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Inadequate completion of advance care directives by individuals with dementia: national audit of health and aged care facilities

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ABSTRACT

Objectives (i) Describe the prevalence and type of advance care directives (ACDs) and other advance care planning (ACP) documentation completed by persons with dementia, healthcare providers and others on behalf of a person with dementia; (ii) identify the personal and ACP programme characteristics associated with having ACP documentation in the health record; (iii) identify the personal and ACP programme characteristics associated with having a self-completed ACD.

Methods A multicentre audit was undertaken in Australian hospitals, general practices and residential aged care facilities. Auditors extracted demographic and ACP data from the records of eligible patients. ACP programme characteristics were provided by a site representative. Logistic and multinomial regression were used respectively to examine the factors associated with completion of any ACP documentation, and self-completion of an ACD by persons with dementia.

Results A total of 1388 people with dementia (33.2%) from 96 sites were included. Overall, 60.8% (n=844) had ACP documentation; 31.6% (n=438) had a self-completed ACD and 29.3% (n=406) had an ACP document completed by a health professional or someone else on their behalf. Older participants were more likely to have ACP documented. Multivariate analyses indicated the odds of having self-completed ACP documents, compared with no advance care plan or ACP completed by someone else, were significantly influenced by age, country of birth, setting and whether the site had ACP training, policies or guidelines.

Discussion While 60% of people with dementia had some form of ACP documentation, only half of the cases in which ACP was documented included an ACD completed by the person themselves.

INTRODUCTION

Dementia is a neurodegenerative condition characterised by the progressive deterioration of memory, thinking, behaviour and the ability to perform activities of daily living.¹ One-third of older people will die from dementia, with residential aged care facilities (RACFs) the most common site of death.² There is increasing evidence that people with dementia face significant challenges in accessing appropriate end of life care. For people with dementia, the last year of life is often characterised by pain, agitation, pressure ulcers and pneumonia; limited access to palliative care services; and receipt of potentially futile treatments.²⁻⁵ As dementia progresses, a person's capacity to independently make and communicate decisions deteriorates, and decisions will then often require the involvement family members or carers,² who may be uncertain about the preferences of their loved one.⁶ Improving the quality of end-of-life care provided to people with dementia is a recognised priority worldwide.^{7 8}

Advance care planning (ACP) is a process whereby an individual considers and discusses their values and preferences about future healthcare, in case they later experience periodic, temporary or permanent loss of capacity.⁹ ACP is widely recognised as a key mechanism for improving the quality of care delivered to people with dementia.¹⁰⁻¹² ACP has been associated with significant reductions in rates of hospitalisation and increased use of hospice services among those with dementia,¹³ as well as reduced stress, anxiety, and depression in surviving relatives in general medical settings.¹⁴ In



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Australia, ACP discussions may lead to the completion of an advance care directive (ACD), a written document recognised by common law or legislation.¹⁵ ACDs enable a person to give instructions about their preferences regarding future care and/or appoint a substitute decision maker (SDM) to make decisions on their behalf when they are unable to do so themselves. In addition to ACDs completed by the person, in some situations ACP documents may be completed on the person's behalf due to a temporary or ongoing loss of decision-making capacity. This may be by a member of the person's family or a healthcare professional involved in the person's care—such ACP documents are not considered legally binding, but can be helpful in guiding clinicians when making treatment decisions.¹⁶

Given the unpredictable trajectory of dementia and cognitive decline, it is important that people with dementia are engaged in ACP as early as possible to ensure they can be meaningfully involved in decision making. However, it is estimated that less than 40% of people with dementia undertake ACP internationally.^{6 17 18} Factors contributing to the low uptake of ACP among people with dementia remain unclear. Different factors are associated with completion of ACDs regarding preferences for future care or nomination of SDMs, suggesting there may be differences in the types of people that complete different types of ACDs and their motivations for doing so.¹⁹ In studies of people with cognitive impairments, rates of engagement in ACP are higher among those with milder cognitive impairment,²⁰ higher levels of education²⁰ and those diagnosed at a younger age.¹⁷ These findings suggest that encouraging ACP during the early stages of dementia may enable participation prior to significant declines in cognitive function. However, qualitative studies have shown that responses to a dementia diagnosis differ, with some preferring to maintain a focus on the present and avoid thinking about the future.^{21 22}

A number of healthcare professional and health service factors have also been shown to influence ACP uptake.¹⁹ Healthcare professionals may be reluctant to initiate ACP discussions with a person with dementia due to concerns about the person's decision-making capacity, especially if they feel under-prepared or under-trained to have these complex discussions.^{23–25} Even those who accept responsibility for initiating ACP discussions may be uncertain about when to initiate them, or lack time or resources to do so.^{23–25} Health service, organisation and system-wide factors, such as complexity and variation in legislation across jurisdictions, also influence ACP uptake. State-specific statutory legislation supporting ACDs result in different procedural requirements, with some states relying on non-statutory ACDs under common law precedent. This can create uncertainty and confusion about the requirements of ACP, its legal force, and the role of

appointed SDMs.²³ Dedicated organisational policies and procedures regarding ACP documentation, and systematic processes to ensure documented plans can be retrieved, have been shown to support implementation of ACP.²³

Given these unique complexities associated with ACP in dementia care, it is important to understand participation in the ACP process by people with dementia, their family members or SDMs, and health professionals involved in their care. Greater understanding of participation of persons with dementia in ACP, and the personal and ACP programme characteristics associated with ACD completion, can help identify those most at risk of not being involved in ACP decisions.

Therefore, the aims of this study were to:

1. Describe the prevalence and type of ACDs and ACP documentation completed by (i) persons with dementia, (ii) healthcare providers and (iii) family, carers or someone else on behalf of a person with dementia.
2. Identify the personal and ACP programme characteristics associated with people with dementia having any ACP documentation identified in their health record.
3. Identify the personal and ACP programme characteristics associated with people with dementia having a self-completed ACD.

METHODS

Design

As part of an Australia-wide study to describe the prevalence of ACD and ACP documentation across health and aged care settings,^{26–28} a prospective multicentre audit was undertaken. This paper reports a secondary analysis of data presenting the findings of individuals with a diagnosis of dementia.

Setting

Hospitals, general practices (GPs) and RACFs located in all eight Australian states and territories.

Site recruitment, eligibility and data collection

An expression of interest (EOI) process was used to identify interested eligible sites for participation. Information about the study was distributed through peak organisation newsletters, websites and social media; via email and letter to primary health networks; at conferences; and via advertisement in academic journals and key stakeholder groups. Information included a description of the study, what would be required of participating sites, and the application process. Registered GPs, hospitals and RACFs were eligible to apply if they had access to a minimum of 30 health records likely to meet inclusion criteria, and resources to support implementation of the protocol. All sites that applied met eligibility criteria and were invited to participate. A proactive recruitment strategy (cold calling) was undertaken across all three sectors to ensure representativeness across jurisdictions and settings in the final sample. The EOI application form captured ACP programme data for each site, with the applicant

for each participating site asked to self-report: whether the site had an ACP programme (eg, ACP offered as part of routine practice, eg, during a routine health assessment); whether ACP training is offered to staff; whether the site had any ACP policy or guidelines; and whether the site had any staff specifically funded to support ACP activities (eg, facilitate ACP conversations; assist with completion of documents).

Participant eligibility

Individuals were eligible for inclusion in the record audit if they were aged 65 years or older. Participants in hospital and RACF settings were required to be admitted for at least 48 hours prior to the conduct of the audit. Participants recruited from GPs were those attending on the study day.

Participant selection

In RACFs and hospitals, a deidentified sample of patients/clients matching the inclusion criteria was drawn from the electronic patient information management system on the day the audit was conducted. An online research randomisation tool was then used to randomise records as either included or not included in the audit. Data extraction was then undertaken for the agreed number of records. In GP, files of eligible individuals consecutively visiting the practice on the day(s) of the audit were identified and included. The number of records audited per participating site was between 30 and 50.

Participant data collection

Data were collected over a 4-month period between October 2018 and January 2019. As only deidentified data were collected, a waiver for the requirement of individual patient consent was obtained. Audits were principally conducted by an employee from each participating site who was trained by a member of the research team. For sites that did not have staff to undertake audits, a trained independent auditor (who was not part of the research team) undertook data collection. Auditors examined each selected paper and/or electronic health record at each facility for a maximum of 15 min. This timeframe was chosen because in order to be useful in practice, documentation needs to be quickly and easily accessible. Demographic and clinical information was recorded using an electronic form.

Measures

The following information was recorded for each participant.

Demographic characteristics

Age, gender, postcode, country of birth, current relationship status and English speaking.

Clinical information

Auditors recorded whether each person had any of the following medical conditions (current or active): cancer; dementia; heart conditions; respiratory conditions; chronic kidney conditions; endocrine, nutritional and metabolic disorders; gastrointestinal conditions; neurological conditions; urinary or reproductive conditions; mental health conditions. Auditors also recorded whether each person had been receiving palliative care (yes/no/unknown); and the person's Eastern Cooperative Oncology Group (ECOG) performance status as noted in the medical records (grade 0–4 or 'not available').²⁹ If ECOG status was not available (the majority of records), the auditor provided an estimate of the person's likely functional status following review of their health record as a whole using six defined categories: no disability (fully active, able to carry out all daily living activities); some disability (restricted in physically strenuous activity, but ambulatory and able to carry out work of a light or sedentary nature, eg, light housework, office work); moderate disability (ambulatory and capable of all self-care but unable to carry out any work activities); severe disability (capable of only limited self-care; confined to bed or chair more than 50% of waking hours); very severe disability (completely disabled; unable to carry out any self-care; totally confined to bed or chair). If they were unable to estimate likely degree of disability, they selected 'insufficient information available'.

Presence of ACDs

A self-completed ACD was defined as 'a type of written structured advance care plan recognised by common law or specific legislation that is completed and signed by a competent adult'. Auditors were trained to identify ACDs recognised by state-based legislation (statutory ACDs) and/or formal documents recognised under common law (non-statutory ACDs).²⁸ The type of ACD located (statutory/non-statutory) and whether it recorded preferences for care or appointed an SDM was recorded. The type of ACD identified and who completed the document was also recorded.

ACP documentation completed by health professionals, or someone else on behalf of the person

Auditors identified ACP documentation completed by a health professional ('an advance care plan completed by a staff member for the person') or someone else ('an advance care plan completed on behalf of the person, eg, by an SDM').

Statistical analysis

Analyses were conducted using SPSS V.26. Descriptive statistics were used to present demographic characteristics for the sample and sites. Auditor-assessed functional status, or ECOG status for those with this recorded, were combined to represent estimated functional status.^{28 30} For site-level variables, unsure

and no responses were combined for the purpose of regression analysis. States were recoded into those states with legislation for documentation of ACD preferences (Victoria, Queensland, South Australia, Northern Territory, Australian Capital Territory and Western Australia and those where ACD preferences are recognised by common law (New South Wales and Tasmania). Those who selected 'other' for gender were excluded from the model due to the low count. Logistic regression was used to assess the relation of person and site level variables with any ACP document completion. Multivariable multinomial mixed effects logistic regression was used to assess the relation of person and site level variables with the ACP document completion outcome. Three groups composed the outcome: 'ACD completed by self', 'ACP document completed by other' and 'no ACD or advance care plan'. Those who had self-completed ACD as well as ACP document completed by other were classified as having self-completed ACD. A random intercept with independent covariance structure was used to account for clustering of observations by site. For each independent variable crude effects were assessed. Linearity of the log odds of the outcome was assessed for age using the Box-Tidwell test. A full model was constructed with all the independent variables including person-level variables and site-level variables to derive adjusted effects. A pseudo intraclass correlation (ICC) is reported for each model to describe the relative variance explained by individual-level and site-level variables.

RESULTS

A total of 100 sites participated in the study. Of 4187 records audited, 1388 people (33.2%) from 96 sites (13 GPs, 25 hospitals and 58 RACFs) had dementia and were included in the analysis. Participant characteristics are provided in table 1. Site characteristics are provided in table 2. The majority of participants were residing in RACF settings (88.9%), multimorbid (84.5%), with severe or very severe disability (74.2%).

Prevalence and type of ACP documentation

Prevalence of ACP documentation by type and setting are presented in table 3. Overall, 31.6% (n=438) of participants had a self-completed ACD, 29.3% (n=406) had an ACP document either completed by a health professional or someone else on their behalf only, and 39.2% (n=544) had no ACD or ACP documentation. Of those with self-completed ACD, the largest proportion had a statutory ACD appointing an SDM (17.3%).

Factors associated with ACP completion

Results of the logistic regression examining associations with any ACP document completion are provided in table 4. The site effect was estimated as 1.313 (pseudo ICC=0.285). In the adjusted model, 153 participants were excluded due to missing data; a sensitivity

Table 1 Participant characteristics (n=1388)

	Mean	SD		
Age	85.3	7.4		
			N	%
Gender	Male	465	33.5	
	Female	919	66.2	
	Other	4	0.3	
Setting	GP	20	1.4	
	Hospital	134	9.7	
	RACF	1234	88.9	
State	New South Wales	515	37.1	
	Victoria	328	23.6	
	Queensland	276	19.9	
	South Australia	182	13.1	
	Australian Capital Territory	39	2.8	
	Western Australia	30	2.2	
	Northern Territory	16	1.2	
	Tasmania	2	0.1	
Relationship status	Married/living with partner	289	28.0	
	Divorced/separated	127	9.1	
	Widowed	674	48.6	
	Single	110	7.9	
	Unknown	88	6.3	
Language	English speaking	1222	88.0	
	Non-English speaking	142	10.2	
	Unknown	24	1.7	
Country of birth	Australia	883	63.6	
	Other	465	33.5	
	Not available	40	2.9	
Morbidity	Unimorbid	62	4.5	
	Comorbid	153	11.0	
	Multimorbid	1173	84.5	
Receiving palliative care	Yes	127	9.1	
	No	1237	89.1	
Estimated functional status	No disability	5	0.4	
	Some disability	52	3.7	
	Moderate disability	279	20.1	
	Severe disability	664	47.8	
	Very severe disability	367	26.4	
	Not available	21	1.5	
Medical condition(s) in addition to dementia*	Cancer (malignant)	165	11.9	
	Heart condition	758	54.6	
	Respiratory condition	264	19.0	
	Chronic kidney condition	131	9.4	
	Endocrine/metabolic/nutritional	425	30.6	
	Gastrointestinal condition	359	25.9	
	Neurological condition	309	22.3	
	Urinary or reproductive condition	428	30.8	
	Mental health condition	614	44.2	
	Musculoskeletal/connective tissue	848	61.1	

*Participant may have more than one (other) medical condition.

GP, general practice; RACF, residential aged care facility.

analysis was performed where the missing values were included as separate levels of the variables in order to enable these participants to be included. The estimated

Table 2 Site level characteristics (n=96)

		N	%
ACP programme	Yes	78	81.3
	No	16	16.7
	Unsure	2	2.1
ACP training for staff	Yes	67	69.8
	No	19	19.8
	Unsure	10	10.4
ACP policy or guideline	Yes	60	62.5
	No	30	31.3
	Unsure	6	6.3
Staff funded to implement ACP	Yes	18	18.8
	No	78	81.3

ACP, advance care planning.

ORs were highly consistent between both models, with the effect of 'any funded ACP support' reaching statistical significance with the additional participants included ($p=0.037$; results not shown in table 4). In the adjusted model, older participants were more likely to have ACP documented ($OR=1.03$, $p=0.009$). Participants born in a country other than Australia ($OR=0.68$, $p=0.019$) and those who did not reside in an RACF ($OR=0.15$, $p<0.001$) were less likely to have ACP documented.

Results of the multinomial regression examining associations between self-completed ACDs, those who only had ACP documentation completed by someone else, and those with no ACD or advance care plan, are provided in table 5. The estimate of site variance component for two comparisons were 1.136 and 1.375 (pseudo ICC=0.257 and 0.295). In the adjusted model, 153 participants were excluded due to missing data. A sensitivity analysis was performed where the missing values were included as separate levels of the variables in order to enable these participants to be included. The estimated ORs were highly consistent between both models.

Age, country of birth, setting, whether the site had ACP training, and whether the site had an ACP

policy or guidelines were all significantly associated with having a self-completed ACD. Older participants had greater odds of having a self-completed ACD ($OR=0.97$), relative to those with no ACP documentation, than those who were 1 year younger. Those with a self-completed ACD had greater odds of being born in Australia ($OR=1.59$), sampled from an RACF ($OR=3.17$) and sampled from a site that reported having an ACP policy or guideline ($OR=1.39$), relative to those with no advance care plan or ACD. However, those with a self-completed ACD had lower odds of being from a site with ACP training ($OR=0.37$) relative to those with no advance care plan or ACD. Relative to participants that had ACP completed by someone else on their behalf, participants with a self-completed ACD had greater odds of being born in Australia ($OR=1.15$), and sampled from a site that reported having an ACP policy or guideline ($OR=3.05$). However, those with a self-completed ACD had lower odds of being sampled from an RACF setting ($OR=0.20$), and sampled from a site with ACP training ($OR=0.09$), relative to those that had ACP completed by someone else on their behalf.

DISCUSSION

This study is the first to provide data about the prevalence and type of ACP documentation in the health records of persons with dementia across health and aged care settings in Australia.

This multicentre audit found that while 60% of those with dementia had some form of ACP documentation in their health record, only half of those had an ACD completed by the person themselves. This rate is somewhat higher than that reported in previous community-based cohort studies,¹⁷ and may reflect the high proportion of participants with multimorbidity in RACF settings, suggesting that participants overall had reached a more advanced stage of dementia. The rates observed here are comparable to those reported in a retrospective (postdeath) survey of family members of people who died with a diagnosis of dementia.³¹

Table 3 Presence and type of ACP documentation completed by persons with dementia, or someone on behalf of the person with dementia, in each health and aged care setting and overall (n=1388)

Presence of ACP documentation	GP N (%)	Hospital N (%)	RACF N (%)	Overall N (%)
No ACD or advance care plan	14 (70)	105 (78.4)	425 (34.4)	544 (39.2)
Self-completed ACD*	5 (25.0)	21 (15.7)	412 (33.4)	438 (31.6)
Statutory ACD—care preferences†	2 (10.0)	3 (2.2)	92 (7.5)	97 (7.0)
Statutory ACD—SDM†	4 (20.0)	19 (14.2)	217 (17.6)	240 (17.3)
Non-statutory ACD†	2 (10.0)	2 (1.5)	164 (13.3)	168 (12.1)
ACP documentation completed by healthcare provider or family member only*	1 (5)	8 (6)	397 (32.2)	406 (29.3)

*A participant with both self-completed documentation and documentation completed by someone else was classified as only having self-completed documentation as self-completed documentation is accorded more weight from a legal perspective.
†A participant could have more than one of these documents.
ACD, advance care directive; ACP, advance care planning; GP, general practice; RACF, residential aged care facility; SDM, substitute decision maker.

Table 4 Logistic regression comparing any ACP documentation (reference; n=756) versus no ACP documentation (n=479)

	Comparison	Crude OR (95% CI)	Adjusted OR (95% CI)	P value
Gender	Male	Ref		0.094
	Female	1.41 (1.06 to 1.85)	1.30 (0.95 to 1.79)	
Age (years)	Per year	1.03 (1.02 to 1.05)	1.03 (1.01 to 1.05)	0.009
Multimorbidity	One	Ref		0.897
	Multiple	1.18 (0.61 to 2.27)	1.05 (0.48 to 2.27)	
Relationship status	Married/living with partner	Ref		0.297
	Other	0.99 (0.75 to 1.32)	0.85 (0.62 to 1.16)	
Country of birth	Australia	Ref		0.019
	Other	0.67 (0.50 to 0.90)	0.68 (0.50 to 0.94)	
Setting	RACF	Ref		<0.001
	Other	0.12 (0.06 to 0.23)	0.15 (0.06 to 0.35)	
Estimated functional status	No or some disability	0.68 (0.34 to 1.39)	1.14 (0.50 to 2.56)	0.630
	Moderate disability	0.77 (0.52 to 1.12)	0.83 (0.55 to 1.27)	
	Severe disability	1.04 (0.76 to 1.43)	1.06 (0.75 to 1.49)	
	Very severe disability	Ref		
Palliative care	Yes	Ref		0.174
	No	0.66 (0.39 to 1.10)	0.68 (0.38 to 1.19)	
Jurisdiction	Common law state for ACD preferences	Ref		0.203
	Legislative state for ACD preferences	0.57 (0.29 to 1.12)	0.63 (0.31 to 1.28)	
ACP programme	Yes	Ref		0.177
	No	0.34 (0.15 to 0.81)	0.52 (0.20 to 1.35)	
ACP training	Yes	Ref		0.655
	No	1.10 (0.53 to 2.27)	1.19 (0.55 to 2.56)	
Any ACP policy or guideline	Yes	Ref		0.579
	No	0.94 (0.48 to 1.89)	1.22 (0.61 to 2.38)	
Any funded ACP support	Yes	Ref		0.545
	No	1.43 (0.75 to 2.70)	1.25 (0.61 to 2.56)	

ACD, advance care directive; ACP, advance care planning; RACF, residential aged care facility.

Those who were older and in RACF settings were more likely to have some form of ACP documentation. These patterns suggest that an increasing frequency of encounters with (and transitions between) health and aged care settings as dementia progresses might serve to prompt ACP discussions, and provide impetus for documentation.³² Higher likelihood of having ACP documentation among those born in Australia compared with those born outside Australia is consistent with previous research among a broader sample from the same project³⁰ and a recent international review of ACP uptake among older adults.³³

While some form of ACP documentation was present for a substantial proportion of people, only half of the cases in which ACP was documented included an ACD completed by the person themselves. The odds of having ACP documents completed by someone else, compared with a person-completed ACD, were significantly greater in the RACF setting. This perhaps reflects difficulties undertaking ACP when a person is more cognitively and functionally impaired, and a pragmatic concern to ensure that some sort of planning is in place.³⁴ However, the extent of this ACP documentation by others on the person's

behalf is concerning given the lack of legal frameworks supporting such documents. Further, research has shown discordant preferences for end of life care³⁵ between family members and people with dementia, indicating the potential difficulties in making decisions for others without clear guidance. Given the lack of information regarding the person's contemporaneous decision-making capacity at the time of ACP documentation, it is not possible to make inferences about the appropriateness of ACP documentation being made on their behalf. While some, for example, some culturally and linguistically diverse groups,³⁰ may prefer to defer decision-making to others, the almost 70% of participants with dementia who had not completed an ACD themselves suggest missed opportunities for promoting ACP discussion earlier in the course of the illness.

ACP programme factors were not predictive of the presence of any form of ACP documentation in the initial logistic regression. However, in the multinomial logistic regression model that considered different types of ACP documentation (person-completed ACD vs ACP documentation by someone else), sites that self-reported having ACP training for staff showed a higher likelihood of the person having no advance

Table 5 ORs (95% CIs) from multinomial multivariable logistic regression comparing those with self-completed ACD (reference) to those with no ACD or advance care plan, and those who only had ACP completed by someone else

		No ACD or advance care plan		ACP completed by someone else		P value	
		Crude OR (95% CI)	Adjusted OR (95%CI)	Crude OR (95% CI)	Adjusted OR (95% CI)	Crude	Adjusted
Gender	Male	Ref		Ref		0.061	0.237
	Female	0.71 (0.52 to 0.96)	0.78 (0.55 to 1.11)	0.96 (0.68 to 1.37)	1.05 (0.7 to 1.57)		
Age (years)	Per year	0.96 (0.95 to 0.98)	0.97 (0.95 to 0.99)	1.00 (0.97 to 1.02)	0.99 (0.97 to 1.02)	0.001	0.030
Multimorbidity	One	Ref		Ref		0.054	0.157
	Multiple	0.45 (0.18 to 1.09)	0.52 (0.18 to 1.48)	0.32 (0.12 to 0.81)	0.34 (0.12 to 1.02)		
Relationship status	Married/living with partner	Ref		Ref		0.221	0.250
	Other	0.90 (0.65 to 1.23)	1.08 (0.75 to 1.55)	0.72 (0.50 to 1.04)	0.78 (0.52 to 1.17)		
Country of birth	Australia	Ref		Ref		0.014	0.033
	Other	1.63 (1.17 to 2.28)	1.59 (1.11 to 2.26)	1.19 (0.81 to 1.76)	1.15 (0.76 to 1.74)		
Setting	RACF	Ref		Ref		<0.001	<0.001
	Other	5.06 (2.55 to 10.0)	3.17 (1.34 to 7.52)	0.33 (0.11 to 0.97)	0.20 (0.06 to 0.66)		
Estimated functional status	No or some disability	1.13 (0.50 to 2.58)	0.71 (0.28 to 1.81)	0.63 (0.26 to 1.53)	0.65 (0.24 to 1.74)	0.018	0.059
	Moderate disability	0.91 (0.58 to 1.41)	0.79 (0.49 to 1.29)	0.45 (0.27 to 0.74)	0.43 (0.25 to 0.73)		
	Severe disability	0.74 (0.51 to 1.07)	0.72 (0.48 to 1.07)	0.60 (0.41 to 0.90)	0.59 (0.38 to 0.90)		
	Very severe disability	Ref		Ref			
Palliative care	Yes	Ref		Ref		0.159	0.298
	No	1.34 (0.76 to 2.39)	1.62 (0.85 to 3.07)	0.72 (0.38 to 1.37)	1.09 (0.55 to 2.15)		
Jurisdiction	Common law state for ACD preferences	Ref		Ref		0.148	0.379
	Legislative state for ACD preferences	1.37 (0.70 to 2.70)	1.64 (0.81 to 3.35)	0.53 (0.24 to 1.16)	0.98 (0.44 to 2.19)		
ACP programme	Yes	Ref		Ref		0.095	0.206
	No	2.44 (1.02 to 5.82)	2.25 (0.85 to 5.95)	0.79 (0.26 to 2.42)	1.82 (0.57 to 5.80)		
ACP training	Yes	Ref		Ref		<0.001	<0.001
	No	0.47 (0.24 to 0.93)	0.37 (0.17 to 0.79)	0.12 (0.05 to 0.29)	0.09 (0.03 to 0.22)		
Any ACP policy or guideline	Yes	Ref		Ref		0.573	0.019
	No	1.30 (0.66 to 2.57)	1.39 (0.69 to 2.78)	1.42 (0.63 to 3.18)	3.05 (1.39 to 6.69)		
Any funded ACP support	Yes	Ref		Ref		0.434	0.526
	No	0.66 (0.35 to 1.24)	0.69 (0.34 to 1.39)	0.89 (0.42 to 1.92)	0.77 (0.34 to 1.77)		

ACD, advance care directive; ACP, advance care planning; RACF, residential aged care facility.

care plan, or an ACP document completed by someone else, compared with a person-completed ACD. On the other hand, sites with an ACP policy or guideline in place had relatively higher rates of person-completed ACDs than the no advance care plan or ACP documentation completed by someone else outcomes. These findings may reflect that having a clear policy or guideline in relations to ACP assists health professionals and those accessing the service to engage in ACP through an understood process that applies across the organisation.³⁶ ACP training for staff was not shown to influence the likelihood of participants having a self-completed advance care plan. This may reflect difficulties related to adequate training due to high staff turnover, or only limited numbers of staff participating in training. The unexpected negative effect of ACP training on ACD completion may reflect the implementation of a training programme as a first step in responding to an identified deficit in practice.

Alternatively, ACP training developed for the aged care setting might place greater emphasis on consulting with family members in cases where a person is in the advanced stages of dementia, rather than proactive communication with the person themselves in the early stages after diagnosis.³⁴ The lack of information regarding the nature of ACP training provided and the extent of implementation across the organisation makes it difficult to draw firm conclusions about this site-level effect, however this is an important area for future research.

Strengths and limitations

The strengths of this study include extraction of ACD and ACP documentation outcomes directly from health records, and multivariate analysis of personal and ACP programme factors associated with completion of ACDs and ACP documentation. This study also has limitations which should be considered when

interpreting the results. While sites were recruited from all eight jurisdictions, the distribution of participating sites was not representative across jurisdictions. There were only a small number of people with dementia from the GP setting, with the majority of the sample residing in RACFs. Our findings therefore have particular relevance in the RACF setting. This study also did not consider the contents of identified ACP documents or their clinical usefulness; this is an important consideration for future work. Those who had both self-completed ACDs and ACP documentation completed by someone else were classified as having 'person-completed ACD', thus potentially underestimating the frequency of ACP documentation by others on their behalf.

Implications for practice

The current study provides insight into current rates of ACD and ACP documentation by persons with dementia in Australia, and may serve as a baseline against which future audits may be compared. Our findings suggest there is a significant population of people with dementia who have no ACP documentation in place, and another group with ACP documentation that has been completed for them by someone else. In the case of a person who never wished to document their own preferences and who has since lost decision-making capacity, this may reflect an appropriate outcome consistent with the individual's values. However, such cases can also be seen as a missed opportunity for promoting ACP earlier in the course of illness to provide people with the choice to plan for their future care needs. This is of particular importance given evidence that there are discrepancies in values and preferences between caregivers of people with dementia, and people with dementia themselves.^{37 38} Further Australian research regarding congruence in care decisions between caregivers of people with dementia and people with dementia themselves is required. Recent studies trialling tailored dementia-specific approaches to ACP that address known barriers to discussion have shown promising early results.³⁹ The implementation of clear ACP policies and guidelines at an organisational level is consistent with existing quality standards in Australia,^{40 41} and can provide a foundation for further initiatives to promote ACP across health and aged care organisations.

CONCLUSIONS

For people with dementia who have no ACP documentation, or whose ACP documentation is completed by someone else, these findings suggest that more needs to be done to support proactive ACP discussion and create opportunities to document preferences prior to decline in decision-making capacity. However, this should recognise that engaging in ACP is a voluntary process, and that some will prefer to defer such decision-making to others. It is likely that both ACDs

completed by the person themselves, and ACP documentation completed by others on a person's behalf, will have relevant roles in promoting optimal care for people with dementia when they are unable to make decisions for themselves. Future research should further investigate the nature of these ACP practices, with the aim of identifying opportunities for supporting people with dementia to express and document their own preferences for future healthcare.

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