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ORIGINAL RESEARCH

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Advance care planning in rural New South Wales from the perspective of general practice registrars and recently fellowed general practitioners

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Abstract

Objective: This study examined advance care planning as delivered by general practice registrars and recently fellowed GPs in New South Wales rural settings. The facilitators and barriers to advance care planning uptake in these areas were investigated, as well as the state of general practice training on advance care planning.

Design: Qualitative descriptive methodology, involving semi-structured face-to-face and telephone interviews.

Setting: Primary care.

Participants: General practice registrars and recently fellowed GPs in New South Wales rural settings. Definition of rural using the Australian Standard Geographical Classification - Remoteness Area. Thirteen participants were included in the study.

Main outcome measures: Thematic analysis of interview transcripts elucidated key issues emerging from participants' accounts.

Results: Key barriers included doctor-dependent uptake, demands on doctor's time and the limited relevant resources available. Facilitators recognised were patient control in end-of-life care and long-standing relationships between GPs and their patients. Uptake among patients was low, and minimal training on advance care planning reported.

Conclusion: The lack of training opportunities in advance care planning during vocational training, especially when combined with the essential role played by rural GPs in initiating advance care planning and providing end-of-life care, appears to be a major problem that might contribute to poor uptake among patients in rural areas. This study demonstrated, however, the significant benefits that advance care planning could bring in patients living in rural communities if delivered effectively. Given that rural GPs face a number of barriers to providing routine health care, these results highlight an important need to provide GPs and rural communities with support, education, incentive, better administrative tools, options and greater awareness of advance care planning.

KEYWORDS

advance care planning, education, end-of-life care, medical treatment decisions, primary care, rural health services

1 | INTRODUCTION

An important component of end-of-life (EOL) care is advance care planning (ACP). Sudore et al (2017) defines ACP as "a 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. The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness."[1] ACP provides guidance for health professionals to meet patient treatment preferences should the patient be unable to make decisions for themselves.[2]

Some of the reported benefits of ACP include ensuring patient preferences for EOL care, increased family satisfaction and reduced hospital admissions[3] and care expenses.[4] The latter is important because the expenditure on EOL care far outweighs that at any other point in an individual's life.[5] A patient with an advanced disease averages up to eight hospital admissions in their last year of life, with a 60%-70% chance of dying in hospital.[6]

With older populations and worse health outcomes[7] than metropolitan areas, the system-level efficiencies potentially offered by ACP in rural areas might be especially attractive. Additionally, in New South Wales (NSW), the rural population has a higher percentage of individuals aged over 65.[8]

However, the prevalence of ACP in Australia appears to below.[9] The factors contributing to low uptake of ACP in rural regions are not well known, but research from urban settings highlights the lack of training of health professionals in EOL care and ACP as a key factor. This is vital, as GPs play an especially critical role in rural health care and hence EOL care and ACP, especially with the lack of palliative care teams and specialists available in such settings.[10,11]

In this study, we conducted interviews with GP registrars and recently fellowed GPs in rural NSW, with the aim of understanding their current level of involvement in ACP, the ACP training they received, and common barriers and facilitators to uptake of ACP in rural NSW.

What is already known on this subject:

- The benefits of advance care planning (ACP) described in the literature include ensuring patient preferences for end-of-life (EOL) care, increased family satisfaction and a reduction in care expenses.
- However, the prevalence of ACP in Australia appears to be low.
- Recent studies have identified a number of barriers to ACP uptake in various parts of rural Australia. However, the experience of recently fellowed rural GPs and GP registrars regarding ACP is relatively unknown.

What this study adds:

- The lack of training opportunities specifically related to ACP during usual vocational training of GPs, combined with the busy workloads of GPs and registrars, appear to be the major problems that might contribute to limited ACP uptake among patients in rural areas. This is problematic, as the study findings also highlighted the influential role played by rural GPs in initiating ACP and providing EOL care.
- GPs and GP registrars identified several enablers of ACP when implemented in the context of rural Australian communities, including long-standing relationships between GPs and their patients that can aid effective delivery of ACP.
- This study highlights key barriers and facilitators of ACP uptake, including the need to provide rural GPs and communities with support, education, incentives, better administrative tools and greater awareness of ACP to increase its uptake and, in this way, obtain the associated benefits for individuals, communities and the health system.

2 | METHODS

2.1 | Participants

The participants included rural pathway GP registrars and GPs who had completed vocational training during the past 5 years, who were working or had worked in rural NSW, as defined by the Australian Standard Geographical Classification - Remoteness Area.[12] Sampling was purposive, taking into account the diversity of locations, experience of the registrars, their sex and country of medical education.

2.2 | Recruitment

Participants were invited via an email distributed by the Rural Doctors' Association NSW, as well as through contacts acquired at conferences, through the University of New South Wales Rural Clinical School and other networking opportunities. Interested respondents completed the Participant Information and Consent Form.

2.3 | Data collection

The interview schedule was developed by the authors, who possess expertise in ACP and general practice research. The

1. What does Advance Care Planning mean for you?
Is it initiating discussions or filling in paperwork?
2. Have you had education or training in ACP?
3. Have you ever been involved in Advance Care Planning or having discussions with the patient or family about end-of-life issues?
Can you tell me about these experiences in your role as a doctor in the rural setting?
4. Have you ever worked in an urban area/large rural centre?
Has practicing in a rural area changed the way you deliver ACP or how is it different?
How did ACP compare between the two settings?
Is there anything that you would like to add that you feel is important about: the time taken, patient characteristics, resources use, family involvement, involvement or support from other health professionals, challenges, dealing with these challenges?
5. In your experience, what is the uptake of ACP among patients in rural NSW?• In your own workplace?• In your town or district?• Other health professionals in the area?
6. In your view, what are the benefits of ACP and which of these are unique to the rural setting?
7. In your view, are there any potential barriers or problems with ACP and are any of these unique to the rural setting?• Do you think these barriers would exist in an urban area?
Are there any aspects of rural healthcare that exacerbate or alleviate these problems?
8. In your experience is there anything that you believe would help to increase or improve ACP uptake in rural areas?
Would say similar methods would work in urban areas?
9. Do you think other rural GP registrars share similar views on ACP?
Demographic questions

FIGURE 1 Interview schedule

questions (Figure 1) were piloted and revised before interviewing commenced. Basic demographical data were collected from the participants. The interviews took place via telephone or face-to-face, lasted approximately 30 minutes, were audio-recorded, then transcribed by a professional agency. Theoretical saturation, in accordance with the qualitative nature of the research,[13] was reached with data collected from 13 participants.

2.4 | Data analysis

The transcriptions were de-identified, then thematically analysed using QSR NVivo 11 software, informed by Sandelowski's Qualitative Description methodology.[14] The first author (JL) completed the coding of all 13 interviews. In addition, six interviews were jointly coded by three co-authors (RH, WL and JR) to increase analytical reliability. The coding was discussed in project team meetings, and any differences were resolved through mutual agreement. The authors also reviewed the emerging coding tree and the first author's coding technique in the project meetings; the recommended changes informed the subsequent coding and analysis of the remaining data.

2.5 | Ethics approval

UNSW Human Research Ethics Panel for a low-risk research project: HC16805 on 28/11/2016.

3 | RESULTS

The 13 participants were aged 25-30 years and engaged in early stages of GP training. Most participants were women, did not have formal training in ACP, and worked in inner regional areas (Table 1).

The significant themes identified have been outlined using quotations from the interview transcripts. Other themes and subthemes not included in the text have been provided in Table 2. The participants also proposed a number of suggestions for increasing the uptake of ACP in rural NSW (Table 3).

3.1 | Uptake of ACP

The uptake of ACP by patients of the interviewees was mostly described as "poor" and often only associated with guardianship paperwork, financial planning and life insurance.

> GP3: So far I haven't actually seen any [patient], like I said before—other than one person—who would actually voluntarily just want to do it.

3.2 | Training in ACP

Ten of the thirteen participants did not receive formal training in ACP (see Table 1), with only non-specific discussions

TABLE 1 Participant demographics (n = 13)

Demographic	Frequency
Age (y)	
25-30	7
31-36	3
37+	3
Sex	
Women	9
Men	4
Stage of training	
GPT1-extended skills (GPT4)*	8
Awaiting fellowship & fellows**	5
Birth country	
Australia	7
Overseas	5
Country of basic medical degree	
Australia	10
Overseas	3
Advance care planning training	
Non-GP*** or nothing formal	10
GP	3
Palliative care training	
No	10
Yes	3
Rural classification[d]	
RA2	9
RA3	4

*GPT1 refers to first 6 month placement in general practice vocational training, which is followed by GPT2 (second 6 month placement), GPT3 and GPT4 (also known as extended skills).
**Fellowship/a Fellow refers to an individual who has completed the GP examinations and is no longer a registrar.
***Refers to a setting that is not in general practice, eg hospital.
[d]Refers to the Australian Government Classification of Rural and Remote; RA2: Inner Regional, RA3: Outer Regional.

at workshops taking place in the initial months of vocational GP training in rural centres. Many participants explained that they had learned about ACP as a junior doctor and that most of their learning in the GP setting was experiential and guided by the anecdotal teaching of supervisors and more experienced GPs within their workplace.

3.3 | Barriers to ACP

Participants described a number of barriers to their involvement in ACP. These factors could be categorised relating to the patient, family, doctor/practice and those related to rurality (Table 2). The following are three of the most pertinent barriers mentioned by the participants.

3.3.1 | Doctor-dependent uptake of ACP

Lack of patient understanding of ACP was reflected as an important barrier. Hence, in order for ACP to occur, participants noted that it had to be initiated by them or another health care professional, with many describing the uptake to be "doctor-dependent."

> GP3: Unless the doctor says let's talk about it, or unless there's some government regulation that says you must do it, [the patients] don't do it.

3.3.2 | Demands on doctor's time

The sensitive nature of ACP and EOL discussions, as well as the complexity of the paperwork, created a substantial barrier for the participants. Difficulties in making the time to help the patient with paperwork or initiate discussions was frequently reported and seen to be more pertinent in rural areas where GPs were considered more time poor.

> GP7: It's hard to practically implement it because you're time short often or running late and I think it's such a personal discussion that you really need to take a good amount of time to sit together with the patient and talk through it.

ACP and EOL discussions did not feature prominently in the routine clinical practice of the interviewees.

> GP9: I think it's something that just mostly gets forgotten amongst the other 30 or 40 things that you're meant to do for every patient in every consult.

3.3.3 | Lack of specialist support in rural areas

Participants frequently commented on the lack of access to palliative care services, specialists and tertiary care in the rural setting. Complex, critical decisions were often made without acute specialist support; for instance on whether to transfer elderly patients for further care, which often involved travelling long distances.

> GP3: …also the lack of specialists. For some patients, when you talk about advanced care planning, say [a patient] with [terminal] cancer—they prefer to see a specialist for a second opinion, and we don't have many specialists

TABLE 2 Other subthemes developed from results

Theme	Category	Subtheme	Quote
Barriers	Patient	No patient interest	
		Patient understanding of advance care planning	
		Patient expectations of health care	
		Patient reluctance to discuss	
		Differing religious and cultural views on death	
	Family	Family not living close by to patient	
		Family expectations and conflict	
	Doctor/practice	Lack of standardised documentation	GP5 "And having a standardised advanced care plan across the state or the country is a big barrier as well… [so having] a standardised form of paperwork that would be able to be used on all different types of medical software everywhere, so that you can just populate it up"
		GP registrars temporary	
		Internationally trained GPs	
		Daunting discussion for GPs to have with new patients	GP2 "I think that we know why it's important, we recognise the importance. Maybe doing it is a little bit daunting"
	Rurality	Rural residents less frequently use health care	
		Anguish involved in transferring between levels of care over long distances	"it will prevent the distress of a patient being transported several hours to a major hospital if they didn't want to in the first place and some advanced care plans"
Benefits and facilitators		Reduce community and medical expenses	
		Patient control and the right to choose	
		Doctor-patient relationship improved	
		Contacting family in crisis is difficult	
		Family, patient and health care professional clarity on care	
		Health care professional assurance of wishes met	
		Minimising cost for rural families in long distance transfers	
		Save on limited resources in rural areas	
		Ability to remain in rural home town	

here. So they are unable to make maybe a well-informed decision on time.

While some participants spoke about this as a barrier, some also acknowledged that ACP could facilitate these transfer decisions.

> GP11: …something where they need to travel to metro areas to get special attention or some specialised treatment, some of them prefer not to do it. But that's when they choose to be in their comfort zone and not travel.

3.4 | Facilitators of ACP

The participants described two key facilitators that can improve the uptake of ACP in rural areas.

3.4.1 | Long-standing relationships in the rural setting

A facilitator of ACP uptake unique to the rural setting was the relationship between GPs and their patients. Over half the participants spoke about the influence of continuity of care on ACP uptake, and their belief that the doctor-patient

TABLE 3 Suggestions for increasing advance care planning (ACP) uptake in rural New South Wales

Better documentation and administration	Complete with financial planning
Complete with Medicare health assessment for older persons (75+)	Create more liaison between GPs, hospital and palliative care team
Culture shift (normalise conversations about ACP)	Target certain groups of people
Remuneration for GPs	Advertising (radio, posters, television)
Ensure family awareness	

relationship was stronger in rural areas than in urban settings.

> GP1: I think they do have a lot of long-standing relationships with GPs in the area. That's something that a lot of rural patients tend to take pride in. And from that point of view, it's easier to have those discussions, I think, rather than meeting a patient for the first time and starting from scratch or not having as much continuity as they may potentially have in the cities.

3.4.2 | Patient's right to choose

Patient control over EOL care was acknowledged by every participant as a key reason for engaging in ACP. Particularly pertinent to rural areas was the ability of patients to express their wishes to stay in a location of their choice to prevent distress associated with changing care levels.

> GP7: So if you're in a rural town, you often need to get transported out if you are sick and so if you had a plan in place…it will prevent the distress of a patient being transported several hours to a major hospital if they didn't want to in the first place.

4 | DISCUSSION

The findings suggest that rural GP registrars and recently fellowed GPs face a number of challenges in engaging in ACP with their patients, and that these are exacerbated by the social and geographical factors that are more common in rural areas.

The study participants shared a common experience of discussing ACP with only a few patients in rural general practice. It was more common to have been involved in ACP in the hospital and aged care settings. This might be due to the majority of the participants being at early stages of GP training, but similar sentiments on minimal involvement were discussed by recently fellowed GPs and supported by the findings of a study conducted in rural Western Australian hospitals where only a minority of patients had any form of ACP on admission.[15]

An important barrier to ACP highlighted in the study is the lack of time of clinicians. The demands on time of rural generalists means that there are significant difficulties in efficiently incorporating all facets of EOL care into planning.[3]

The study also found a pattern of doctor-dependent uptake of ACP. Participants described how essential doctor initiation was in the ACP process and how, when combined with a number of doctor-related barriers, this leads to poor uptake of ACP. This finding is supported by Sinclair et al[16] who found a positive association between doctor confidence and likelihood of initiating ACP. The need for multidisciplinary input, such as that from a practice nurse, might be a way to alleviate this pattern, but was beyond the scope of this study.

The participants identified that in rural areas there is the added difficulty of assisting patients with EOL decisions without access to specialists and palliative care teams, in addition to little training received. This means that specialist opinions on EOL decisions can be difficult to obtain. These findings are consistent with concerns raised in the literature of lack of access to health care in rural areas, associated with higher levels of chronic disease and worse health outcomes.[17] As suggested by the participants, the provision of additional training in ACP and EOL care might equip the rural registrars with the knowledge and resources to successfully integrate ACP into practice.

However, the current study demonstrated the benefit of ACP in rural areas; planning ahead enables patients to decide on at which point they would like to be transferred to higher level care, and when they prefer local treatment options close to home.

Participants perceived that in rural areas the relationship between the GP and patient acted as a facilitator to ACP uptake. This was due to the continuity of care provided by GPs, and better understanding of the patient's social contexts. These findings add to the insights from the literature that rural residents often have a greater sense of community and belonging than their metropolitan counterparts.[18]

The findings indicate that relatively little education on ACP is provided to GPs during vocational training and that the majority of confidence in ACP comes from experience. Most participants did not receive dedicated teaching on ACP but it might have been covered during a session on palliative care. Most of this teaching occurred in hospital whilst as a junior doctor, or during medical school.

This study aimed to gain an insight into the thoughts and experiences in ACP of registrars and recently fellowed GPs in

rural NSW. The lack of training opportunities in ACP during vocational training, combined with GP barriers to providing EOL care, appears to be a major problem that might contribute to poor uptake in rural areas. However, this study has demonstrated the significant benefits that ACP could bring to patients living in rural communities. There is an important need to provide GPs and rural communities with support, education, better administrative tools and greater awareness of ACP.

4.1 | Limitations

Due to the geographical distances of participants, many interviews were conducted using the telephone. This might have led to a reduction in social cues detected during interviews.[19] The role of the multidisciplinary team in ACP in the GP setting was also not addressed.

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CONFLICT OF INTEREST

None declared.

DISCLOSURE

The primary investigator received a medical student scholarship from GP Synergy for the completion of a research project.

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