Care Planning Australia, which captured the prevalence of advance care directives and other types of advance care planning documentation in Australian health and residential aged care facilities.¹⁰ These data were useful to Top End clinicians regarding the impact of the recently introduced GOC framework. Health records of people aged 65 years and older who had been admitted for 48 hours were reviewed for advance care directives and medical orders or clinical care plans. The GOC forms are non-statutory (not based in legislation) and were classified as medical orders. The prevalence of medical orders in audited health records at Royal Darwin Hospital was 46%. By comparison, the average prevalence of medical orders across all participating hospitals was 49%. The majority of these reflected either some limitation of treatments or were aimed at symptom control. A small number of patients (eight out of 50) had both an APP and a GOC plan. Only one document showed an incongruence between the APP wishes and the GOC wishes. This was related to the documentation of CPR provision in a patient who had stated in their APP that they did not wish to have CPR. Despite being only a single example, this discrepancy is consistent with findings elsewhere indicating that clinicians have a tendency to provide

more care or more interventions than patients would choose were their wishes specifically discussed and followed.¹¹

Communications training

As part of the strategy to enhance the concept of shared decision making, which underpins patient-centred care, the TEHS provided the first set of communications training workshops in March 2019. The workshops were iValidate (developed and delivered by Barwon Health) and Paediatric SimCom training (developed by Deakin University). Over 40 clinicians including nurses, doctors, allied health workers, Aboriginal health practitioners from hospital and community as well as primary health care practitioners attended the training. Additional Aboriginal and non-Aboriginal participants were trained “on the run” as actors and helped to develop scenarios alongside experienced iValidate simulation actors. This enhanced the cultural context and the clinical authenticity of the scenarios used. Further workshops were held in June and a workshop was held in a regional hospital in November 2019. Facilitator training has also commenced in parallel to the communications courses in order to develop a local facilitator faculty enhancing the sustainability of the program.

Next steps

The development of a GOC framework and a culture of shared decision making is an evolving process. The next step is specific research on the effectiveness of GOC frameworks from the patient’s perspective and the development of communications training that is increasingly informed by the concept of shared decision making.

Significant areas that remain to be addressed include an improvement of the end-of-life experience on wards outside of the hospice, bereavement services within the hospital, mortuary services, and services to those who wish to die in regional hospitals, at home or on country.

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References are available online.

Supporting Information

Additional Supporting Information is included with the online version of this article.

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