

# Advance care planning in dementia: a qualitative study of Australian general practitioners

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**Abstract.** As the population ages, so does the prevalence of dementia, a condition in which timely advance care planning (ACP) is recommended. This study explored the barriers and enablers of ACP for Australian GPs caring for people with dementia. Semi-structured qualitative telephone interviews informed by the theoretical domains framework (TDF) were conducted with 16 GPs from the south-east region of metropolitan Melbourne. The most prevalent domains of the TDF were: (1) environmental context and resources; (2) beliefs about consequences; and (3) social/professional role and identity. Further thematic analysis found that: (1) ACP was felt to be within the scope of general practice, but more so before the onset of dementia because lack of confidence in capacity assessment acted as a barrier once a diagnosis was made; (2) beliefs about the perceived benefits of ACP motivated GPs to engage patients in ACP; and (3) doctors felt that patients were often reluctant to discuss ACP, especially in the time-pressured context of the standard consultation. This study's use of the TDF provides direction for potential interventions to alleviate challenges faced by Australian GPs with ACP in dementia. Improving ACP in general practice may require a focus on public health campaigns to educate patients about the benefits of ACP before the onset of dementia. GPs' difficulty assessing a patient's decisional capacity may be addressed through skills development workshops.

**Keywords:** advance care plan, advance care directive, dementia, cognitive impairment, general practice, qualitative research, theoretical domains framework, implementation science, patient-centred care, decision-making capacity.

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## Introduction

Advance care planning (ACP) is a process of reflection, discussion and communication that enables a person to plan for their future medical treatment when they will no longer be able to make decisions (Royal Australian College of General Practitioners (RACGP) 2012). It leads to increased concordance between preferred and delivered care (Houben *et al.* 2014). ACP is particularly relevant for people with dementia because the condition eventually precludes the affected individual from taking part in their own medical treatment decisions.

GPs play a key role in dementia ACP (Bally *et al.* 2020), yet only 3.2% of audited records of patients aged  $\geq 65$  years in Australian general practice had a formal advance care directive (ACD) (Detering *et al.* 2019). Reasons behind the low uptake of ACP within the context of Australian general practice remain understudied. A recently published systematic review on the barriers and facilitators for GPs in dementia ACP did not identify any study of Australian GPs (Tilburgs *et al.* 2018). The aim of this study was to address this gap by exploring factors that influence ACP among Australian GPs caring for people with dementia.

## Methods

### Study design

A qualitative study design informed by the theoretical domains framework (TDF) (Atkins *et al.* 2017) was used. The TDF was developed through an international collaboration of behavioural scientists and implementation researchers. In this study, the TDF provided a framework to comprehensively investigate aspects of dementia ACP that may be amenable to intervention. We followed published guidance on how to operationalise the TDF and developed an interview schedule drawn from the 14 domains of TDF version 2 (Atkins *et al.* 2017) (Table 1). Subject-specific questions for each domain were initially adapted from existing examples in the literature (Michie *et al.* 2005; Huijg *et al.* 2014) and further refined after conducting two pilot interviews with GP researchers. Data from these pilot interviews were not retained for analysis.

The study was led by an academic GP registrar (AA). An experienced qualitative researcher (CB) provided advice and close guidance throughout the research process. A recently fellowed GP with experience conducting qualitative research

**Table 1.** Example questions from the interview guide based on the TDF

Domain	Question
Knowledge	What is your understanding of advance care planning?
Social/professional role and identity	What role do you think GPs play in advance care planning for people with dementia?
Skills	When it comes to advance care planning for people with dementia, what types of skills do you think are important?
Memory, attention and decision processes	When considering advance care planning for those with dementia, what are the factors that influence your decision on which patients to engage?
Beliefs about consequences	When thinking about incorporating advance care planning in the routine care of your patients with dementia, can you see any potential benefits? What about potential risks?
Beliefs about capabilities	How confident do you feel in your ability to initiate advance care planning for people with dementia?
Goals and intentions	When thinking about your patients with dementia, is advance care planning on the agenda?
Optimism	How do you expect consultations to unfold in regards to advance care planning for patients with dementia?
Behavioural regulation	Once a decision to follow through with advance care planning has been taken, how do you keep a track of everything?
Environmental context and resources	What resources do you have to help with advance care planning for people with dementia?
Social influences	To what extent do social factors impact on your practice of advance care planning among people with dementia?
Emotion	How does the thought of advance care planning for people with dementia make you feel?
Reinforcement	What would encourage you to incorporate advance care planning into your routine care for people with dementia?
Concluding question	Do you have any other recommendations for what can be done to better enable advance care planning for patients with dementia?

and undertaking a PhD (PP) helped with data analysis and write up. The final author (DM) was the lead supervisor responsible for steering the overall direction of the study.

### Recruitment

Initially, a random sample of 500 GPs registered with the Monash Practice-Based Research Network (MonReN) were approached to participate in the study. The MonReN database comprises 1800 GPs working across the south-east region of metropolitan Melbourne, and the list was randomised using Microsoft Excel. Each GP received a postal invitation to participate that included the explanatory statement and consent form. Prospective participants had the option of returning the signed consent form via an enclosed reply-paid envelope, email or fax. A reminder was sent approximately 6 weeks after the initial mail-out.

We received 30 signed consent forms, a response rate of 6.6% after excluding 47 undeliverable letters (Fig. 1). Respondents were contacted to arrange one-on-one semi-structured interviews, which were scheduled in the order that the consent forms were received, up to the 13th interview. The remaining participants were purposively sampled for maximum variation of sexes. The stopping criterion was data saturation (Francis *et al.* 2010), which was reached by the 16th interview.

### Data collection

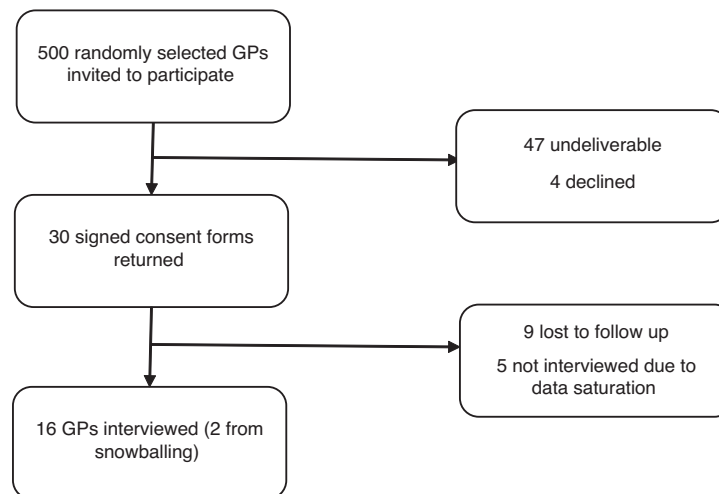
Interviews were conducted by one of the authors (AA) over the telephone for participant convenience. We used in-depth interviewing principles (Minichiello *et al.* 2008) with open-ended questions to encourage participants to share their unique personal narratives and experiences. In addition, field notes were taken (by AA) after every interview and a reflective journal was kept. After initially undertaking three interviews, transcripts and notes were reviewed by two authors (AA and CB) to ensure the interviews were working well. Data from these three interviews were included in the final analysis.

Interviews were conducted between August and November 2019, digitally recorded and transcribed verbatim by an external transcription service. Unedited transcripts were mailed to respective participants along with an A\$200 gift voucher. As part of member checking, all participants were given the opportunity to review their transcript for accuracy, to make clarifications or expand on what they had described in the interview. Two participants returned their transcripts with changes, which were minor clarifications.

### Data analysis

Data were analysed in two steps. First, data were analysed deductively to determine the most pertinent domains and then inductively to identify overall themes (Atkins *et al.* 2017). Two authors (AA and PP) independently reviewed the first five transcripts and participants' responses were distributed among the previously determined theoretical domains within the framework, through directed content analysis. Transcripts were read line by line, with whole segments of text assigned to relevant domains. After coding text from the first five transcripts to one or more of the 14 TDF domains, discrepancies were discussed and resolved with input from a third author (CB) to increase rigour. A final coding guideline was developed by the team, and the remaining transcripts were then analysed by a single author (AA).

Once text from each transcript had been assigned to domains, the contents were further analysed by a single author (AA) following the steps of thematic analysis (Braun and Clarke 2006). Phase 1 of gaining familiarity with the data occurred through the process of conducting the interview, referring to the field notes and deductive analysis of the transcripts. Instead of generating novel codes, domains of the TDF served as the initial coding framework for Phase 2. The remaining Phases 3–6 of the thematic analysis methods of Braun and Clarke (2006) were followed as per published guidance. All data were managed using NVivo 12 Plus.



**Fig. 1.** Flow chart for recruitment.

**Table 2.** Participant characteristics

Variable	No. respondents (%)
Sex	
Male	8 (50)
Female	8 (50)
Years post-fellowship	
1–5	3 (18.75)
6–15	6 (37.5)
16–25	5 (31.25)
>25	2 (12.5)
Years in current clinic	
1–5	4 (25)
6–15	11 (68.75)
15–25	1 (6.25)
Practice nurse present	16 (100)
Nursing home/aged care involvement	5 (31.25)

### Ethical considerations

The study was approved by the Monash University Human Research Ethics Committee (Project ID 18800). Participants provided written consent before interviews and confidentiality was assured by deidentification. The external transcription service also adhered to a confidentiality agreement.

### Results

Sixteen GPs were interviewed (eight males, eight females). The duration of the interviews ranged from 32 to 70 min, with a mean of 44 min. One participant's primary place of work was an Aboriginal Medical Service. Years spent in general practice ranged from 1 to 25 years (Table 2). Data on age, ethnicity and country of graduation were not collected because time in practice was deemed to be more relevant to interpreting the data.

The most prevalent domains were: (1) environmental context and resources; (2) beliefs about consequences; and (3) social/professional role and identity. This prevalence was determined by the number of times interview content was

ascribed to a domain within the TDF. Table 3 contains illustrative quotes for each of the 14 domains and Table 4 maps the major themes to relevant TDF domains. Three major themes were identified from the inductive analysis, namely the role of the GP, the contribution of ACP in promoting patient-centred care and the burden of responsibility, and these are described in detail below.

### Role of the GP

GPs felt that engaging patients in ACP early was a big part of their role, especially before the onset of dementia. In addition, practice nurses may assist in bringing ACP to the attention of patients as part of routine health assessments. Furthering the conversation and following through with the paperwork was still seen as the responsibility of the doctor:

Well I think it's massive, it's massive...I think putting into place plans before people get dementia, while they're of sound mind, probably in their aging is a good idea. And of course when people do have dementia, putting in plans and having plans in place is a very good idea too. So I think pre-planning, and planning at the time. GPs are critical because especially in the pre-planning stage we know the patients generally really well [GP16, male, 22 years post-fellowship].

Our participants felt they possessed sufficient knowledge and skills for ACP. They understood ACP as an iterative process and identified rapport, active listening, clear communication and empathy as key to success with ACP. However, depending on the stage of dementia, discomfort in assessing a patient's capacity posed a major challenge to ACP and often led to specialist involvement:

I think I'm moderately confident about advance care planning, but I'm incredibly unconfident [sic] about advance care planning in patients with dementia. I think that's a very difficult situation – difficult enough, I think that I probably would secede in many situations to a geriatrician [GP4, male, 1 year post-fellowship].

**Table 3. Domains and themes**  
CALD, culturally and linguistically diverse; MBS, Medicare Benefit Schedule

Theoretical domain	Codes	Illustrative quotation(s)
Environmental context and resources	Posters and flyers may be beneficial, including multilingual resources	...it would be a good idea not having just information in English, having in other languages because Australia's a multiethnic country anyway (GP11)
	Raising public awareness about ACP will increase its uptake	...sometimes patients come in because they've seen something on TV, and like they'll book a separate appointment just to talk about that (GP8)
	Lack of time and funding are significant barriers for ACP	I think GPs know how to do it, we're too time poor to actually do it, there's no remuneration other than the you know consult for us to do it (GP15)
Beliefs about consequences	Hospitals can influence ACP in primary care	...they're sort of prompted at the door when they're going into hospital and it remains on their minds when they leave hospital so that when they come to see the GP after these life-threatening episodes, they want to discuss the advanced care plan at that stage (GP7)
	Lack of carer availability can be a barrier	...if the patient is quite elderly, trying to get them to bring a family member in with them can sometimes be hard (GP5)
	Alignment of patient, carer and provider goals leads to better outcomes	...having it written down properly ensured that her mother's wishes were respected and that was the bottom line for that family and they said that was a very peaceful death and that was the best way that it could have happened (GP12)
Social/professional role and identity	Adherence to ACP is not guaranteed	...it's often out of the GPs hand[s], I mean at the time the person is often in hospital when these decisions have to be made because they have got some sort of major illness... the actual wishes of the patient is they have documented it somewhere and may not turn up in time [sic]... the hospital resident doesn't ring the GP to find out what was the patient's wish. They make their decisions based on their own judgements and talking to members of the family (GP2)
	Risk of not updating preferences	...they may sort of change their mind, or see – you know, things may change (GP8)
	Potential impact on patient–doctor relationship is a concern	The main risk for me is the relationships with the family and patient. If you don't do it sensitively enough you will lose them – you will lose their trust (GP6)
Reinforcement	GPs play a vital role in facilitating premorbid ACP	I think we should be, actually having that discussion early with people, before they become demented (GP1)
	Practice nurse involvement varies	Our nurses are involved in the home health assessments... but as far as an advance care directive, that is not a part of it (GP14)
	Specialists should support ACP in dementia	Once they've actually reached that point of dementia, it's almost too far because then, in my opinion, it becomes the role of a geriatrician to assess whether they are of sound mind to be able to make these decisions (GP9)
Social influences	Allied health may also contribute to ACP	Probably the person that is more likely to be influential in the process will probably be our Aboriginal health workers in my clinic (GP6)
	ACP works best when integrated into existing workflow	It's a matter of being able to incorporate that into GP training and having prompts to make this part of routine care such as with health assessments – not easy to do but I think over time I think GPs are aware that we need to be (GP2)
	Reminders may enhance ACP	...it's [ACP] not actually brought to our attention... if you want me to pay attention, then send me the propaganda, because that's what makes me go, oh, yeah, that's a good idea (GP14)
Memory, attention and decision processes	Support for a new Medicare item number is lacking	I'm sure if the MBS introduced an advance care planning item number, suddenly every brother and his mother would have an advance care plan... I don't think that's actually something that I would advocate for myself, because I feel that were the intentions clouded or muddled that way, you would have advance care plans... not worth the paper they're written on (GP4)
	Patient reluctance to engage in ACP is a barrier	I have brought up the issue with patients... there's often a bit of awestruckness to it, they're sort of hit from left field (GP7)
	ACP can be more challenging in some cultures	It's really difficult to encourage patients to do an advanced care plan or even just to entertain the concept... when they're from a CALD background or an Aboriginal background (GP6)
Beliefs about capabilities	Clinical deterioration can trigger ACP	I must say that sometimes when somebody is getting a bit frail then a member of the family will start to think about well what's going to happen in the future, and that might prompt me to think well one of the things that they might think about is an advanced care plan (GP2)
	Competing priorities hinder ACP	...if we're very busy then I think it will be very difficult because other things will take priority (GP3)
	Lack of confidence for ACP in dementia	I think I'm moderately confident about advance care planning, but I'm incredibly unconfident [sic] about advance care planning in patients with dementia (GP4)

(Continued)

Table 3. (Continued)

Theoretical domain	Codes	Illustrative quotation(s)
Knowledge	Participants were not specifically familiar with the guidelines, but had a good understanding of recommendations	I can imagine it but again I haven't read the guidelines (GP6)
Skills	Participants felt they possessed the skills necessary for ACP, but struggled with assessing capacity in dementia	I think, communication and empathy and explanation, like education... I think we play a very big educating role. And also, assessing competency. I think, actually for the dementia part, like knowing whether or not they're competent to make that decision can sometimes be really hard (GP5)
Intentions	Participants were intent on engaging patients in ACP and were more motivated to do so when they saw value in it	I think my issue is that I see the patients at the end of life, and I see how valuable it is. I don't know that all GPs do that. Because all GP[s], you know some GPs don't go to nursing homes, so they don't see the value in it, you know when you're struggling with the families and try and decide what they want, that really is a struggle (GP15)
Goals	Timing, completion, documentation and review of ACP varied	Well we upload it on the MyHealth record... Yeah, we review it annually (GP12)
Emotion	ACP can be emotionally charged for patients, but most GPs are able to remain objective	... sometimes you can't help but be subjective and feel emotions. But having said that, you know, we're here to do a job, as well as be objective in terms of how we go forward, and ultimately, it's what's in the patient's best interests, what's the most compassionate thing to do (GP14)
Behavioural regulation	Interview stimulated some GPs to reflect on their practice	I probably have to sit up and actually remind myself to do it (GP1)
Optimism	Pessimism about the impact of ACP exists	... it sort of is helpful, but I would say is it essential, not; is it much different how people are dying twenty years ago we didn't have advanced care and now, I don't think so make a huge difference (GP3)

Table 4. Summary of themes and links to the TDF

Theme	TDF domains
Role of GP	Social/professional role and identity Beliefs about capabilities Knowledge Skills Intentions Goals
ACP promotes patient-centred care	Beliefs about consequences
Burden of responsibility	Social influences Environmental context and resources Reinforcement Memory, attention and decision-making processes

Participants acknowledged the role of other healthcare providers. Hospital-based junior doctors, nurses and social workers may contribute to ACP in primary care by triggering a conversation during an inpatient encounter that continues with the GP after discharge from hospital. The challenge of navigating ACP in a culturally appropriate manner means that cultural and Aboriginal health workers are likely to have increasingly important roles in some settings.

#### *ACP promotes patient-centred care*

The belief that ACP would help align the goals of patient, carers and clinicians emerged as a significant motivator for GPs. As one participant put it:

After her mum passed away she said to me having that advanced care planning form was the best thing because

they were able to go in when the mother got admitted, show the admitting doctor this is all the paperwork we have written. We clearly don't want anyone to do this or that. We just want to be kept comfortable and so even though her mother doesn't speak English she didn't worry [GP12, female, 18 years post-fellowship].

Although a strong conviction in the usefulness of ACP was shared among most participants, there was some pessimism about the utility of ACP documents, such as formal ACDs. Some GPs thought hospital clinicians may not be able to gain access to an ACD to guide critical decision making or an ACD may lack sufficient detail to assist with all clinical scenarios. There were also concerns regarding possible damage to the doctor-patient relationship if approached insensitively:

The main risk for me is the relationships with the family and patient. If you don't do it sensitively enough you will lose them – you will lose their trust. The other thing I think is a risk is if you don't do it well the patient doesn't get what they want in the hospital or where they are [GP6, male, 19 years post-fellowship].

#### *Burden of responsibility*

GPs commented that within the standard consultation ACP was most likely to proceed if initiated by patients, but few patients present specifically with the goal of ACP in mind. Perceived patient reluctance was often a barrier:

I have brought up the issue with patients... there's often a bit of awestruckness to it, they're sort of hit from left field. They don't feel that it may be appropriate for them at the time, so you've got to come back to them in a year or whenever [GP7, male, 17 years post fellowship].



GPs expressed a desire for patients to take greater responsibility for initiating ACP. They believed that improved patient awareness on the benefits of ACP would encourage more patients to visit their GP for ACP. To this end, several participants recommended increased public health messaging to overcome societal taboo around discussions that require individuals to grapple with the concept of death and dying. There was also a sense that increased availability of culturally and linguistically diverse patient education resources may also assist with raising awareness about ACP in today's multicultural society.

Our practitioners experienced greatest success with ACP when it was incorporated into existing preventive care workflow, such as health assessments. Some GPs were also concerned about the out-of-pocket cost to patients who may need multiple consultations for ACP. Even when lack of funding was identified as a problem, participants were ambivalent in their support for a new Medicare item number dedicated to ACP; although some believed it would incentivise more GPs to initiate ACP, others were worried it would dilute the quality of ACP:

I'm sure if the [Medicare Benefit Schedule] introduced an advance care planning item number, suddenly every brother and his mother would have an advance care plan. I don't think that's actually something that I would advocate for myself, because I feel that were the intentions clouded or muddled that way, you would have advance care plans...not worth the paper they're written on [GP4, male, 1 year post-fellowship].

In addition to the patient factors and systems-level barriers mentioned above, some participants admitted that ACP was not necessarily on their agenda. A range of competing priorities often draws the GP's attention away from ACP unless there are clinical triggers, like progression of chronic illness or a significant new diagnosis. Participants mentioned a role for external reminders, such as articles about ACP appearing in journals and talks from those interested in increasing the uptake of ACP:

...it's not actually brought to our attention...if you want me to pay attention, then send me the propaganda, because that's what makes me go, oh, yeah, that's a good idea [GP14, male, 12 years post-fellowship].

## Discussion

This study found that Australian GPs see themselves as having an important role in facilitating ACP, especially before the onset of dementia. It confirms previously reported barriers of patient reluctance to engage in ACP and clinician lack of time (Rhee *et al.* 2012; Scott *et al.* 2013; Howard *et al.* 2018; Tran *et al.* 2018), but also highlights that GPs' beliefs about the benefits of ACP can act as an enabler.

To our knowledge this is the first study to explore ACP in Australian general practice using the TDF, and our use of an implementation sciences framework may assist in developing interventions to increase the uptake of ACP in dementia in primary care. Of the 14 TDF domains, the ones we found to be most relevant to the practice of ACP correlated with those of a scoping review by a research group in the US (Nelson-Brantley

*et al.* 2020), which also found social/professional role and identity, as well as environmental context and resources, to be important determinants in initiating ACP.

This study provides valuable insights from a sample of GPs motivated to improve ACP in primary care. Among our participants there was a strong sense that patient factors were a key barrier to ACP. GPs advocated for public health campaigns to raise patient awareness of the benefits of ACP, a perspective supported by the literature (Rhee *et al.* 2012; Scott *et al.* 2013). Efforts in this domain should be culturally specific so that they can permeate various minority groups. Although lack of time and funding were also identified as barriers at the systems level, designing interventions to address this perennial issue in primary care is challenging.

The debate around benefits of a dedicated Medicare Benefits Schedule item number for ACP remains unresolved in the literature (Pereira-Salgado and Watts 2017) and there was no clear consensus on this issue from our participants. Although the Medicare fees for existing health assessments do not have a strong evidence base (Scott and Connelly 2011), our participants found that health assessments provide time and space to subtly prompt patients to think about ACP while discussing other preventive care issues. Currently, Medicare-funded health assessments are only available to certain segments of the general population, such as those aged 45–49 years or  $\geq 75$  years. This misses ACP opportunities for those  $>65$  years of age who are already at risk of developing dementia (Australian Institute of Health and Welfare 2018). Expanding the existing criteria to include periodic health assessments every 5–10 years of life is likely to lead to more ACP before a diagnosis of dementia.

At the level of the practitioner, several of our participants self-identified lack of confidence in assessing capacity as a barrier to ACP in dementia. Therefore, efforts at increasing the uptake of ACP in dementia should focus on improving GP competency in assessing decisional capacity rather than simply focusing on communication skills required for ACP. A Dutch intervention study that involved training GPs in ACP through role-playing workshops demonstrated short-term improvements in ACP for people with dementia (Tilburgs *et al.* 2020), and this may serve as a template for a similar project in Australia.

## Limitations

This exploratory qualitative study reports findings arising from interviews with a small number of GPs. Our findings may not reflect the experience of GPs in all areas of metropolitan Melbourne, or GPs in rural or remote Australia, so care should be taken in generalising these findings to other contexts. Although we set out to understand how ACP works for patients with dementia, some of our findings are not dementia specific. This is likely due to an overlap in the approach to ACP for people with and without dementia.

## Conclusions

The RACGP recognises ACP as the embodiment of person-centred health care and promotes its incorporation into routine care (RACGP 2012). As people live longer, we can expect ACP to become an increasingly important aspect of healthy aging. Culturally diverse public health campaigns may prime more

patients to engage in conversations about future care. At the practitioner level, education for capacity assessments may improve GP confidence in dementia ACP. Future studies may investigate ACP for GPs based in regional, rural and remote areas, explore the insights of practice nurses and investigate the patient and carer perspectives of minority populations.

### Data availability

The data supporting this study will be shared on reasonable request to the corresponding author.

### Conflict of interest

The authors declare no conflicts of interest.

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