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# Advance care planning participation by people with dementia: a cross-sectional survey and medical record audit

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## ABSTRACT

**Objectives** To describe among individuals with dementia: (1) self-reported awareness of, and engagement in, advance care planning; (2) presence of advance care planning documentation in the health record and (3) concordance between self-reported completion of advance care planning and presence of documentation in the health record.

**Methods** An Australian prospective multicentre audit and cross-sectional survey. Individuals diagnosed with dementia who were able to speak English and were judged by a healthcare provider as having decision-making capacity were recruited from self-selected hospitals, residential aged care facilities and general practices across Australia.

**Results** Fifty-two people with dementia completed surveys and were included. Overall, 59.6% of participants had heard about advance care planning and 55.8% had discussed advance care planning with someone, most often a family member (48.1%). While 38.5% of participants had appointed a medical substitute decision maker, only 26.9% reported that they had written down their values and preferences for future care. Concordance between self-reported completion of advance care planning and presence of documentation in the health record was low (56.8%,  $\kappa=0.139$ ; 57.7%,  $\kappa=0.053$ ).

**Conclusion** Effective models that promote discussion, documentation and accessible storage of advance care planning documents for people with dementia are needed.

## BACKGROUND

Dementia is a progressive irreversible condition characterised by impairments in memory, reasoning and communication skills that compromise decision-making capacity. Family or other informal carers

are often required to inform or make complex health decisions on behalf of a person with dementia. However, carers may be unaware of the preferences of the person with dementia.<sup>1</sup> To promote the delivery of person-centred dementia care, the participation of people with dementia in advance care planning is recommended.<sup>2</sup>

Advance care planning is an ongoing process ‘that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care’.<sup>3</sup> It can include discussions about values and preferences with loved ones, healthcare providers, or the completion of written documents recording preferences or appointing a medical substitute decision maker. Advance care planning can improve communication between patients (while they retain capacity), carers and healthcare providers, and improve concordance between preferred and actual care.<sup>4</sup>

Despite widespread recognition of the importance of advance care planning for people with dementia, few studies have examined their levels of engagement in advance care planning. Rates of engagement vary widely from 5.2% to 92% among individuals with dementia living in the community<sup>5,6</sup> and up to 66% among those residing in residential aged care facilities.<sup>7</sup> These discrepant findings highlight the need for further information about the participation of people with dementia in advance care planning across different contexts.

To fully realise the benefits of advance care planning, ideally an advance care directive containing written values or

instructions should be available at the point of care to inform decision making.<sup>8</sup> In a recent study of older Australians, while 54% self-reported completion of documentation, only 48% had documentation in their health record.<sup>8</sup> No previous studies have examined concordance between self-reported advance care planning and the presence of advance care directives at the place of medical care among people with dementia. These data are critical to identify gaps in care with regard to the acceptability and feasibility of advance care planning engagement for Australians with dementia.

### Aims

To describe among individuals with dementia:

1. Self-reported awareness of, and engagement in, advance care planning.
2. Presence of advance care planning documentation in the health record.
3. Concordance between self-reported completion of advance care planning documentation with the presence of documentation in the health record.

### METHODS

This study is part of a larger study describing the prevalence of advance care planning in selected hospitals, residential aged care facilities and general practices. The protocol and full results are published elsewhere.<sup>8–10</sup> This study focused on individuals with dementia.

### Design and setting

A multicentre audit of facility-held health records and a cross-sectional survey.

### Participant eligibility

#### Audit

Individuals aged  $\geq 65$  years ( $\geq 50$  years Aboriginal or Torres Strait Islander people). Participants from hospitals and aged care facilities needed to be admitted for  $\geq 48$  hours prior to the audit and were randomly selected for participation. In general practice, consecutive patients visiting on the day(s) of the audit were included.

#### Survey

Individuals whose records were audited and they spoke English, had decision-making capacity (judged by a healthcare provider) and were not too unwell or expected to die  $< 24$  hours.

### Data collection

Data were collected between September 2017 and January 2018.

#### Audit

A trained auditor examined paper or electronic health records at each facility. Demographic and clinical

information, including a dementia diagnosis, was extracted from records.

#### Survey

Participants who provided written consent completed either an electronic survey on a touchscreen computer or a pen-and-paper survey.

### Measures

#### Audit

An individual was deemed to have completed advance care planning if the auditor found in their health record within 15 min (1) an advance care directive recording preferences for care; (2) an advance care directive appointing a substitute decision maker or (3) any other documentation written by the person about their preferences for medical care.<sup>8</sup>

#### Survey

Participants provided responses to demographic questions. Participants were asked about their awareness of advance care planning; whether they had discussed advance care planning; whether they had written down their goals, values, beliefs or preferences (and if so, where this document was kept); and whether they had signed a legal document to appoint a substitute decision maker.

### Statistical analysis

Analyses were conducted in SPSS Version 25 (IBM). Descriptive statistics were used to present demographic characteristics using counts and percentages. Chi-square tests were used to determine differences between survey completers and non-completers. Concordance between advance care planning documentation by self-report and identification in health records was determined through calculation of Cohen's  $\kappa$  and prevalence-adjusted bias-adjusted  $\kappa$ . For self-reported advance care planning documentation, the response 'I don't know' was coded as 'No'.

### RESULTS

Of 2285 records audited, 719 people had dementia. Of these, 579 (80.5%) were not eligible to participate in the survey, primarily as they lacked decision-making capacity ( $n=575$ ). Of those eligible, 52 consented to survey participation (37%). Survey completers were significantly more likely to reside in Victoria than non-completers ( $p \leq 0.001$ ). There were no statistically significant differences in survey completion with regards to age, gender or setting of recruitment. The online supplemental file 1 presents the sociodemographic characteristics of the sample. The average age of participants was 81.8 years, and 92% of participants resided in aged care facilities.

Table 1 provides data about participation in advance care planning. Overall, 31 participants (59.6%) had heard about advance care planning. Twenty-nine

**Table 1** Engagement in advance care planning (N=52)

	n (%)
Ever discussed advance care planning	
Yes	29 (55.8)
Family member*	25 (48.1)
Friend*	2 (3.8)
Doctor or nurse*	5 (9.6)
Other*	2 (3.8)
No	13 (25.0)
Cannot remember	10 (19.2)
Completion of advance care planning documentation—goals, values, beliefs and preferences for care	
Yes	14 (26.9)
No	20 (38.5)
Cannot remember	17 (32.7)
No response	1 (1.9)
Completion of advance care planning documentation—legal document appointing a substitute decision maker	
Yes	20 (38.5)
No	15 (28.8)
Cannot remember	17 (32.7)

\*Participants could select more than one response. Totals, therefore, do not sum to 29.

participants (55.8%) had discussed advance care planning with someone, most often family (48.1%). Fourteen (26.9%) participants reported writing down goals, values and beliefs, and 20 (38.5%) reported appointing a substitute decision maker.

Advance care planning documentation was located in the health records of 20 (38.5%) survey participants (table 2). Concordance between self-reported and audit-identified advance care planning was low (56.8%,  $\kappa=0.139$ , PABAK 0.154; and 57.7%,  $\kappa=0.053$ , PABAK 0.154). Of 24 people who self-reported documentation, 11 (46%) had documentation in their record. Nine participants (17.3%) who reported not completing advance care planning documentation had documentation in their health record.

## DISCUSSION

Overall, 40% of participants had not heard of advance care planning. Lack of awareness and knowledge is a common barrier to advance care planning for people with dementia and older adults generally.<sup>11</sup> As individuals with dementia may have a shorter time frame for meaningful advance care planning engagement, this is an important gap in dementia care.

Higher rates of self-reported discussion about advance care planning with family compared with health professionals are consistent with the existing literature.<sup>12</sup> However, only 38.5% of participants had advance care planning documentation in their health records. This is higher than the 29.8% reported in the larger multicentre audit of older adults from which this sample is drawn.<sup>9</sup> This may reflect the significant proportion of our sample from aged care facilities, where advance care planning is increasingly promoted at admission.<sup>13</sup> However, this rate is lower than the larger cohort (n=719) of persons with dementia from which our sample is drawn, which found 46.9% had one or more advance care directives.<sup>14</sup> Given the high risk that people with dementia will lose decision-making capacity, approaches to improve advance care planning uptake are essential. Early initiation of advance care planning, education/training for healthcare providers, and adoption of shared decision-making and case-management approaches are advocated to overcome the challenges of implementing advance care planning with people with dementia.<sup>2 11</sup>

Concordance between self-reported completion of advance care planning and documentation in facility records was low (57%), and slightly lower than the overall concordance rate reported for older adults without dementia (64%), and for participants from aged care facilities (66%) in the larger study sample.<sup>8</sup> This is not unexpected, given that our sample included individuals experiencing cognitive decline. Interestingly, a similar number of participants in both samples who reported not completing advance care planning had documentation in their record. Initiatives that promote a systematic

**Table 2** Concordance between self-reported completion of advance care planning documentation, self-reported storage of advance care planning documentation at the current point of care and identification of advance care planning documentation in the health record

Advance care planning documentation identified in health record, n (%)							
	Yes	No	Total	Concordance (%)	$\kappa$	PABAK	P value
Self-reported completion of advance care planning documentation							
Yes	11 (21.2)	13 (25.0)	24 (46.2)	56.8	0.139	0.154	0.312
No	9 (17.3)	19 (35.6)	28 (53.8)				
Total	20 (38.5)	32 (61.5)	52 (100.0)				
Self-reported storage of advance care planning documentation at current point of care							
Yes	6 (11.5)	8 (15.4)	14 (26.9)	57.7	0.053	0.154	0.693
No	14 (26.9)	24 (46.2)	38 (73.1)				
Total	20 (38.5)	32 (61.5)	52 (100.0)				
PABAK, prevalence-adjusted bias-adjusted kappa.							

PABAK, prevalence-adjusted bias-adjusted kappa.

approach to preparing and storing advance care planning documents that are accessible and can be shared across healthcare sectors are needed.<sup>8</sup>

### Limitations

Study findings should be considered in light of several limitations. The sample was small, primarily comprised residents of residential facilities, and participants without decision-making capacity were excluded, limiting the generalisability of findings. As residents of aged care facilities are more likely to have engaged in advance care planning than community-dwelling older adults,<sup>9</sup> our data likely do not provide an accurate estimate of the prevalence of advance care planning by community-dwelling people with dementia. The sample also primarily comprised women (71%) and 65.4% of participants were from one Australian state. While the small sample size precluded examination of sociodemographic differences in engagement in advance care planning or concordance, other research has found that women are more likely to formally appoint someone to make medical decisions on their behalf<sup>15</sup> and that engagement in advance care planning varies by state.<sup>9</sup>

### CONCLUSIONS

Given individuals with dementia experience cognitive decline leading to an eventual loss of decision-making capacity, effective models that promote discussion, documentation and accessible storage of advance care planning documents for people with dementia are needed.

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