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Sophie Fletcher

*University of Western Australia*

Craig Sinclair

*University of Western Australia*

Joel J. Rhee

*University of New South Wales, jrhee@uow.edu.au*

Desiree Goh

*Rural Clinical School of Western Australia*

Kirsten Auret

*University of Western Australia*

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## Rural health professionals' experiences in implementing advance care planning: A focus group study

### Abstract

Advance care planning (ACP) is described as an ongoing discussion between a patient, their family and healthcare professionals (HCPs) to understand a patient's wishes for future health care. Legislation supporting ACP in Western Australia is relatively new and HCPs are still learning about the process and implementation. This study aimed to provide a rich description of rural health professionals' perceptions and experiences with ACP within the context of their professional role and to identify systemic issues and training needs. Ten focus groups were conducted throughout 2014 with a total of 55 rural participants including general practitioners ( $n \leq 15$ ), general practice registrars ( $n \leq 6$ ), practice nurses ( $n \leq 18$ ), community nurses ( $n \leq 4$ ) and hospital nurses ( $n \leq 12$ ) in the south-western regions of Western Australia. Thematic analysis has identified the following themes regarding ACP: benefits to patients and families; professional roles in ACP; barriers and enablers; and systems for communicating ACP. HCPs have self-determined their roles in the ACP process, which currently leaves some components of the process unaccounted for, suggesting that collaboration between HCPs working together in a rural health setting and a standardised system for distributing these documents may assist with the implementation of ACP.

### Disciplines

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# Rural health professionals' experiences in implementing advance care planning: a focus group study

Sophie Fletcher<sup>A,D</sup>, Craig Sinclair<sup>A</sup>, Joel Rhee<sup>B</sup>, Desiree Goh<sup>C</sup> and Kirsten Auret<sup>A</sup>

<sup>A</sup>The Rural Clinical School of Western Australia, UWA Albany Centre, 31 Stirling Terrace, Albany, WA 6330, Australia.

<sup>B</sup>UNSW Medicine, UNSW Australia, Sydney, NSW 2052, Australia.

<sup>C</sup>The Rural Clinical School of Western Australia, M701, Hackett Avenue, Crawley, WA 6009, Australia.

<sup>D</sup>Corresponding author. Email: sophiecflletcher@gmail.com

**Abstract.** Advance care planning (ACP) is described as an ongoing discussion between a patient, their family and healthcare professionals (HCPs) to understand a patient's wishes for future health care. Legislation supporting ACP in Western Australia is relatively new and HCPs are still learning about the process and implementation. This study aimed to provide a rich description of rural health professionals' perceptions and experiences with ACP within the context of their professional role and to identify systemic issues and training needs. Ten focus groups were conducted throughout 2014 with a total of 55 rural participants including general practitioners ( $n = 15$ ), general practice registrars ( $n = 6$ ), practice nurses ( $n = 18$ ), community nurses ( $n = 4$ ) and hospital nurses ( $n = 12$ ) in the south-western regions of Western Australia. Thematic analysis has identified the following themes regarding ACP: benefits to patients and families; professional roles in ACP; barriers and enablers; and systems for communicating ACP. HCPs have self-determined their roles in the ACP process, which currently leaves some components of the process unaccounted for, suggesting that collaboration between HCPs working together in a rural health setting and a standardised system for distributing these documents may assist with the implementation of ACP.

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## Introduction

Advance care planning (ACP) is described as an ongoing discussion between an individual, their carers/family and their healthcare team about their values, beliefs, treatment, care options and, in particular, their wishes for future care should they no longer be able to make decisions (Government of Western Australia Department of Health 2014). ACP has been shown to improve the quality of end-of-life care (Detering *et al.* 2010), but effective ACP requires proactive initiation of discussions by supportive health professionals (Sinclair *et al.* 2013) and reliable systems for the recording, retrieving and communicating of these ACP discussions across organisations. Rural areas typically have less access to specialist palliative care services (Rosenwax and McNamara 2006); hence, it is important that generalist health professionals are able to guide patients through the ACP process.

Uptake of ACP across Australia has been low (Bezzina 2009; Bradley *et al.* 2014), particularly in Western Australia (White *et al.* 2014). Different models for providing ACP have been suggested. The Royal Australian College of General Practitioners (RACGP) states that 'GPs should aim to incorporate ACP as part of routine healthcare' (RACGP 2012, p. 2). The Respecting Patient Choices program demonstrated that trained facilitators – both nurses and allied health workers – can effectively facilitate ACP discussions in a metropolitan hospital setting (Detering *et al.*

2010). However, there has been little research exploring the optimal design of sustainable ACP programs in rural areas.

In this study we aimed to provide a rich description of participants' perceptions and experiences with ACP within the context of their professional role, and to identify systemic issues and training needs.

## Methods

A qualitative, descriptive framework was used (Manias and Street 2001; Sandelowski 2000). Ethics approval was obtained through the Western Australia Country Health Service (WACHS) Research Ethics Committee (no. 2013 : 32).

## Setting

This study took place in south-western regions of Western Australia between January and October 2014. Participants were recruited from two regional centres – Albany, Australian Standard Geographic Classification (ASGC) Remoteness Area 3 (RA3; Government of Western Australia Department of Health 2007) and Bunbury (RA2), where GPs work in primary care and the hospital provides a secondary care service staffed mainly by salaried doctors, and two rural towns, namely Denmark (RA3) and Mount Barker (RA3), which have smaller community-based hospitals with all health services coordinated by GPs.

**What is known about the topic?**

- Advance care planning has been shown to improve quality in end-of-life care; however, uptake has been low, particularly in Western Australia.

**What does this paper add?**

- This paper provides an insight into the experiences of rurally based healthcare professionals with advance care planning.

*Participants*

Healthcare professionals (HCPs) identified as potentially involved in ACP were purposefully recruited to participate in focus group discussions. In the rural setting, generalist HCPs often work across primary and secondary care settings, with ACP occurring in both settings. Participants – including GPs, general practice registrars, practice nurses, community nurses and hospital nurses – were recruited from both the primary care and hospital settings.

Previous research has shown how power relationships between different health professions can hamper inter-professional teamwork and communication (Manias and Street 2001). To prevent such relationships from biasing the data, we chose to recruit participants into intra-professional focus groups. This technique has been employed previously as a way of exploring role perceptions among medical and nursing students (Aase et al. 2014).

A definition of ACP was introduced at the beginning of each discussion. Focus group discussions were semi-structured, using a discussion guide (Box 1) that was developed following literature review, and discussion within the research team. The focus groups were facilitated by an academic GP registrar (SF). All discussions were audio-recorded, transcribed verbatim and organised with the aid of NVivo Version 10 (QSR International, Melbourne, Vic., Australia). Demographic data were obtained via a written questionnaire.

Recruitment was coordinated by phone calls and emails to clinical leaders in the different professions. A total of 55 participants were recruited, with 10 separate group discussions conducted (see Table 1).

*Data analysis*

A thematic analysis approach was used to interpret the data. Particular attention was given to identifying HCPs' experiences with ACP, the components of ACP, and HCPs' self-identified roles in ACP. Regular team meetings enabled review of focus group discussions and a collaborative approach to data analysis, which informed the ongoing conduct of subsequent focus group discussions. The data were initially analysed by one member of the research team (SF), who coded the transcripts and developed an initial framework. These codes were then compared for concordance following independent coding of a subset of transcripts by two other members of the research team (CS and JR). Similar codes occurring across different focus group discussions were explored using 'horizontal reading', to ensure consistency in coding across transcripts (Gardner and Chapple 1999). Emerging

**Box 1. Discussion guide**

In your context what would you identify as the key elements of high quality Advance Care Planning (ACP)?  
Tell me about your involvement in ACP. How and when do you use ACP?  
Can you tell me a bit more about how that works in your workplace?  
Can you expand on that?  
What factors influence your judgement that an ACP discussion is required?  
In your context, what makes it difficult to initiate ACP discussions? How can these difficulties be overcome?  
Is anyone willing to talk about the case that they described for the preliminary work and discuss this further amongst the group?  
If you could change one thing so that ACP achieves its goal of improving quality of end-of-life care what would it be?

themes were recorded and the data were searched explicitly for disconfirming evidence. As Sandelowski (2000) indicates, there is always an element of interpretation in a descriptive study. However, several measures were used to improve the rigour of the methods. Discussion with other team members contributed to confirmability of the reported results (Guba and Lincoln 1982); data were collected across different towns and different professional groups, contributing to transferability (Guba and Lincoln 1982); and the use of an intra-professional group approach, and endeavouring to build rapport and trust with participants, contributed to credibility in the methods (Guba and Lincoln 1982).

**Results**

Through thematic analysis the following themes were identified: benefits to patients and families; HCPs' roles in ACP; barriers and enablers; and systems for communicating ACP.

*Benefits to patients and families*

Across all groups, participants expressed agreement with the core principles of ACP. They identified benefits, including better understanding patient wishes, making goals of care clearer and establishing treatment decisions to guide care. However, while there was agreement on the benefits of ACP, differences emerged in the way that ACP was described and implemented in the different settings. In community settings, participants discussed an open-ended approach in which patients are encouraged to contemplate their wishes and consider further discussion about ACP. Practice nurses described broaching the idea of ACP, typically as part of the Medicare-funded annual health assessment available to patients over the age of 75:

*It's just that spark of knowledge, and then they [patient] can also go and speak to their kids, before they come in to see the GP and have a further discussion about it [ACP].*  
(Practice nurse, rural town)

Conversely, hospital-based participants described high acuity settings, necessitating urgent decisions regarding medical care. They emphasised the need for specific, binding directives that provided clear direction to the clinical team in responding to urgent situations. Their support for ACP was typically motivated by the difficulty of responding to patient deterioration when there was no clear treatment plan in place:

**Table 1. Demographics of focus group participants**

Data show the number of participants in each group

	GPs	General practice registrars	Practice nurses	Community nurses	Hospital nurses
No. participants	15	6	18	4	12
Gender					
Male	7	4	1	1	1
Female	8	2	17	3	11
Age (years)					
18–39	1	5	1	0	5
40–59	12	1	13	2	6
60+	2	0	4	2	1
Location					
Regional centre	5	4	14	0	12
Small rural town	10	2	4	4	0

*Some of the procedures you end up doing if they don't have [ACP] are so horrible and uncomfortable that you really want it to get sorted before it gets to that point. (Hospital nurse, regional city)*

#### HCPs' roles in ACP

Several components of ACP were identified, and HCPs commented on their roles within the broader ACP process (Fig. 1). Practice nurses described broaching ACP, typically while providing routine information and then referring interested patients on to their GP. GPs typically referred to their role as broaching ACP, but also engaging patients and involving family members, while providing prognostic and medical advice, with the majority of their discussion focused on documenting ACP discussions and communicating ACP to other health professionals:

*If someone has chronic renal impairment, whether it's going to be worthwhile having dialysis or not – you know, that's a medical decision and that's what we do talk about. . . and that's our role. (GP, regional city)*

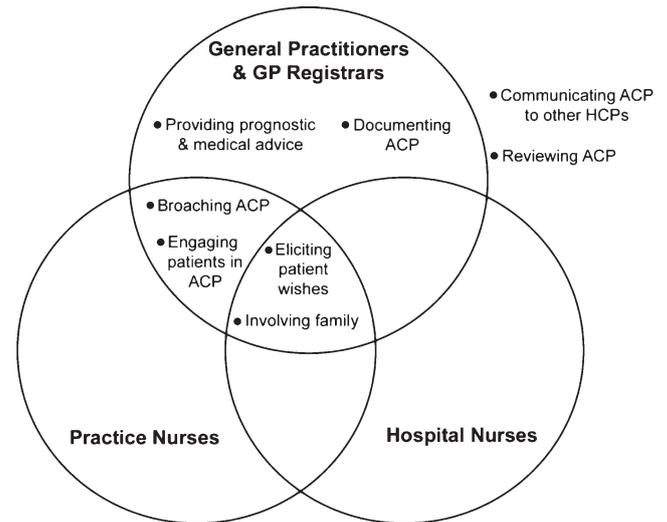
Hospital-based nurses talked mostly about eliciting patient wishes and involving family members in ACP discussions. They referred to discussions about treatment decisions being a doctors' role and outside their scope of practice. They discussed the importance of having ACP discussions documented to support their implementation of agreed care decisions:

*Once they're an inpatient then it's [ACP] got to be a doctor-led discussion. Generally we don't do it – as nurses, you don't start that one. If they want one [ACP], then you just get the [medical] team involved and they do that. (Hospital nurse, regional city)*

#### Barriers and enablers

Across the groups, several barrier and enabling factors were identified as influential in the use of ACP. Community-based nurses typically identified lack of time and confidence as barriers to discussing ACP:

*Being able to actually explain what advance care planning is for – people don't understand what it means and . . . as*



**Fig. 1.** Components of Advance Care Planning (ACP) identified and endorsed as part of role, by different healthcare professional (HCP) groups.

*a health professional, being able to relay that, which I don't feel that confident doing. (Practice nurse, regional city)*

Conversely, a small number of community-based nurses had specific experience that enabled their participation in ACP. One practice nurse indicated that her previous experience as a hospice manager made her very comfortable with ACP, while a similar opinion was expressed by a community nurse with experience completing the ACP process.

In the discussions with GPs and GP registrars, the desire to 'preserve hope', lack of patient engagement in ACP and complexity of ACP were identified as barriers, while past experience in ACP was an enabler. One GP with experience completing ACP was keen to assist other relatively inexperienced GP colleagues at the practice to learn more.

Hospital-based nursing staff identified legal concerns as a barrier preventing them from discussing ACP with patients.

#### Systems for communicating ACP

Participants in all groups discussed documentation of ACP and communication of these discussions both within the primary care health team and across healthcare settings. Participants recognised that there was no single, consistent process and proposed that there should be a standardised system for communicating ACP:

*How is it recorded? Who knows? I haven't had those discussions with the hospital about that. (GP, regional city)*

In rural communities some HCPs, particularly GPs, work across different healthcare settings. Some GPs working in rural towns suggested that ACP discussions do not need to be documented because, based on past discussions, GPs know what care their patients would want, and would typically provide care for their patients in primary care and local hospital settings. If not, they expected to be contacted by the treating HCPs for confirmation of the treatment plan. Some suggested that documenting ACP discussions would unnecessarily formalise the

discussions, proposing that this is required only if there is family conflict or to provide clarity for other HCPs caring for a patient:

*To me, the piece of paper was just a formality because I think we know our patients quite well most of the time. It's very rare that we have no idea about anyone or what they want to do. That's a very rare thing.* (GP, rural town)

## Discussion

The findings suggest that HCPs broadly agree with the concept of ACP and its benefits for patients and families, but also experience difficulties in practically implementing ACP in the rural context.

This study highlights significant differences in how rural HCPs conceptualise the process of ACP and their respective roles in it. The lack of clarity and understanding of each other's roles may lead to gaps in the ACP process and prevent its implementation in patient care. As recommended in a previous study examining the conceptualisation of ACP by key stakeholders (Rhee Zwar and Kemp 2011), there is a need for role clarification and a standardised system for distributing ACP documents. In particular, *reviewing ACP and communicating ACP to other health professionals* were highlighted by participants in this study as areas requiring improvement. Given the lack of enthusiasm shown for these roles, a dedicated coordinator may be needed to ensure that the process is completed.

The Australian Medical Association (AMA) states that 'The role of a doctor is characterised by their capacity to assume ultimate responsibility for a patient's care' (Australian Medical Association 2011). In this study, the majority of nurse participants looked to the doctor for leadership in ACP. However, a GP-led model, as proposed by the RACGP (RACGP 2012) has shown up several barriers, including lack of time and financial constraints (Rhee Zwar and Kemp 2012). Further, the GPs in our study recognised their own limitations in the coordinating role, associated with the demands of generalist practice in the rural setting.

Shanley and Wall (2004) suggest that nurses have attributes that make them appropriate to perform ACP. However, this study identified barriers to nurses' involvement, including the perception that ACP was 'a medical issue', lack of confidence, lack of time and concerns related to the legal aspects of ACP.

If practice nurses are going to expand their role in the ACP process, they require either previous experience, as shown in the study, or support and significant investment in training and mentorship from experienced ACP facilitators. This could potentially allow them to work collaboratively with GPs to coordinate ACP processes and provide enhanced care for patients.

## Study limitations

This study was conducted across rural and regional areas in south-western WA, hence the results may not be applicable to urban settings that have greater access to allied health professionals, medical specialists and tertiary hospital care. Several HCP groups (e.g. social workers, aged-care facility staff) who could potentially be involved in ACP were not represented in this study. Our discussions used homogeneous, intra-professional groups for safety of the participants but if inter-professional groups had

been used, this may have enabled HCPs to further refine ideas about professional roles (Aase *et al.* 2014).

## Conflicts of interests

None declared.

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