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Research

Barriers and facilitators to nurse-led advance care planning and palliative care practice change in primary healthcare: a qualitative study

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Abstract. Primary care settings are ideal for initiating advance care planning (ACP) conversations and assessing palliative and supportive care needs. However, time constraints and a lack of confidence to sensitively and efficiently initiate such discussions are noted barriers. The Advance Project implemented a national multicomponent training package to support Australian general practice nurses (GPNs) to work with GPs to initiate ACP and palliative care conversations in their practice. This paper reports on semistructured interviews conducted with 20 GPNs to explore barriers and facilitators to implementing the Advance Project model. Participants identified a range of factors that affected implementation, including lack of time, limited support from colleagues, lack of knowledge about systems and funding processes in general practice and a need for better alignment of the Advance Project resources and practices with general practice information management platforms. Barriers related to professional roles, particularly the lack of clarity and/or limitations in the scope of practice of GPNs, highlighted the importance of defining and supporting the roles that different primary health practice staff could play to support implementation of the model. The findings underline the need for complementary training in the Advance Project model for GPs and practice managers to enable a team-based approach to implementation.

Keywords: advance care planning, general practice, primary healthcare, palliative care, general practice nurses, patient care.

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Introduction

Numerous barriers continue to affect Australians' experiences of end-of-life care, including timely access to appropriate care. One way to facilitate early access to palliative care and advance care planning (ACP) is through primary care (Franklin *et al.* 2020). The growth of the general practice nursing workforce

Box 1. Definitions of key terms used in this study

Advance care planning is a 'process of reflection, discussion and communication that enables a person to plan (in advance) for their future medical treatment and other care, for a time when they are not competent to make, or communicate, decisions for themselves' (RACGP 2016).

Palliative care can be defined 'as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual' (WHO 2016).

Supportive care is care that eases the symptoms of a disease or the side effects of treatment for a disease. Supportive care does not cure the disease. Its aim is to improve quality of life and it addresses the psychological, social and spiritual needs of the patients and their carers (Fitch 1994).

creates an opportunity for nurses to fill this gap in care delivery (Stephen *et al.* 2018; Rogers *et al.* 2019; Franklin *et al.* 2020). The definitions of 'advance care planning', 'palliative care' and 'supportive care' used in this study are provided in Box 1.

The Advance Project (www.theadvanceproject.com.au) supports general practice nurses (GPNs) and GPs to initiate ACP and palliative and supportive care needs assessment into general practice. The first phase of the project (Phase 1; 2016–17) focused on GPNs as a key to system change. The training comprised an evidence-based toolkit and multicomponent training program to support GPNs to: (1) promote awareness of ACP among older people and those with chronic and complex conditions; (2) identify patients who may benefit from a palliative approach; and (3) undertake an assessment of needs, including symptoms, questions, concerns and carers' needs. The learning package was designed to build GPN capacity to tailor their approach to each patient in accordance with the person's needs and preferences, and to identify those requiring specialist palliative care referral.

The Phase 1 toolkit was informed by a literature review (Lawrence and Tieman 2016), and expert and stakeholder input. The toolkit includes six screening and assessment tools to facilitate initiating ACP and the identification of palliative and supportive care needs, as well as a guide providing a structured approach to using the tools in general practice (Supplementary Appendix S1). The training program included: (1) online modules that demonstrated how to use the tools with patients and carers in routine practice and how to explain the program to GPs; (2) face-to-face workshops; and (3) telementoring support from a specialist palliative care nurse for the duration of the project. The program sought to equip GPNs to lead system-level change by giving them the knowledge, confidence and tools to undertake evidence-based ACP and needs assessment of patients and carers.

There are many known barriers to implementing new programs and practice-level change in general practice (Reeks *et al.* 2020). Among the most commonly reported barriers are 'time constraints', a term often used for a range of associated issues, including problems incorporating interventions into already busy workloads and sustaining interventions without funding (Stephen *et al.* 2018). Other barriers commonly reported include organisational factors, such as insufficient trained staff, and incompatible information technology systems (Miller *et al.* 2019). Patient characteristics, such as a reluctance to talk about dying and death, cultural background, language preferences and patients' perspectives of their relationships with healthcare providers, have been reported as barriers to implementing ACP interventions in primary care settings (Rogers *et al.* 2019). Existing resources to support GPs in the area of ACP and palliative care are available (e.g. Program of Experience in the Palliative Approach 2021); however, there are frequent reports that GPs lack time to initiate ACP or palliative care needs assessment (Franklin *et al.* 2020). A recent review of barriers to GPN-led chronic disease management interventions reported inadequate GPN preparation, lack of support, workload and lack of funding as key barriers to interventions (Stephen *et al.* 2018).

This paper reports the findings of one component of the evaluation of Phase 1 of the Advance Project and addresses the question, 'What barriers and facilitators to introducing advance care planning and palliative care practice change were experienced by general practice nurses?'.

Methods

Study design

A qualitative study was embedded in the larger Advance Project evaluation (Nagarajan *et al.* 2019). Semistructured interviews were undertaken with GPNs to assess the costs, feasibility, acceptability, perceived utility and impacts of delivering the training and implementing the toolkit in general practice. The focus of this paper is specifically on the barriers and facilitators.

Recruitment and sample

GPNs who registered to undertake one or more components of Phase 1 training were eligible to participate in the study. Participants had to be a registered or enrolled nurse who was currently working in a general practice in Australia. At the time of recruitment, 240 GPNs had completed all components of the online training and 166 had completed some components. Twenty-seven workshops were held across all states and territories, including 10 rural/regional locations. These workshops were attended by 348 nurses.

Potential participants were given the option, via the project website, to consent to researcher contact for a semistructured interview. Potential participants were sent an information letter and consent form to obtain written consent and schedule an interview time.

Data collection

Semistructured interviews were conducted via telephone by the evaluation coordinator (SN). Interview questions were derived from a literature review and expert input. A sample of these items is provided in Box 2. All interviews were audio recorded and transcribed verbatim. Interview duration ranged between 30 and 60 min.

Box 2. Excerpt from the interview schedule

What was your overall experience in taking part in the Advance Project training?

Have you used the Advance Project assessment tools in your practice?

i. If not, why not?
ii. What would help you to implement the Advance assessment tools in your practice in the future?

Were you able to engage the people you work with regarding implementing the Advance assessment tools in your practice (e.g. GPs, practice managers)?

i. If yes, what was this like?
ii. If no, how might they be engaged in the future?

What impact did using the Advance assessment tools have on your workload and workflow in the general practice? How feasible was it to implement the assessments into your practice?

Overall, is it feasible for you to implement the Advance care screening interview/full supportive care assessment/carer assessment tool and any follow up into your routine practice? If not, why not?

Data analysis

Data were analysed using the thematic analysis steps proposed by Braun and Clarke (2006). Each transcript was read at least twice by the lead qualitative researcher (SN) to note down initial ideas and key messages. The transcript was coded with appropriate labels and codes, along with field notes. The codes were then combined and categorised into higher-level themes, again consolidating all data relevant to each theme identified. The interview transcripts and codes were shared and discussed collaboratively among the team, and a final thematic structure was developed.

Following this initial inductive analysis the Theoretical Domains Framework (TDF) was used deductively as a sensitising lens through which to review and refine themes. The TDF recognises that practice change will depend on many factors and is built on a synthesis of concepts from a range of theoretical approaches (Cane *et al.* 2012). The TDF has been used widely in practice change and implementation research, including in primary care (Phillips *et al.* 2015; Reeks *et al.* 2020). The extent to which barriers and facilitators identified by participants through the inductive analysis reflected the TDF domains was discussed by the team as a way of considering potential mechanisms and processes affecting implementation, as well as implications for future strategies that may support practice change.

Ethical considerations

Ethical approval was obtained from the University of Sydney Human Research Ethics Committee (Project no. 2016/1025), and written consent was obtained from all interview participants. The Consolidated Criteria for Reporting Qualitative Health Research (COREQ) was used to guide reporting this study (Tong *et al.* 2007). Participants were provided a A$50 gift card as reimbursement for their time.

Results

Twenty GPNs participated in the interviews. Participants were all female and employed across five Australian states (Table 1). Most (65%) were from metropolitan areas and worked in small (1–2 GPs/0–1 GPNs) to medium (>2 GPs/>1 GPNs) practices. Most participants worked part-time; their experience working in general practice ranged from 1 to 20 years and they came from a mix of clinics that used mixed or bulk billing.

Table 1. GPN participant demographics

M, mentoring; NSW, New South Wales; O, online training; SA, South Australia; W, workshop; WA, Western Australia

Participant	Experience working in general practice (years)	State	Practice classification	Advance Project training completed
P1	<3	Queensland	Metropolitan	O, W, M
P2	17	NSW	Metropolitan	O, W, M
P3	<1	WA	Metropolitan	O, W, M
P4	18	SA	Rural	O, W, M
P5	6	SA	Rural	O, W, M
P6	10	Victoria	Metropolitan	O, W, M
P7	<1	NSW	Metropolitan	W
P8	3	Victoria	Metropolitan	O, W
P9	13	Victoria	Metropolitan	O, W
P10	4	WA	Metropolitan	O, W
P11	>10	SA	Rural	O, W, M
P12	2.5	SA	Metropolitan	O, W, M
P13	8.5	Victoria	Metropolitan	O, W
P14	2	NSW	Regional	O, W, M
P15	3	SA	Metropolitan	O, W, M
P16	4	NSW	Regional	O, W, M
P17	7	Victoria	Rural	O, W, M
P18	17	Queensland	Metropolitan	O, W
P19	>20	WA	Regional	O, W
P20	15	NSW	Metropolitan	O, W

Approximately half the participants had implemented one or more of the Advance Project tools. Many participants reported they had started having ACP discussions for the first-time after training. Participants also reported writing detailed patient records regarding ACP discussions and greater engagement with GPs about patients' ACP or palliative care needs after training. Participants who had implemented tools noted positive patient outcomes, including patients feeling more supported and satisfied with care, additional services being provided and greater engagement with health professionals.

Data revealed eight key barriers and two facilitators. Barriers to implementing the tools included: lack of practice support, workforce issues, lack of time, practice infrastructure issues, scope of GPN roles, costs of implementation, patient characteristics and lack of referral options to meet identified needs. Facilitators to practice change could be classified into two broad categories: involving the whole practice in planning for change and incorporating practice change into routine workflow.

Barriers

Lack of practice support

Lack of support from GPs and practice managers was the most frequently described barrier. This was described in various ways, including as a culture of resistance to change, lack of interest, difficulty achieving consensus about change sometimes due to a large number of practice staff and a general reluctance of GPs to raise difficult topics, such as dying, with patients. GPs were also described as being more interested in discussing disease- or treatment-related issues rather than ACP or supportive care matters:

> GP buy-in, that's the big barrier – is that often the GPs don't feel these questions are necessary and don't feel that the time taken to really discuss with a patient their needs and their requests…So that is actually a little bit difficult [Participant (P) 13].

Workforce issues

Participants described lack of familiarity with the tools among other staff, including other GPNs or GPs, as a barrier. Some participants stated that because junior nurses at their practices were still learning, they could not be overburdened with additional training. Participants also described staff shortages, a casual workforce and shift work that affected the skills mix:

> …but my difficulty with the young nurses as well is both of them are doing training at the moment…they're studying for that. So for me to introduce another thing…at the moment, they've just got too many other things on their plate [P18].

Lack of time

A key concern was the perception that the tools were time consuming to implement and a shift in model of care:

> That isn't a conversation where you just get to hand them a piece of paper. It's a bigger conversation…That can sometimes open up a dialogue that takes much longer than the time that's typically allocated for a GP consultation. So I guess in general GPs are very reactive. They deal with what the patient's concerns are when they present on the day. They don't in general tend to proactively then explore or probe into other issues that the patient hasn't raised [P20].

Practices had many priorities to juggle, and other priorities, such as accreditation, seasonal factors and addressing the other needs of patients in a busy clinic, were prioritised over toolkit implementation. Some GPNs did not initiate ACP or screening conversations with patients because they believed that the appointments would consume more time than was available, particularly if question arose:

> I came away from that education with grand ideas of changing the world and getting them in place straight away but it's just not so easy when you're looking at all these patients that have come in for all different things that we do here. I do wound dressings and immunisations and baby checks and there's so many other things that you do that it is really hard to fit stuff in [P11].

Practice infrastructure issues

The use of paper-based tools separate to electronic medical records was perceived as a barrier to their uptake. Not having project tools as part of existing practice software programs inhibited practice change:

> We don't want paper really, so we want to have things that we can fill in that are part of, even for it to be part of our software that we use then that would be really helpful [P2].

Further, the GPNs' ability to perform assessments was limited because patient histories were not always clear or provided:

> …sometimes the doctors don't tell you as much information so you don't know exactly what's happening with some people when they ask you to say do an [electrocardiogram] or something, you don't necessarily know what's going on with them [P19].

Lack of privacy or physical space to conduct assessments were also reported as barriers:

> …it's about the opportune times, but sometimes I work in the treatment room. That's a bit of a fast-paced area. It's actually not that private. It's about having the opportunity to speak with someone privately [P13].

GPN role

Some participants were also unsure about who was responsible for initiating and managing ACP discussions. In some practices, the GPN role focused on tasks such as vaccinations or wound checks, rather than on ACP or palliative and supportive care needs assessment:

> Well yeah, the fact that the nurses aren't utilised really to do this. We just do the straight-out clinical checking of people and that's it. So yes the barrier is the fact that the nurses aren't as involved with that type of thing where we are [P12].

Some participants reported a lack of confidence to initiate ACP or supportive care discussions despite the training. Reasons for lack of confidence included limited GPN experience or their work setting, including part-time employment and difficulties in engaging GPs. Other participants described a lack of experience in presenting practice change to their practice. They believed they needed to have clarity about how they would use the tools before approaching GPs to discuss their implementation:

> I spoke to the practice managers initially, and like I said they were keen and said, okay, discuss it at one of the meetings. I wasn't exactly sure how to go about that yet because I've not really presented anything at a meeting yet, so that can be my own personal barrier, my own thing to get through which I look forward to doing, but I'm not sure how to approach it yet [P9].

Costs of implementation

Some participants reported concerns about the costs of implementing practice change, including the lack of clarity regarding which Medicare item numbers could be used for billing. Other cost barriers included the absence of funding for GPN time and no explicit funding or financial incentives to initiate ACP or palliative and supportive care needs assessment:

> So asking all those questions would add say at least a good 10 minutes more again and then financially for the practice, that's an issue because then needing more time and it costing the practice then because they've got to pay us nurses and there's no way to be reimbursed for our time [P19].

> Well the thing is, right, if we want something to happen in general practice that isn't happening, and there's lots of history of this…Well the government has put the practices into place, which then allowed for there to be resources allocated to that, and the practice would see the financial return. Let's face it, at the end of the day, they're small businesses [P20].

Patient characteristics

Some participants described patients' reluctance to engage in discussions:

> …the main barrier is patients – being able to talk to patients and being able to explain to them what it's about. Because they're all a bit reluctant when you first try to talk about it [P15].

The level of literacy required to use the tools was seen as a barrier for patients from non-English-speaking backgrounds or patients with low literacy (reading and writing) skills, those who were too frail and those with poor mental health. Participants described how some patients prioritise immediate health problems rather than their future wishes. Some participants reported that patient reluctance to complete the tools could be based on their assumptions about understanding that their GP has about their preferences.

> …sometimes literacy can be a problem. However, I believe the people that I gave it to were [literate] so that's why I gave it to them; but they were quite elderly and they didn't write down main problems. They used the tick box. They didn't want to explain any problems because they believe that the GP knows them that well. They also believe that some of them don't want to bother the GP with some of those things… [P4].

Participants also emphasised a need to not overload patients with information during health assessment appointments, and that a balanced approach was needed between verbal and written information.

> …like everyone when you talk about something if you give them too much information then you know you've lost them. Then they'll go home and they'll probably either put it on the bench or they'll do what a couple of the doctors said to me, they then turn around and see the doctor next time and say I don't know what this is about…So I've got to be careful not to give too much information so that too much information I find is a problem [P19].

Lack of referral options

The lack of or limited access to palliative or supportive care services was described as a barrier by some participants. Participants identified that patients were sometimes not happy with care options located a long distance from home or not subsidised by funding, and some participants said this interfered with their use of the tools:

> The doctor will say, 'Well Mrs Smith needs a podiatrist, can we do anything for her?' Then you'll talk to Mrs Smith and you can arrange it but then the Medicare criteria are very, very strict so they may not be eligible-…Then there's the financial side, some providers in the allied health will not bulk bill, so they have a gap fee which is fair enough because some of them I know do extremely long consults and really good service for very little money [P19].

Facilitators

Involving the whole practice

Many participants emphasised the need to have a good plan for implementation to enable systematic patient identification and management. Elements of the plans included practice policies to include assessments within chronic disease and health assessments (HA) for those aged 75 years and older (75+ HA), and piloting implementation to identify and address any challenges. Developing a good working relationship with GPs, and building their trust and confidence, was described as important for successful implementation. Some participants introduced and discussed implementation during practice meetings:

> When we came back [after training] and we took it to our first clinical meeting they were interested in what we had been and learnt. So I've spoken with them [GPs] and kept on saying to them, well, would you be surprised and should we be offering more supportive care if they qualify on the tool…I'm more familiar with them now since that training…the doctors were receptive but I have to keep pushing it [P17].

Other facilitators included being organised, managing time effectively and using less busy times for the assessments.

Incorporating new practices into existing consultations

Although some participants acknowledged lack of time to include the tools in existing consultations, others identified using consultations such as the 75+ HA to initiate ACP conversations as a facilitator to uptake. This meant that time spent conducting assessments could be funded by existing Medicare item numbers, overcoming the issue of lack of funding for GPN time:

> Well we already do like sometimes a 75-year-old assessment and we give them half an hour to do it. Because basically we do it and then give it to the doctor to take over. So, it could be definitely implemented and it's definitely beneficial because it does identify things that probably patients wouldn't tell their doctors. They'll forget anyway. You know when people come in and they forget. So yeah, it probably could be implemented. It would probably have to be done on a day that is not busy. So not a Monday, not a Friday. Pick another day so the

> doctor could get them to come back. It doesn't have to be all done in the one hit, it can be done over several appointments [P3].

Discussion

To our knowledge, this is the first study of barriers and facilitators to implementing a national program for ACP and palliative and supportive care assessment led by GPNs. The barriers and facilitators identified in this study are consistent with past research and evaluation findings regarding implementation of practice change in primary care (McInnes *et al.* 2015, 2017; Stephen *et al.* 2018; Rogers *et al.* 2019; Reeks *et al.* 2020).

The barriers and facilitators identified reflected domains from the TDF (italicised terms below). There was good evidence (Nagarajan *et al.* 2019) that participants had acquired appropriate procedural *knowledge* about how to use the Advance Project tools, and had the *skills and confidence* and willingness to use them and appreciated their value for their patients. In contrast, these interviews revealed low levels of *knowledge* about general practice funding and systems (e.g. appropriate Medicare item numbers, billing systems and how bulk billing and private billing processes in their practice work). This finding has direct implications for implementation and sustainability, because it limits the ability of GPNs to address cost implications of new practice changes and to overcome cost-related barriers. Implementation can be facilitated if practices where GPNs work have good knowledge of suitable billing options for the appointment, support the identification of opportunities to use less busy times for activities that are not billable or have discussions about in-depth topics over multiple appointments.

Barriers related to lack of clarity and/or limitations in the scope of practice of GPNs highlighted the importance of defining *professional roles* (TDF domain) for implementing the Advance Project tools. The GPNs in this study saw their professional role very clearly as one of supporting GPs in providing holistic patient care. However, concerns were also raised about limitations with professional boundaries of GPNs in general, and participants spoke about the need to develop close working relationships with GPs to get them on board with the concept of GPNs initiating ACP and palliative and supportive care needs assessment. This reflects an implementation factor acting at the system, context and individual levels. The TDF suggests that a coherent set of desired professional behaviours and personal qualities of GPNs is needed for successful implementation of models of care or interventions (Cane *et al.* 2012). This should include descriptions of the roles that different primary health practice staff, including GPs and practice managers, could play to support the implementation of the model. Challenges around definitions of roles of different primary healthcare professionals have been previously identified in GPN-led interventions (Stephen *et al.* 2018). Future interventions need to consider how to explicitly define and discuss roles to promote collaboration and shared understandings.

To achieve successful practice change, the TDF would suggest that general practices need to ensure that they provide an *environmental context and resources* that encourage capacity building, independence, social competence and adaptive behaviour. This includes ensuring that tools and resources are compatible with common medical records systems and that practice infrastructure is developed to support implementation. Such culture change has to engage GPs and practice managers.

Interestingly, although other ACP studies have identified health professionals' fear of discussing end-of-life issues as a barrier to implementing ACP (Slort *et al.* 2011; Lund *et al.* 2015; Crimmin *et al.* 2021), the nurses who participated in the present study did not raise this as an issue to implementing the Advance Project resources. The GPN interview participants stated that, in fact, the Advance Project training gave them the confidence and structure to initiate ACP conversations. A previous pilot study showed that a GPN-led approach to initiating ACP discussions with older general practice patients during routine health assessments was acceptable and feasible for both nurses and patients (Franklin *et al.* 2020). Miller *et al.* (2019) similarly reported that with adequate training and mentoring support, GPNs are able to initiate and facilitate ACP conversations with patients, and, furthermore, their involvement in ACP can have significant benefits for patients.

This study had some limitations; in particular, it only represents GPNs' views. Gathering perspectives from all practice staff and patients would enhance our understanding of how ACP and palliative care could be better integrated into primary care.

Conclusion

Implementation of the Advance Project resources was helped when it was consistent with GPNs' existing roles and the GPN had practice support for change. Given that many of the barriers noted in this study mirror those found in other investigations of general practice intervention, it is timely for these to be addressed by policy makers, primary care organisations and practices. Finally, this study highlighted a need to engage GPs and practice managers in similar training to enable a stronger practice-based approach to implementation of advance care planning and palliative care needs assessment. The study findings have informed development of the second phase of the Advance Project, which includes an expanded suite of resources and training for nurses, GPs and practice managers to enable team-based initiation of advance care planning and palliative care needs assessment, now available through the Advance Project website (www.theadvanceproject.com.au).

Data availability statement

As per ethics approval, full interview transcripts are only available to the research team.

Conflicts of interest

Virginia Lewis is the Editor-in-Chief of *Australian Journal of Primary Health* but was blinded from the peer-review process for this paper.

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