



A cross-sectional study assessing concordance with advance care directives in a rural health district

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Abstract

Objective: To measure compliance with Advance Care Directives (ACDs) for decedents in a rural setting.

Design: Observational, cross-sectional medical records audit comparing requests in ACDs with actual outcomes.

Setting: Rural Australian coastal district.

Participants: People who had an ACD, died during the study period (30 May 2020 to 15 December 2021) and participated in a local research project.

Main Outcome Measure(s): Compliance was measured by comparing stated requests in the ACD with outcomes recorded in medical records. This included the place of death and a list of 'unacceptable interventions'.

Results: Sixty-eight people met the inclusion criteria (age range of 46–92 [mean 67 years; median 74 years]; 42 [62%] male). The main cause of death was cancer ($n = 48$; 71%). Preferred place of death was not stated in 16 ACDs. Compliance with documented preferred place of death was 63% (33/52): 48% (16/33) when the preferred place of death was home; 78% (7/9) when sub-acute was preferred; and 100% (10/10) when hospital was preferred. Compliance was 100% with 'unacceptable interventions'.

Conclusion: These results demonstrate strong compliance with rural patients' requests in ACDs, particularly 'unacceptable interventions'. Home was the most common preferred place of death, but the compliance measure (48%) was the lowest in this study. This requires further exploration.

KEYWORDS

advance care directive, end-of-life, palliative care, rural

1 | INTRODUCTION

Advance Care Planning (ACP) leading to the formulation of documented Advanced Care Directives (ACDs) is a

key strategy for people facing the end of their life to make informed choices about where and how they die, and to negotiate palliative care and End-of-Life Care (EOLC) options.¹ However, uptake of ACDs in rural Australia is

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appears to be low.² The rural Australian context presents its own problems, including the proportion of people over the age of 65 years is higher in rural areas, with this percentage estimated to increase in the future.³ Rural areas also have higher rates of some chronic illnesses and lower life expectancy,³ plus poorer access to end-of-life care (EOLC) than other Australians.⁴

The recently released National Consensus Statement for safe and high-quality end-of-life care in Australia (2023)^{1,5} provides evidence-based guiding principles and outlines essential elements for EOLC. The value and importance of ACP is highlighted throughout the Statement, not only for the individual but also the carers and healthcare personnel. Inevitably, barriers and enablers to ACP exist. From a healthcare staff perspective, barriers have included: a lack of knowledge, education and confidence in facilitating ACP conversations⁶⁻¹⁰; 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} In relation to enablers, one of the biggest predictors of having ACP was being asked by a healthcare professional to complete an ACD.⁹ In contrast, when staff are more confident with ACP, they are more likely to initiate conversations and integrate ACP into standard care, thereby enhancing patient uptake.¹¹ Early initiation of ACP discussions before individuals reach a crisis point in their terminal care, and having specialist ACP facilitators have been found to be important in reducing anxiety and stress for individuals, their carers and family and increasing ACD uptake.¹²⁻¹⁴ The role of ACDs appears to be two-way by providing a point of focus for ACP discussions while, once completed, demonstrating the individual's choices.

Studies of barriers and enablers have predominantly focused on metropolitan health services,^{15,16} with limited research in more resource-constrained rural environments. In response to these challenges and the release of a comprehensive examination of rural ACP issues,¹² a 3-year multi-site project was initiated. This project sought to reduce these barriers and increase the uptake and quality of ACDs by providing additional staff training, clinical governance, promotion and professional networking.

Results from the intervention (reported in another publication under review) illustrated a substantial increase in the proportion of people completing ACDs. This paper reports on the key indicators used to reflect a successful ACD, include the concordance between people's end-of-life wishes, actual place of death and medical interventions utilised.¹⁷

Although around 70% of Australians would prefer to die at home, only between 12% and 14% did so in 2015.¹⁸

What is already known on this subject?

- Studies generally concur that ACDs assist in helping patients to have their EOLC preferences met and that this is beneficial for the individual, their family/carers and the health service providers.
- The majority of work assessing the uptake of and concordance with ACDs has been conducted in urban areas, with little work in rural Australia.

What does this study add?

- This multifaceted approach to support the completion of ACDs may have been associated with: (a) the majority of participants dying in their preferred place of death, and; (b) full compliance with individuals' preferences in relation to the use of life-prolonging interventions.
- Increased attention to training health service staff in the use of ACDs has benefits for patients, families/carers and likely the health service.

Another two Australian metropolitan studies and a systematic review have estimated that around two-third of patients die at home when they state this as their preference and that this increases with staff training.^{16,19}

While more data are available on concordance with medical interventions, internationally this has ranged from a low of 14% through to 98% across nine studies.¹⁷ Importantly, preferences to withhold CPR and life-prolonging treatment are known to have higher levels of concordance than other requests, such as withholding antibiotics.²⁰ In dementia care settings, there is also a strong concordance between desired and actual care where ACP interventions took place.²¹⁻²³

As such, the aim of this study was to measure the concordance with ACDs for people who died in a rural setting in relation to place of death and medical interventions.

2 | METHODS

2.1 | Design

Observational, cross-sectional medical records audit comparing requests in ACDs with actual outcomes.

2.2 | Setting

The study was conducted in a rural Australian coastal district spread across 11 000 square kilometres and a population of 220 000 dispersed across Modified Monash Model (MMM) 3–5 areas.²⁴ Demographically, 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% across NSW and 17.2% nationally.²⁵ The district offers a range of services including acute hospital care, community services and palliative care.

2.3 | Participants

The measure of compliance with ACDs was determined post-mortem by assessing the records of those who had an ACD, died during the study period (30 May 2020 to 15 December 2021) and had provided informed consent to participate in a local research project to enhance ACD uptake. The inclusion criteria for the larger study from which these participants' results were extracted, were key groups within the general population who may benefit most from ACP, including people of any age who^{26–28}:

- were diagnosed with a life-limiting illness or disability; or
- had multiple comorbidities and are 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.

Participating health professionals were asked to consider the following factors in line with contemporary approaches,²⁹ which indicate that a person may benefit from ACP:

- 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 reaches or experiences a significant milestone, for example, advancing age (i.e. 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

- The person, family member or carer raises ACP with a health professional.

2.4 | Ethics

Informed, signed consent was required and ethics approval was obtained from the Hunter New England Local Health District Research Ethics Committee (Approval number 2019/ETH11902).

2.5 | Intervention

Field researchers consisting of clinical nurse consultants and a social worker, held education sessions focused on upskilling clinicians' knowledge and ways to integrate ACP into their routine practice. Over 600 clinicians attended these sessions including general practitioners, nurses, doctors and allied health representatives across hospitals and community settings. Education sessions were delivered both face-to-face and virtually during COVID-19.

All patients and family members referred to the project were offered face-to-face consultations about how ACDs could be used to support and discuss their end-of-life wishes. These discussions were conducted in patients' homes and in outpatient and inpatient settings, with home visits the most widely preferred option.

2.6 | Main outcome measure(s)

Compliance with the ACD was measured by estimating the number of outcomes recorded in medical records as a proportion of the participant's stated requests in the ACD. Variables for place of death were home, hospital, sub-acute care (palliative care and residential aged care) and unknown/not recorded. Participant requests for 'unacceptable interventions' were cardio-pulmonary resuscitation, artificial ventilation, renal dialysis and continuous drug infusions.

All ACDs were assessed independently for compliance post-mortem by three trained researchers, each with medical expertise. If there were discrepancies in the coding agreement, a confirmatory process between the researchers was used to determine the relevant coding to be applied. In addition, a randomly selected sub-sample of 10% of cases was quality assured by two alternate researchers to ensure the validity of results.

3 | RESULTS

Overall, 68 of 112 study participants died during the study period and were included in analyses. The age range was 46–92 (mean 67 years; median 74 years), with 42 (62%) identified as male. The most common cause of death was cancer ($n=48$; 71%). There were 10 deaths due to cardiac and/or chronic diseases (10%). Cause of death was unknown or not recorded in 10 cases (16%).

Preferred place of death was documented in the ACD in 52 of the 68 cases. When preferred place of death was recorded, the majority of participants documented 'home' (33/52; 63%) as their preferred place of death; 'hospital' was documented in 10 records (19%); and 'sub-acute/palliative care' was documented in nine records (17%). Overall compliance with preferred place of death was 63% (33/52), including 48% (16/33) when the preferred place of death was home, 78% (7/9) when sub-acute/palliative care was preferred and 100% (10/10) when hospital was preferred. Preferred place of death was not stated in 16 ACDs (Table 1).

The reasons for variance from preferred place of death when home was chosen were recorded as 'unable to support at home' (11/33; 33%), 'died before discharge' (3/33; 9%) and reason not stated (3/33; 9%). Twelve participants (36%) that chose home died in sub-acute/palliative care and five (15%) died in hospital.

All ACDs stated that cardio-pulmonary resuscitation, artificial ventilation, renal dialysis and continuous drug infusions were 'unacceptable'. Compliance was 100%, with no recorded cases of these interventions being used.

4 | DISCUSSION

In this cross-sectional medical record audit, the findings give confidence to people and their families/carers that completion of an ACD will assist in having their wishes for EOLC upheld. For this rural cohort, decedents predominantly were elderly, male and with a cancer diagnosis.

The finding that just under half of decedents (48%) who chose home as their place of death died at home has some worthwhile comparisons with other studies, and implications for EOLC home support planning. While place

of death has not been widely assessed, a 2020 Australian study suggested that around 70% of Australians would prefer to die at home.¹⁸ A recent study in two Australian metropolitan areas has indicated that 81% died in their preferred place. Of the 45% that sought to die at home, 62% did. Meanwhile, compliance for those wishing to die in hospital and aged care was 97% and 92% respectively.¹⁶ In our rural study, overall 63% of persons died in their preferred place. Close to 100% of decedents that stated a preference to die in hospital or in sub-acute/palliative care did, a figure commensurate with that outlined in the Saurman et al. study.¹⁶ However, the proportion of persons that wished to die at home (48%) was lower in this rural study than the metropolitan cohort (62%).¹⁶ Potentially underpinning this variation in home as the actual place of death is the issue that rural areas have less access to EOLC and specifically community-based care, than their metropolitan counterparts.⁴ Further, while personal choices can and do change over time relating to preferred place of death, it has been proposed that as an individual's health declines and death becomes more imminent, that enhanced medical support is sought.¹⁵ As such, some reduction in the proportion of those who state a preference initially to die at home and those who actually do is consistent across studies. This may be entirely appropriate as a person's condition deteriorates and they have the option of their needs being met in palliative or hospital ward environments. Notwithstanding this the variation between the overall metropolitan (81%) and rural (63%) preferences attained is considerable. This raises a question regarding unmet needs in rural areas and the provision of greater support for individuals, their carers and families in these later stages of EOLC, especially in regards to community-based assistance in the final stages of terminal illnesses.

The concordance with preferred medical interventions in the study was excellent. This is in keeping with the general direction of information available and specifically so in relation to cardio-pulmonary resuscitation.^{20–23}

Overall, the findings of this study have considerable implications for EOLC in rural Australia and more broadly nationally. As described the study area currently has 26.7% of the population aged 65 years and older.²⁵ Meanwhile, by the year 2050, it is predicted that Australia

Place of death	Documented preference (n)	Number who died in preferred place (n)	Concordance (%)
Home	33	16	48
Hospital	10	10	100
Sub-acute	9	7	87
Total	52	33	63

TABLE 1 Preferred place of death when stated in ACD versus actual place of death from medical records.

will have around 23% of its total population in this age cohort (currently 17.2%).^{25,30} Consequently, demographically this region provides a snapshot to examine future issues that may arise not only in rural areas but also nationally for effective and efficient EOLC as the population ages, with ACP an important component.

All health services are stretched in terms of both capacity and financing; however, there has been a particular emphasis on limitations within rural areas for some time.³¹ Assessing EOLC on the basis of cost benefit has been highlighted as a potentially ethical dilemma.³² However, both international and Australian studies suggest that ACP leading to care that is concordant with an individual's preferences, not only minimises negative issues for individuals, families and carers at end-of-life but also reduces health service costs.^{18,32,33} Within resource constrained rural environments, such issues are essential to consider. As illustrated in this study, there is potential for greater extension of community-based services to further enhance meeting preferences for place of death. In addition, the data suggest that specific ACP training initiatives for health staff can assist individuals in meeting intentions for both preferred place of death and medical interventions.

4.1 | Strengths and limitations

A strength of this study is its rural geographical location, as there are little data available in this context. However, the study area is just one rural region within NSW and may not adequately represent other rural localities due to variations in demographics, health service capacity and locally available resources. It is also possible for some bias to be present with the analyses of the medical records being undertaken by the team that was also responsible for the education sessions with health service personnel underpinning study. While noting these analyses were undertaken independently, plus the objective measures used and the inclusion of quality control checks on the data, bias may still be present. There are also known limitations of medical record audits;³⁴ however, the high-level medical interventions used as variables in the assessment are very likely to be included in the medical record.

The relatively small cohort of decedents and lack of a control group also limit the interpretations and generalisability that can be made. While the original study design included a control group located within another rural Local Health District of NSW, organisational issues compounded by Covid-19, meant that this arm of the study did not proceed. Furthermore, while no direct measures of the impact of education sessions on health service staff has

been undertaken, the outcome indicators (concordance with 'place of death' and 'unacceptable interventions') was high. This is suggestive of the value of the education sessions and their positive influence on ACD completion and compliance. It would be worthwhile to delve more deeply into the impact of the intervention, particularly education sessions, but this was beyond the resources of this study.

Future studies should seek to ensure that a control group is present and that direct quantification of the fidelity, completeness and impacts of training health service personnel are included. Given the relatively high staff turnover reported in many rural health services,^{35,36} steps to assess the longevity of the effects of such training and/or supplementary booster training may be required moving forward.

From a policy perspective, the findings of this study are in accordance with the bulk of literature in suggesting that improving the skills of health service staff to be involved in ACP discussions has direct benefits for the individual, their carers and family.⁵ This also aligns with a report prepared for the Australian Commission on Safety and Quality in Health Care relating to end-of-life care, which included recommendations to structured approaches to ACP and the need for ongoing support of healthcare professionals providing end-of-life care in all settings and the newly released Consensus Statement for safe and high-quality end-of-life care.^{1,5}

5 | CONCLUSION

This rural cross-sectional study supports the proposition this multi-faceted intervention can be important in meeting EOLC needs. Overall, there was moderately high concordance with preferred place of death and excellent compliance with the individuals wishes in regard to life-sustaining medical interventions. This is particularly important in a resource-constrained rural health context. The findings for this cohort, reinforce that individuals and their families/carers, can have confidence that completion of an ACD will assist in having their wishes for EOLC upheld.

AUTHOR CONTRIBUTIONS

Dan Curley: Conceptualization; methodology; investigation; writing – review and editing; supervision; funding acquisition; project administration. **Leigh Kinsman:** Conceptualization; methodology; investigation; validation; formal analysis; supervision; project administration; funding acquisition; writing – original draft; writing – review and editing. **Graeme Mooney:** Methodology; data curation; investigation; validation; writing – review

and editing. **Gail Whiteford:** Conceptualization; methodology; investigation; validation; supervision; funding acquisition; project administration; writing – review and editing. **Tony Lower:** Conceptualization; methodology; supervision; funding acquisition; project administration; writing – review and editing; writing – original draft. **Megan Hobbs:** Conceptualization; methodology; data curation; investigation; validation; formal analysis; supervision; funding acquisition; project administration; writing – review and editing. **Beverley Morris:** Methodology; data curation; investigation; formal analysis; validation; project administration; writing – review and editing. **Kerry Bartlett:** Methodology; data curation; investigation; validation; project administration; writing – review and editing. **Alycia Jacob:** Methodology; data curation; investigation; validation; supervision; writing – review and editing.

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CONFLICT OF INTEREST STATEMENT

The authors declare they have no competing interests.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

Ethics approval was obtained from the Hunter New England Human Research Ethics Committee (2019/ETH11902).

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