Communication of advance care planning decisions: a retrospective cohort study of documents in general practice

CURRENT STATUS: UNDER REVIEW

BMC Palliative Care

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DOI:
10.21203/rs.2.24056/v1

SUBJECT AREAS
Anesthesiology & Pain Medicine

KEYWORDS
Advance care planning, End-of-life care, Palliative medicine, General practice
Abstract
Background Doctors, particularly general practitioners, play a significant role in assisting patients to create advance care plans. These documents are important tools to ensure that the end-of-life care a patient receives is in alignment with their personal preferences. Despite this, little is known regarding the availability of these documents in hospitals. The aim of this study was to identify the proportion of people who died in hospital without an advance care plan and how many of these had advance care planning (ACP) documents in their general practice records.

Methods A retrospective cohort study was conducted of patient hospital records in a large regional Australian hospital with a catchment population in excess of 300,000. The study sample was patients aged 75 years and over who died in the hospital between 1 January 2016 and 31 December 2017. The hospital records of these patients were examined to identify those which did not have a system alert for ACP documents on the file. Alerted ACP documents were limited to those legislated in the state of Victoria: advance care plan, Enduring Power of Attorney (Medical Treatment) or Enduring Power of Guardianship. Where no ACP document system alert was found in the hospital record, the corresponding general practice file was examined. Data were tested for normality and analysed using descriptive statistics.

Results Of the 406 patients who died in hospital, 76.1% (309) did not have a system alert for any ACP document. 144 corresponding general practice records of the 309 hospital files without a system alert were examined. Of these, 14.6% included at least one ACP document, and four patients had an advance care plan that was not available in hospital.

Conclusions Unless ACP documents are consistently communicated from general practice, advance care plans may go unreferenced during end-of-life care. It is important that both doctors and patients are supported to use connected electronic health records to ensure that documents are readily available to healthcare staff when they are required.

Background
Education campaigns have aimed to increase both the awareness and prevalence of advance care planning (ACP) documents. (1, 2) Health practitioners have become more confident in their ability to
use these documents to ensure that patients’ wishes are fulfilled during end-of-life care. (3) In Australia, ACP documents primarily include an advance care plan as a written statement of preferences or a document formally appointing a substitute decision maker; however, the specific terminology varies across state jurisdictions. (4, 5) These documents play a particularly important role when a patient has lost decision making capacity and can no longer communicate for themselves. (6) Ensuring a patient’s wishes are fulfilled is the most common priority for health practitioners during end-of-life care. (3)

The importance of general practitioners in guiding patients’ ACP is well documented. (4, 7) There are many studies examining how the uptake of ACP in general practice can be promoted, (7, 8) but little is known about how (if at all) these documents are communicated across the healthcare system for use during end-of-life care. (9) Literature supports ACP documents being created with the assistance of health practitioners. Historically, legal representatives have been involved in the development of substitute decision maker documents. (10)

For people who died in high-income countries between 2010-15, (11) 47-60% died within the acute hospital setting. (12-14) In 2017, there was a discrepancy between the proportion of Australians who preferred die at home (70%), and the number who actually did so (50%). (15, 16) Identifying temporal trends in these data is complicated by both a paucity of population-level data around patient preferences, and the concept that such preferences can change over time. Location of death is unpredictable, so general practitioners remain central to ensuring advance care plans and end-of-life care is aligned with patient preferences where medically indicated and appropriate. Given that many patients die in hospital, to ensure patient preferences are met during end-of-life care, ACP documents must be readily available and communicated both between, and within, healthcare services.

Internationally, various legal rulings, legislations and guidelines outline how ACP is incorporated into medical practice. (10, 17-22) In Australia, the Victorian state law outlines that health practitioners
must make a *reasonable effort* to determine the existence of an advance care plan. (4) While the creation of advance care plans is well documented, there is a dearth of literature analysing the communication of documents between parts of the healthcare system. Research concludes that a formal pathway is not often followed, leading to uncertainty as to whether advance care plans that are made in general practice are accessible to hospital staff. (23)

The importance of ACP document communication has been supported by a High Court ruling in the United Kingdom (UK), determining that all general practitioners must communicate any ACP documents to another treating healthcare service. (24) National registries and health records, such as the National Health Service Digital (NHS Digital) in the UK or My Health Record in Australia, may assist in bridging this gap in communication (25, 26) but as at December 2019, the number of ACP documents uploaded to these platforms was 0.11%. (27) While many countries are transitioning to electronic health records, these are not necessarily accessible to hospital staff. Within countries, there are inconsistencies in where ACP documents are stored within electronic health records. (28, 29) Electronic record system alerts can be used to inform hospital staff that a patient file includes an ACP document. Defining this ‘missing link’ in the ACP process may assist in more people’s preferences being known and respected during end-of-life care.

The aim of this study was to 1) identify the proportion of patients who died in a regional hospital without an ACP document system alert, and 2) determine whether these patients had an uncommunicated ACP document(s) remaining in their corresponding general practice record. The findings of this study will support policymakers seeking to identify strategies to improve the communication of ACP documents across health services and ensure that patients’ preferences are respected during their end-of-life care.

**Methods**

**Study design and participants**

A retrospective cohort study of decedents’ hospital and linked general practice records was
conducted. This study was based in one large regional public hospital in Victoria, Australia and 35 general practices in the immediate surrounding local government area (LGA). The hospital services a population of over 300,000 people across 58,986 km². (30)

The study sample was patients aged 75 years and over who died in the hospital between 1 January 2016 and 31 December 2017. For the assessment of linked general practice records, only those who died within the immediate surrounding LGA were included. The Australian Government Productivity Commission mandates that ACP form part of the general practice Medicare Health Assessment for Older Persons (75 and over), thus forming the rationale for the inclusion of the cohort age group and general practices. (31) This Health Assessment is only applicable to individuals aged over 75 years who lived at home. (32) ACP documents were limited to those legislated in the state of Victoria: advance care plan, Enduring Power of Attorney (Medical Treatment) or Enduring Power of Guardianship. (33)

The presence of ACP documents in hospital medical records was assessed via the ACP system alert on the record. The general practice of decedents, who had lived in the immediate surrounding LGA, was noted. Thirty-five local general practice clinics were identified and invited to participate in the study via email and/or phone call to their respective Practice Managers. This invitation was followed by a hand-delivered explanatory statement and consent form. In addition, the lead researcher met with a senior general practitioner from each clinic to explain the study. General practice clinics that had closed or changed owners were excluded as these decedents’ records were no longer accessible. Manual record linkage occurred via the decedent’s name and date of birth, with ACP document data then extracted.

Data collection tool and extraction

Data analysis
Following cleaning, the data were tested for normality using the Shapiro-Wilk test. (38) Non-normal data were presented as medians with inter-quartile ranges. Frequencies and corresponding percentages are reported for categorical data. Data were analysed using Statistical Package for Social Sciences (SPSS) for analysis. (39)

Results
Of the 406 hospital decedents, 309 (76.1%) died in hospital without an ACP document system alert on their hospital record (see Figure 1).

Of the 35 general practices invited to participate, 17 (48.6%) consented and 15 (42.9%) declined to participate. Two general practice clinics no longer existed, and one other had changed ownership which resulted in the current practice not having access to previous patient records. Decedent numbers ranged from 3-21 per practice. This led to 144 (46.6%) decedent hospital and general practice records being linked.

The characteristics of general practice decedents are outlined in Table 1. Most decedents were aged 80 years or older. The median time the decedent had attended their nominated general practice clinic was 7.3 years (IQR=2.0-16.3). One in five of decedents lived in a RACF prior to death in hospital. The remainder were home residents and would have been eligible for a Medicare Health Assessment for Older Persons (75 and over) prior to their death. Of those who were eligible, half had participated in one of these health assessments.

Of the 144 general practice records, 21 (14.6%) contained at least one ACP document that had not been communicated to the study hospital. Of these records, 14 (66.7%) had only one document, either an Enduring Power of Attorney (Medical Treatment) (n=11) or an Enduring Power of Guardianship (n=3). Four (19.0%) records included two ACP documents; two (9.5%) included three documents. Of the four decedents with a written advance care plan, each had an Enduring Power of
Attorney (Medical Treatment). Two of these also had an Enduring Power of Guardianship. Most ACP documents were made with the assistance of a lawyer or at their respective general practice. The median time from an ACP document being made to death was 2.5 years (IQR=0.5-4.9).

Discussion
To our knowledge, this is the first Australian study to examine the communication of ACP documents from general practice to a hospital. We found most decedents (76.1%) did not have an ACP document system alert in their hospital record. 14.6% of these patients had ACP documents in their general practice records that were not communicated to the hospital nor alerted in their hospital record. This means these documents were unavailable to be used during end-of-life care.

Previous research has highlighted a discordance between the creation, communication and availability of ACP documents. A 2015 systematic review reported 21-53% of patients had completed an advance care plan but between 1-44% of these were available in ED records. (9) Our study only included decedent records; arguably those who we would expect to have the highest rates of ACP completion and availability during end-of-life care. In Australia, there are numerous estimates (14-29%) (35, 40) of completion of ACP in a range of population groups and the prevalence of ACP in hospital patients is approximately 16%. (41)

General practitioners spend time and effort creating ACP documents, despite limitations in remuneration for their time. (42) This workload should be reflected in accessible documents that hospital staff can use to enhance the quality of their patient’s end-of-life care.

Without a sustainable approach to the communication of advance care plans from general practice to hospital, these documents may go unreferenced when clinically required if a patient loses decision making capacity. Although electronic, shared patient records can play a part in facilitating document communication to a hospital service, utilisation and access to these records in general practice and
hospitals is not consistent and it continues to face considerable public resistance regarding information sharing and safety. (43-45) In Australia, an amendment to the My Health Records Act 2012 allows ACP documents to be uploaded by doctors on behalf of patients. (46) This may alleviate a barrier to uploading documents for older people as this age bracket is known to have poorer computer literacy than their younger counterparts. (47) As noted earlier, only 0.11% of My Health Record accounts contain an ACP document and not all hospitals can access these records in the acute setting. (27) Though accessibility will improve in time, the issues of communication and the implications of this persist.

In Australia, general practice and hospital records are not electronically linked. The current methods of communicating ACP documents from general practice to hospitals (for example, facsimile, email, postal services and, in some rural areas, manual collection) are not sustainable. (23) Concerns regarding the confidentiality of these records continue and in Australia, facsimile technology is being phased out of healthcare settings. (48) In locations where both the general practice and hospital(s) staff can access electronic health records, such as My Health Record, this mode of communication should be encouraged. Where these are not accessible, other methods need to be utilised. In rural areas, the local hospital is often the only provider of acute healthcare so it may be efficient to extend the use of existing electronic referral software to transmit ACP documents. (23) In metropolitan areas, patients may attend any number of hospitals so My Health Record could improve document availability for patients and doctors.

This study had limitations. It was based in a single regional Australian public hospital and surrounding general practices, so the results may not be generalisable to other healthcare systems or metropolitan settings where patients may attend one of many hospitals. It was beyond the scope of the study to manually check all 409 decedents’ hospital records for documents so there may have been some ACP documents in the hospital records that were not included on the hospital alert system. Due to the low prevalence of ACP documents, we were unable to determine whether an
association between a Medicare Health Assessment for Older Persons (75 and over) and ACP document creation exists. We only included ACP documents found in general practice records and did not examine RACF records. Although some RACFs have a protocol that a patient’s record be copied when they are transferred to hospital, the presumption that RACFs send ACP documents with the patient may not be actuated. (49) Further research is needed to identify the prevalence of ACP documents remaining in RACF records.

Conclusions
General practitioners commit time and resources to ensure their patients’ end-of-life care wishes are documented. We found most (76.1%) hospital decedents did not have an ACP document system alert and a further 14.6% of these had ACP documents that remain in general practice that were unavailable for use during end-of-life care.

Electronic health record systems may be a long-term solution to the inconsistent communication of ACP documents from general practice to a hospital service. In the short-term, alternative methods of communication are needed to ensure health professionals are aware of documents, and where medically indicated, can respect patients’ wishes during end-of-life care.

Abbreviations
ACP: advance care planning
LGA: local government area
NHS Digital: National Health Service Digital
RACF: residential aged care facility
UK: United Kingdom

Declarations
Ethics approval & consent to participate
Ethical approval was granted by Monash University (reference: 12314) and the study hospital (reference: LNR/17/BHCG/63) Human Research Ethics Committees. Consent was granted by a representative of each of the participating general practices. A waiver of consent was granted by the
ethics committee so that decedents’ medical records could be examined.

Consent for publication
Publication consent was granted by the study hospital.

Availability of data & material
An anonymised form of the dataset used in this study is available from the corresponding author upon request.

Competing interest
No author has declared any competing interests.

Funding
This work has been supported by Better Safer Care Victoria. The funder has no role in the study design; data collection or analysis; article writing nor decision to submit this article for publication.

Authors’ contributions
All authors (LP, PH, MJA, DOC, BW) were involved in the project conception. LP created the data collection tool, recruited general practices for participation and collected all data from the records. LP, BW and PH performed data analysis. LP drafted the initial manuscript. The final draft was reviewed by all authors (LP, PH, MJA, DOC, BW).
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Table 1
Table 1 Characteristics of General Practice Decedents

|                               | n=144          |
|-------------------------------|----------------|
| Gender, n (%)                 |                |
| Female                        | 63 (43.8)      |
| Male                          | 81 (56.2)      |
| Age (years), median (IQR)     | 84.9 (81.0 – 89.4) |
| RACF resident                 |                |
| Yes                           | 31 (21.5)      |
| No                            | 103 (71.5)     |
| Unknown                       | 10 (7.0)       |
| Length of general practice enrolment (years), median (IQR) | 7.3 (2.0 – 16.3) |
| Medicare Health Assessment for Older Persons (75 and over)* |                |
| Yes                           | 51 (49.5)      |
| No                            | 49 (47.6)      |
| Unknown                       | 3 (2.9)        |
| Time between final Health Assessment and death (years)*, median (IQR) | 1.0 (0.5 – 1.9) |
| Time between ACP document creation and death (years)†, median (IQR) | 2.5 (0.5 – 4.9) |

*Only applies to decedents who lived at home prior to hospital admission
†Only applies to decedents with an ACP document in their general practice record
Some percentages may not add up to 100% due to rounding

RACF, residential aged care facility; IQR, interquartile range; Health Assessment, Medicare Health Assessment for Older Persons (75 and over); ACP, advance care planning.

Figures
Figure 1 Decedent record analysis

Patients ≥75 years who died in study hospital
1 Jan 2016 – 31 Dec 2017
n=406

No hospital ACP system alert
n=309

Hospital ACP system alert present
n=97

Excluded: general practice record not available/ consent not obtained
n=165

Linked general practice records audited
n=144

ACP, advance care planning