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Increasing the uptake of advance care directives through staff education and one-on-one support for people facing end-of-life

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ABSTRACT

Background An advance care plan outlines a patient's wishes regarding medical treatment or goals of care in the case that they become unable to communicate or to make decisions. An advance care directive (ACD) is an advance care plan that has been formally recorded and has legal status. Despite ACDs playing an important role in person-centred end-of-life care, an earlier retrospective medical records audit demonstrated that only 11% (58/531) of people who died due to a terminal illness had an ACD. The aim of this project was to increase the proportion of patients with a terminal illness completing an ACD. A secondary outcome was to measure the impact of ACDs on hospital and intensive care unit (ICU) admissions in the last 6 months of life.

This multifaceted project comprised (1) education for health professionals and the public; (2) individual support for patients on request; (3) development of online resources for health professionals and the general public; and (4) monthly team meetings.

Method The proportion of ACDs completed and hospital and ICU admissions during the last 6 months of life, were extracted via medical record audits.

Written consent was required for patients to participate, including being contacted by the project team and accessing their medical records.

Results 112 patients consented to participate in the project and 109 (97%) completed an ACD. There was no reduction in the average number of hospital admissions, while ICU admissions reduced from 14% (n=74) to 0%.

Conclusion The targeted, multifaceted approach to education and support for completion of ACDs, resulted in a significant increase in ACD completion and a major reduction in ICU admissions.

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Advance care directives (ACDs) play an important role in end-of-life planning, but completion rates are low and may be further compromised in rural settings. It is timely and urgent to test and evaluate initiatives that increase ACD completion rates.

WHAT THIS STUDY ADDS

⇒ A multifaceted approach comprising key enablers of staff knowledge, communication skills and having an ACP specialist (in this case, nurses and a social worker) available for people facing end-of-life decisions substantially increased ACD completion. It appears that ACD completion is associated with a significant reduction in intensive care unit admissions.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Complicated, difficult-to-use technology is a barrier for rural people wishing to have a digital copy of an ACD available in My Health Record, Australia's digital health record. Co-design, with rural consumers, of a user-friendly digital system is recommended.

⇒ Targeted ACP education and the provision of specialist ACP roles available for people facing end-of-life decisions should be incorporated into health service planning.

PROBLEM

Despite the benefits of advance care directives (ACDs) (a plan for end-of-life care that has been formally recorded and has legal status), uptake in rural Australia has been limited.[1 2] For instance, there are approximately 2050 deaths in our rural Australian health district annually, with estimates that 1300–1500 are somewhat predictable.[3 4] To understand the problem in the local context a retrospective 12-month audit of all 'predictable' deaths was conducted to measure the proportion of patients dying with an ACD, and the number of hospital and intensive care unit (ICU) readmissions per person during the final 6 months of life. The audit covering the 12 months of 2019 demonstrated that: (1) 11% (58/531) of people died with an ACD; (2) each person was admitted to hospital an average 1.5 times; and (3) 14% (74/531) were admitted to ICU.

This project aimed to increase the proportion of patients with a 'predictable' death having an ACD to 40% within 18 months of the project implementation. It was anticipated that there would be a subsequent reduction in hospital and ICU admissions during the last 6 months of life.

The project was conducted in a rural Australian coastal district spread across 11 000 square kilometres with a dispersed population of 220 000. The range of services across the district includes six inpatient hospitals, palliative care services and primary care. The area has one of the oldest populations in Australia, with 26.7% aged 65 years and older at the 2021 national census. This compares with 17.6% nationally.[5]

BACKGROUND

Advance care planning (ACP) and subsequent completion of ACDs have been the subject of many studies focusing on the perspectives of health professionals. The most common barriers identified include: a lack of knowledge, education and confidence in facilitating ACP conversations[6–10]; a lack of clarity around whose role it is to initiate ACP discussions and whether those discussions are within their scope of practice[9 11]; plus, the lack of time to do ACP in time pressured environments.[6–9 11]

A few studies have concentrated on the predictors of people undertaking ACP and reported a range of enablers relating to communication, timing of discussions and staff preparation. One of the biggest predictors of ACD completion was being asked by a healthcare professional to complete one.[9] It is, therefore, no surprise that when staff are more confident with ACP, they are more likely to initiate conversations and integrate ACP into standard care and patient uptake is enhanced.[11] The timeliness of ACP conversations is key, with early initiation of discussions before individuals reach a crisis point in their terminal care, found to be important in reducing anxiety and stress for individuals, their carers and family.[12] Additionally, having specialist ACP facilitators also increases uptake.[13 14]

There has been limited research in resource-constrained rural environments and knowledge of barriers and enablers mostly comes from studies in metropolitan health services. By using these same known enablers of staff knowledge, communication skills and having an ACP specialist available for people facing end-of-life decisions, this multifaceted quality improvement initiative was designed for a rural health service.

MEASUREMENT

The primary measure was the proportion of participants who completed an ACD. Medical records were audited for the presence of an ACD and calculated as a percentage of the total number of project participants.

Secondary measures were: (1) number of hospital admissions during the last 6 months of life per participant, and; (2) proportion of participants admitted to ICU during the last 6 months of life. These outcomes were extracted via medical records from participants who died during the project reporting period.

Data availability statement

This project did not seek ethics approval for sharing data sets from the medical records audit beyond the project team.

DESIGN

Two experienced registered nurses and a social worker, under the guidance of a project team, were responsible for:

- Education sessions for health professionals focused on upskilling clinicians' knowledge and ways to integrate completion of ACDs into their routine practice, and to promote referral of eligible people for individual consultations.
- Individual and family consultations about how ACDs could be used to support and discuss their end-of-life wishes.
- Development of educational resources for health professionals and the public to be available online.

For the purposes of this project, eligible people for participation were groups within the general population who may benefit most from ACDs, including people of any age, who:

- Were diagnosed with a life-limiting illness or disability; or
- Had multiple comorbidities and were at risk of deterioration; or
- Had early and/or mild cognitive impairment; or
- Manifest general indicators of frailty; or
- Were living with chronic progressive deterioration of disease; or
- Were approaching the end of their life.[11]

To provide further clarity, participating health professionals were asked to consider the following factors, which indicate that a person may benefit from an ACD:

- Would you be surprised if the person were to die in the next year?
- The person is experiencing symptoms and signs that indicate declining health; or
- The person is experiencing indicators of decline related to their specific disease or condition; or
- The person reached or experienced a significant milestone, for example, advancing age (ie, aged >65 years or older or >55 years if the person identifies as Aboriginal or Torres Strait Islander), retirement, bereavement, admission to community or aged care facility; or
- A person, family member or carer raised ACD with a health professional.[11]

STRATEGY

The project was overseen by a project management team meeting monthly from 2020 to 2022. The team comprised a palliative care specialist, a primary health representative, hospital management, two experienced registered nurses and researchers from partner universities. Using a structured agenda, each meeting was guided by feedback from the project workers (nurses and social worker). This included their interactions with participants about facilitators and barriers to completion of an ACD, along with uploading ACDs to digital systems and progress with education sessions. Fluctuating restrictions during the COVID-19 pandemic meant the team needed to be agile in their progress, including offering online education and consulting with participants via phone.

Feedback and improvement initiatives included:

Technological barriers

For those who completed an ACD, the project aimed to upload these to Australia's online My Health Record in order to facilitate the timely access to and use of ACDs by health professionals. All clinicians involved in the individual's care, both internal and external to the health department, are able to view and follow the directive. Participants reported severe difficulty in uploading their ACD. A simple step-by-step guide was prepared to support patients uploading their own ACDs, but very few had the confidence, knowledge and/or internet availability to do so. Field researchers found they had to sit with participants to upload, when requested. Information technology remains a major barrier to uploading ACDs to My Health Record. The team has shared its experiences with the Australian Digital Health Agency in the hope that more supportive, accessible technology can be developed.

Accessible education for public and health professionals

Easy-to-follow videos were developed over the course of the project, including how to complete an ACD, what is ACP and an ACD, plus a summary of the lessons learnt during this project. These videos have been tested with general public members and now publicly via the health district's webpages:https://mnclhd.health.nsw.gov.au/advance-care-planning.

Targeting key health professionals

Feedback from participants and health professionals, gave the team direction for the inclusion of influential healthcare staff. The team reached out to key staff and incorporated education into orientation and education programmes. In particular, emergency department staff were identified as key decision-makers in instigating and using ACDs. Education sessions focused on upskilling clinicians' knowledge about ways to integrate ACP into their routine practice and have conversations about ACP. This focus included how to communicate risks and benefits to patients and complete clear, high-quality ACDs. There was considerable engagement with 79 sessions attended by 677 clinicians, demonstrating a clear need within their professions for further training. Clinicians from many specialties attended including emergency doctors, general practitioners, nurses and allied health representatives across hospitals and community settings. These education sessions were delivered both face-to-face and virtually, highlighting the adaptability of the team and participants during COVID-19.

Facilitating a translational working group

As results reflecting the impact of the project on ACD uptake became available, a working group was established to make recommendations on how to translate study findings into policies, procedures and practices and to sustain improvements beyond the course of the project.

Representatives participated in two workshops where project results were summarised and the 'PARIHS Framework'[15] was used to guide responses and recommendations.

11 people representing senior management, clinical services, staff education, Aboriginal health, information technology and the research team, formed the working group and participated in workshops in April and May 2022.

The group produced the following recommendations:

1. That the results and learnings continue to be promoted by senior, experienced clinicians in the district.
2. That user-friendly, readily accessible education resources be available online for staff and the public.
3. That the fixed, dedicated positions (such as those employed on the project), significantly improved the uptake of ACDs and the quality of end-of-life care. Consequently, they should be considered for incorporation into existing, ongoing roles.
4. Further education was required to address ongoing staff uncertainty in their role in ACP, along with the right questions and forms to use.

There has been progress on recommendations 1, 2 and 4. Reports and presentations are continuing at senior levels, including the education resources developed. A fixed, dedicated position has not yet been created.

RESULTS

ACD completion

112 people who met the criteria and provided consent participated. Of these 109 (97%) completed an ACD. See figure 1 for project flow and ACD uptake.

Hospital admissions

The average number of admissions during the last 6 months of life for 'predictable' deaths prior to the project was 1.5. There were 61 deaths of participants during the project and the average number of hospital admissions during the last 6 months of life was 1.4.

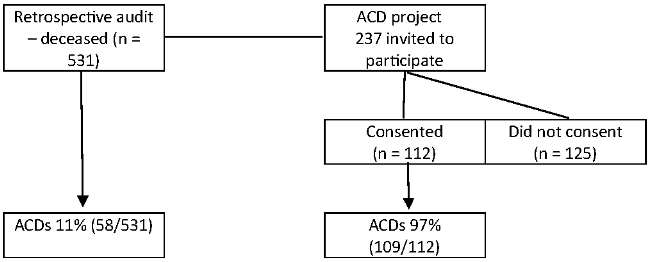

Figure 1 Flow chart of participants and ACD presence in medical records. ACD, advance care directive.

ICU admissions

The retrospective audit prior to the project revealed that 14% (74/531) of people were admitted to ICU during their last 6 months of life. There were 61 deaths of participants during the project, with none (0/61) admitted to ICU.

LESSONS AND LIMITATIONS

There was a substantial increase in project participants with an ACD when compared with the pre-project audit (97% vs 11%). This is likely attributed to the activities undertaken to support ACD completion for participants and staff education. While the project participant numbers were small compared with the pre-project audit (112 vs 531) making statistical comparisons complex, it remains undisputed that 109 people completed an ACD during an 18-month period compared with 58 in the entire pre-project audit. There were some biases that compromise direct comparison between the pre-project audit and project samples. In particular, the decision to seek ethics approval and the subsequent requirement to gain informed consent meant that more than half of those meeting project inclusion criteria did not consent to participate and were not included in the medical records audit. For future studies it is worth considering a design where all eligible medical records are audited, not just project participants, so that an overall change in ACD completion is measured and pre audit and project samples can be compared more directly. However, even if the uptake of ACDs was low in non-participants the overall uptake of ACDs would remain higher than the study aim of 40% uptake. This result strengthens findings from other studies reinforcing that having a dedicated ACP position increases ACD completion.[13 14]

While there was no difference in hospital admissions in the last 6 months of life between project participants and the pre-project audit (average 1.4 vs 1.5), there was a sudden cessation in ICU admissions. The result that no participants were admitted to the ICU compared with 14% reflects the contribution that ACD completion makes to compliance with end-of-life wishes. Further analyses of ACDs indicated that all participants requested no cardiopulmonary resuscitation, ventilation or renal dialysis and that these wishes were complied with. These interventions would often require ICU admissions and, thus, give confidence that the result that no participants were admitted to ICU, can be attributed to the presence of an ACD.

A contributing factor from the project activities is likely to be the education sessions for over 600 staff. This large and influential group of staff reported greater confidence in asking about ACDs and understanding their importance in patient decision-making. The nurses and social worker dedicated to the project also reported they observed a ‘change in language’ regarding ACDs and end-of-life discussions with staff during the project. This is consistent with international research indicating that education of health professionals that enhances their comfort with ACP discussions increases compliance with patient’s wishes.[11]

The project sample was small as consent was required for participation and measurements in the last 6 months of life could not be recorded until the participant was deceased. That there were 61 deaths of participants during the project compared with the total pre-project audit of 531 deaths creates less certainty in this finding relating to hospital and ICU admissions. The total number of deaths of those consenting to participate will naturally increase in time, so it is worth considering another medical records audit in 12 months to affirm, or otherwise, the trend seen in hospital and ICU admissions.

Technology was a barrier to uploading ACDs to digital health records (‘My Health Record’). Most participants were unable to navigate the complex process of scanning their ACD and meeting privacy requirements to access their records which required a second mobile device before the upload process could commence (multifactor authentication). At this point, which most participants did not reach, bandwidth was also often inadequate and uploading failed. This later difficulty may be exacerbated by the rural Australian context of more erratic internet access than those in metropolitan areas. The development of a user-friendly system for uploading ACDs would negate the need for people to carry around a hard copy of their ACD and make access for health professionals easier and more predictable. It is recommended that the co-design of user-friendly technology for uploading ACDs to online medical records systems such as My Health Record, be urgently prioritised.

That more than half of those eligible declined to participate in the project, including access to one-on-one consultations about ACP, may reflect the reluctance of some people to face end-of-life discussions or to see the value of research participation during a stressful period of their life. Access to the one-on-one consultation was voluntary while the other component of consent involved approval to audit their medical records, so it is unlikely that time commitment was a barrier. This multifaceted project focused on engagement with those consenting to discussions with a nurse or social worker and education of key health professionals, but did not consider strategies for people not wishing to engage. While this was beyond the scope of this study, it is entirely possible that the far-reaching education programme with 600 local health professionals may enhance staff confidence and knowledge and, indirectly, influence ACP in those who did not consent to participate.

The focus of this project was on increasing the uptake of ACDs specifically in people facing the end of their life, so has limited generalisability to the wider population.

CONCLUSION

This project team was able to work one-on-one with people facing end-of-life decisions and to educate a broad range of health professionals across multiple sectors to increase completion of ACDs and reduce ICU admissions during the last 6 months of life for people facing a predictable death. Education videos and resources have been developed for the public and health professionals to support understanding around the role of ACDs and how they are completed. This paper aims to share the improvements from this initiative, beyond the rural local health district where the study was conducted. To ensure the benefits realised through this project, the team also recommends the appointment of a local health professional specialising in supporting people to complete ACDs.

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Contributors All authors contributed to the writing process. LDK, GW, TL, MH and DC developed the research proposal and protocol. MH, LDK, GM, BM, KB and AJ led data collection and analyses. Implementation of the intervention was led by DC, GM, BM and KB. LDK is the guarantor.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Consent obtained directly from patient(s).

Ethics approval This study involves human participants and was approved by Hunter New England Human Research Ethics Committee (2019/ETH11902). Participants gave informed consent to participate in the study before taking part.

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