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Emilia Fan
University of New South Wales

Joel J. Rhee
University of New South Wales, jrhee@uow.edu.au

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Abstract

Nurses are well positioned to initiate and conduct advance-care planning (ACP) conversations; however, there has been limited research on practice nurses performing this role in Australia. The aim of the present study was to understand the beliefs, attitudes, perceptions, confidence, training and educational needs of New South Wales practice nurses with regards to involvement in ACP. A cross-sectional online survey was conducted in August to October 2014. Nurses were recruited through nursing organisations and Medicare Locals. There were 147 completed surveys (n = 147). Participants were mostly female registered nurses, with a median age of 50, and 6 years of practice-nurse experience. Practice nurses were generally positive towards their involvement in ACP and believed it would be beneficial for the community. Their confidence in initiating ACP increased as their familiarity with patients increased. They showed a high level of interest in participating in training and education in ACP. Barriers to their involvement in ACP included the lack of a good documentation system, limited patient-education resources and unclear source of remuneration. Nurses were also concerned over legalities of ACP, ethical considerations and their understanding of end-of-life care options. Nevertheless, they were highly receptive of integrating ACP discussions and were willing to enhance their skills. These findings uncover a need for further training and development of practice nurses for ACP discussions.

Keywords

self-reported, survey, wales, practice, nurses, conducting, advance-care, planning, (acp), initiatives, general-practice, setting, levels, confidence, motivation, south

Disciplines

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A self-reported survey on the confidence levels and motivation of New South Wales practice nurses on conducting advance-care planning (ACP) initiatives in the general-practice setting

Emilia Fan^{A,B} and Joel J. Rhee^A

^ASchool of Public Health and Community Medicine, The University of New South Wales, Sydney, NSW 2052, Australia.

^BCorresponding author. Email: emilia_fan_aimin@ttsh.com.sg

Abstract. Nurses are well positioned to initiate and conduct advance-care planning (ACP) conversations; however, there has been limited research on practice nurses performing this role in Australia. The aim of the present study was to understand the beliefs, attitudes, perceptions, confidence, training and educational needs of New South Wales practice nurses with regards to involvement in ACP. A cross-sectional online survey was conducted in August to October 2014. Nurses were recruited through nursing organisations and Medicare Locals. There were 147 completed surveys ($n = 147$). Participants were mostly female registered nurses, with a median age of 50, and 6 years of practice-nurse experience. Practice nurses were generally positive towards their involvement in ACP and believed it would be beneficial for the community. Their confidence in initiating ACP increased as their familiarity with patients increased. They showed a high level of interest in participating in training and education in ACP. Barriers to their involvement in ACP included the lack of a good documentation system, limited patient-education resources and unclear source of remuneration. Nurses were also concerned over legalities of ACP, ethical considerations and their understanding of end-of-life care options. Nevertheless, they were highly receptive of integrating ACP discussions and were willing to enhance their skills. These findings uncover a need for further training and development of practice nurses for ACP discussions.

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Introduction

End-of-life (EOL) care is important and needs to be incorporated and introduced into primary-care settings to reduce health inequity and prevent avoidable suffering (Sixty-Seventh World Health Assembly 2014). When nearing life's end, advance care planning (ACP) is valued when the individual is unable to decide for themselves on issues regarding their medical care (Shanley and Wall 2004). The advance care plan holds information on the conversations and understandings of a patient's comprehension on their health status, wishes, ethical beliefs and available resources (Ratner *et al.* 2001). It enables healthcare providers to arrange quality care consistent to the wishes of an individual (Badzek *et al.* 2006). The policy importance of ACP is well established. The New South Wales government has recognised the importance of ACP in caring for individuals with chronic illnesses and EOL care by mapping out plans to encourage its success (NSW Ministry of Health 2013). The Victorian Government has also announced similar interests (Victorian Department of Health 2014). Despite the recognition that ACP is important, it has not been conducted well as a whole (Black and Emmet 2006) or, specifically, within Australia (Rhee *et al.* 2012). The process is complex, requiring the presence of some level of expertise and resources that contribute to its proposed outcomes (Jeong *et al.*

2010) and ethical considerations for its acclaimed benefits (Robins-Browne *et al.* 2014).

Although the GP is excellently positioned to initiate ACP, its uptake has been limited. There are various reasons to why ACP has not been conducted routinely in the primary-care setting. Rhee *et al.* (2013) interviewed Australian general practitioners (GPs) who discussed a range of issues, including legal concerns, uncertainty regarding whether recorded wishes would be respected, ambiguous health conditions or illness trajectories, family acceptance and understandings, institutional policies and staff attitudes towards EOL. Similar accounts from UK health professionals demonstrated the belief that ACP was a noble idea; however, there were practical limitations of ensuring that an appropriate time was chosen, efforts to complete multiple documents, legal costs, and the ambiguity of application to real medical situations (Robinson *et al.* 2013). And despite the challenges of lack of time, space and lack of remuneration (Simon *et al.* 2015), including some healthcare workers showing reluctance or personal discomfort with engaging in EOL conversations (Clinical Excellence Commission 2013), ACP was still deemed as useful intervention that assisted patients and their families through periods of distress (Rhee *et al.* 2012).

Nurses have a critical role in promoting discussion in EOL care and enabling patients and families to experience good EOL

What is known about the topic?

- The benefits of having Advance Care Planning conversations have been recognised in improving the quality of life and allowing good death; however, primary-care physicians appear to face difficulties conducting these discussions.

What does this paper add?

- New South Wales practice nurses are willing to undertake a greater role in advance care planning, especially with patients that they are familiar with.

care (Briggs and Colvin 2002). Community nurses in the US were four times more likely to be favoured by carers to be the ones who would provide ACP discussions (Tung and North 2009). The involvement of other healthcare professionals could address the barriers of insufficient time, lack of remuneration, and the lack of knowledge and confidence and lack of training in ACP. However, insufficient ACP knowledge, unclear roles and a lack confidence to discuss EOL issues are known to have deterred nurses (Boddy *et al.* 2013). Therefore, so as to promote more involvement and positive outcomes, we seek to better understand practice nurses' beliefs, attitudes, level of confidence, willingness in discussions and training, potential challenges and barriers, and supportive measures to ACP involvement.

Methods

The study was conducted as a cross-sectional survey, using an online survey tool. The survey questions were designed by the research team that consisted of a registered nurse and a GP with expertise in ACP and primary palliative care. The items were not formulated from previous studies because of lack of research in the topic. Before the questionnaire was refined, finalised and uploaded, a pilot survey was conducted with three professionals with ACP expertise, two of whom are palliative-care physicians. The tool comprised 18 questions that measured beliefs, attitudes, experiences and perceived confidence and willingness of practice nurses to conduct ACP. Majority of the questions involved a five-point Likert scale with levels of agreement (strongly disagree, disagree, neither disagree nor agree, agree, strongly agree). Participants could choose not to answer any questions and there were no compulsory questions.

Quantitative analyses were conducted using IBM SPSS Statistics (ver. 22, IBM Corp., Armonk, NY, USA). This included descriptive statistics to analyse the frequency of responses and to describe the demographic characteristics of respondents. Pearson's chi square (or Fischer's Exact test) and Mann-Whitney *U*-tests were used to analyse the correlation between several independent and dependent variables. The survey also included one open-ended question. The responses were coded and analysed for broad themes.

Recognising the differences in the terminology and legislation on ACP among Australian states, and territories, the team invited the participation of practice nurses working in New South Wales to prevent inconsistencies in responses. Emails containing an invitation to participate in the survey were sent to several

professional nursing organisations, Medicare Locals and websites of primary-care research organisations. When they responded positively to participate, the second email containing the survey link, participation information sheet, and additional study information was sent to them. The organisations then circulated the information and the survey link to their members or nurses in accordance to their usual electronic communication methods, which included email, electronic newsletters and websites. On completion of the survey, participants could participate in an online gift-voucher draw, which was delinked from the survey data.

The research protocol was approved by the University of New South Wales (UNSW) Human Research Ethics Advisory Panel. Computer-generated identification numbers represented each participant. The survey website was encrypted and password protected to ensure confidentiality of information.

Results*Demographics*

There were 147 fully completed responses of a total of 179 surveys commenced. The survey link was viewed approximately over 400 times and the mean completion time was 10 min. Data from incomplete surveys were not removed and actual responses for each item were analysed. A large proportion of participants were female, Australian-born nurses who worked in general practice (Table 1). The majority were registered nurses with an average nursing experience and practice-nurse experience of 24 years and 6 years respectively. More participants worked in rural regions of New South Wales than in suburban regions.

Who should be conducting ACP

A large proportion of participants (73.2%) strongly disagreed or disagreed that ACP should be conducted solely by GPs. Nurses strongly agreed or agreed (84.2%) that nurses should be involved in starting and conducting ACP discussions with their patients, and 86.8% believed that this service would be beneficial to their patients. Slightly more participants felt that patients preferred to see the doctor (39.2%) rather than the nurse (28.1%).

Attitudes towards ACP

Majority of the nurses (88.7%) strongly agreed or agreed that ACP discussions are important for GP patients in the community. Opinion was mixed about whether ACP involved a lot of paperwork, with 26% agreeing or strongly agreeing, compared with 34.4% who disagreed or strongly disagreed. Most nurses (78.5%) felt that these discussions should commence in the community before hospital admissions.

Knowledge and confidence in conducting ACP

In total, 50% of the participants agreed or strongly agreed that they had good knowledge of ACP. Data on involvement in EOL discussions in any setting (e.g. clinic, hospital, residential aged-care facilities and community) showed that 132 participants had prior participation and 22 had never been involved, 25 nurses did not choose either option or declined to answer.

Nurses were asked to rate their level of confidence on introducing ACP subjects to the following three different groups of patients:

Table 1. Demographics (personal and professional characteristics) of New South Wales practice nurses
NA, not applicable

Parameter	Value	Number of participants	Percentage
Age (years) (<i>n</i> = 138)			
Median	50	NA	NA
95% CI	46.37–49.9	NA	NA
s.d.	10.39	NA	NA
Range	48 (21–69)	NA	NA
Sex			
Female	NA	142	99.3
Male	NA	1	0.7
Missing	NA	36	NA
Country or region of birth			
Australia	NA	118	83.1
New Zealand	NA	4	2.8
United Kingdom	NA	9	6.3
Europe	NA	2	1.4
Asia	NA	4	2.8
Africa	NA	2	1.4
South Pacific	NA	2	1.4
United States	NA	1	0.7
Missing	NA	37	NA
Highest level of education			
Certificate or diploma	NA	59	41.8
Bachelor's degree	NA	58	41.1
Postgraduate certificate or diploma	NA	4	2.8
Master's degree	NA	15	10.6
Other	NA	5	3.5
Missing	NA	38	NA
Current position			
Nurse practitioner	NA	5	3.5
Registered nurse	NA	128	89.5
Enrolled nurse	NA	10	7
Missing	NA	36	NA
Current work location			
Inner city	NA	9	6.5
Suburban	NA	42	30.4
Outer metro	NA	17	12.3
Rural	NA	66	47.3
Two or more regions	NA	4	2.9
Missing	NA	41	NA
Current work setting			
General practice (GP)	NA	130	92.9
Non-GP	NA	10	7.1
Missing	NA	39	NA
Overall clinical experience (years) (<i>n</i> = 138)			
Mean	24.39	NA	NA
95% CI	22.44–26.35	NA	NA
s.d.	11.63	NA	NA
Range	44 (2–46)	NA	NA
Practice nurse experience (years) (<i>n</i> = 142)			
Mean	8.83	NA	NA
95% CI	7.71–10.3	NA	NA
Median	6	NA	NA
s.d.	7.64	NA	NA
Range	31.75 (0.25–32)	NA	NA
Average number of working hours per week (<i>n</i> = 137)			
Mean	28.93	NA	NA
95% CI	27.36–30.50	NA	NA
s.d.	9.3	NA	NA
Range	42 (8–50)	NA	NA

- Group 1: established patients of the practice whom they personally know.
- Group 2: established patients of the practice whom they personally do not know.
- Group 3: new patients of the practice.

Majority of the nurses felt comfortable with discussing ACP with all three groups of patients. When familiarity decreased between nurses and patients, the percentage of nurses who felt confident about approaching ACP with patients also decreased, being 78.4% for Group 1, 62.8% for Group 2 and 48.6% for Group 3.

Factors that influence participant attitudes, perceived knowledge and confidence in ACP

The nurses who perceived that they had good knowledge of ACP were more likely to report personal experiences with ACP ($\chi^2 = 18.02$, d.f. = 1, $n = 56$, $P < 0.01$; Table 2). And these nurses who agreed that they have good knowledge were also likely to feel confident in discussing ACP with Group 3 patients ($\chi^2 = 36.2$, d.f. = 1, $n = 53$, $P \leq 0.001$). There was also a statistically significant association between perceived good knowledge of ACP and confidence in having ACP discussions with Group 1 (Fisher's exact test, $P < 0.001$) and Group 2 ($\chi^2 = 27.9$, d.f. = 1, $n = 60$, $P < 0.001$) patients.

The correlation between demographic characteristics of participants and beliefs and attitudes regarding ACP were analysed with the Mann-Whitney *U*-test. There was a statistically significant ($P = 0.009$ from $Z = -2.595$) difference between the age of nurses and perceived knowledge of ACP (good knowledge of ACP, median = 53 v. not believing good knowledge, median = 48.5). There was no difference in years of ACP

experience ($P = 0.115$ from $Z = -1.575$) between nurses who believed that ACP was the sole responsibility of doctors (median = 2.5) and those who did not believe that ACP was the sole responsibility of doctors (median = 5).

Barriers to involvement in ACP and nurse training needs

The majority of practice nurses strongly agreed or agreed that there should be a separate Medicare item number for their involvement in ACP (Fig. 1). Remuneration in conducting ACP was highlighted as inadequate by similar number of nurses. Whereas most nurses felt that there was insufficient patient-education material on ACP available at their practices, there appears to be sufficient privacy and space for ACP discussions. Most of the surveyed nurses were interested in participating in mentorship (70.8%), observational sessions (81.7%) and training programs in ACP (90.6%). We compared educational level, clinical experience and willingness to attend ACP training programs against self-reported confidence levels in discussing ACP with different groups of patients and found that there was no significant association.

There were 71 responses to the following single open-ended question: 'What do you think should be included in the context of ACP educational/training programs to facilitate ACP discussions with patient in your practice?' Responses were categorised into the following four broad themes: clarification, system-wide communication, challenges and resources. Participants expressed the need for 'clarification' on the ambiguity of ACP components, legality of documents in different states, ethical issues and communication across the healthcare system. 'System-wide communication' captured comments from nurses that implied gaps in the continuity of care and communication for ACP. There were comments on the doctor-nurse disconnect,

Table 2. Relationship between the participants' perception of good knowledge of advance-care planning (ACP) with selected demographics characteristics and confidence in discussing ACP

Parameter	I have good knowledge of ACP		Total
	Agree or strongly agree	Disagree or strongly disagree	
Past personal experience and perception of good knowledge of ACP			
Have you had previous personal experience with ACP (i.e. self, family, friend)			
Yes			
Count	56	11	67
%	83.6	16.4	100
No			
Count	15	20	35
%	42.9	57.1	100
Total %	69.6	30.4	100
Pearson's χ^2	18.024	d.f. = 1	$P < 0.001$
Perception of good knowledge and confidence in discussing ACP with a new patient of the practice (Group 3)			
Confidence of discussing ACP with a new patient of the practice			
Agree or strongly agree			
Count	53	4	57
%	93.0	7.0	100.0
Disagree or strongly disagree			
Count	11	22	33
%	33.3	66.7	100
Total %	71.1	28.9	100
Pearson's χ^2	36.20	d.f. = 1	$P < 0.001$

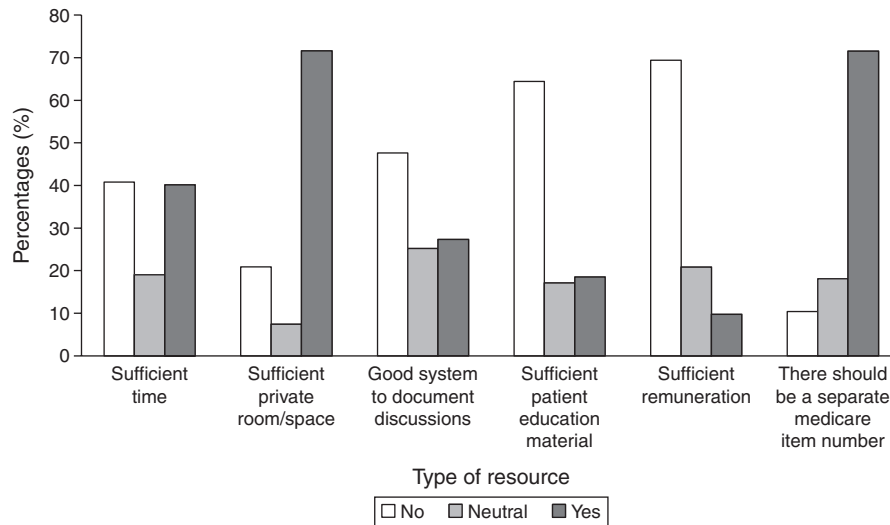


Fig. 1. Perceptions of surveyed nurses on adequacy of advance-care planning (ACP) resources.

and indications how this may result in decreased quality of care. Nurses wrote about several ‘challenges’ they faced because of a lack of discussion skills, documentation and clear policies on ACP in the practice. Nurses who talked about ‘resources’ wrote about the practicality of learning discussion techniques, roleplaying various scenarios and participation in webinars. Many requested for more information on user-friendly templates, guidelines, relevant skills and language specifics on how to open up an ACP discussion with patients. Some participants indicated a strong interest to use technology to lead conversations, store data nationwide and to connect patients by using easy-to-understand content. Participants acknowledged the ideal position of the practice nurses for ACP discussions.

Discussion

The majority (89.5%) of participants were registered nurses, with the median age of 50 years and working an average of 28.9 h per week (Table 1). These figures are consistent with those of a recent national survey that showed that majority of the practice nurses were aged 50–59 years, 60.2% worked <29 h per week and, in New South Wales, 90.9% were registered nurses (Australian Medicare Local Alliance 2012). This provided increased confidence that our participant sample was similar to the overall practice-nurse population in New South Wales.

The participants believed that the community was the ideal place for ACP discussions to take place and believed that these discussions were part of their responsibilities, were important and their involvement would benefit patients. This is consistent with other studies, showing that the hospital is not a conducive place to conduct ACP discussions because of the patients’ state of ill health (Boddy *et al.* 2013) and that ACP discussed in primary-care settings help resolve conflicts and could be conducted as part of daily nursing-routine responsibilities (Seymour *et al.* 2010).

In our study, there was a significant association between self-reported past personal experience with ACP and self-perception of good knowledge on ACP. Actual ACP knowledge levels

were not tested in the present survey. However, there was lack of parallelism between personal and professional views, with only 65.2% ($n=92$) reporting that they had past personal experience with ACP v. 84.2% feeling that practice nurses should be more involved in ACP (Table 2). Experience increases the ease of interactions and ACP communication between patients and providers (Black and Emmet 2006); thus, there is a need to resolve the lack of parallelism between personal and professional views (Badzek *et al.* 2006).

The participants had a higher level of confidence in discussing ACP with patients that they knew personally, a lower level of confidence with established practice patients without a personal relationship and the lowest with new patients of the practice. Our findings, therefore, indicated that a natural place to start a program of ACP led by practice nurses would be for patients who are well known to the practice, ideally, the ones who already have a relationship with the nurses. The importance of relationship between health-care professionals and patients in ensuring success in ACP has been highlighted in the literature (Ramsaroop *et al.* 2007; Rhee *et al.* 2013).

Training and education in ACP is important. With increased training and policies tailored for community needs, US health professionals reported higher levels of confidence and comfort (Baughman *et al.* 2012) and, for rural Victorian physicians, self-confidence in ACP was enhanced after training (Detering *et al.* 2014).

Qualitative comments from our survey showed concerns and apprehension with the lack of defined guidelines, policies and legalities of ACP. Ambiguity of ACP components and uncertainty on legal status have been discussed previously in the literature, among other barriers to ACP (Butterworth 2003; Simon *et al.* 2015). Our findings suggested discordance between current practice and best-practice recommendations to improve consistency among states, enable sufficient training of healthcare providers, raise community awareness of ACP and build a national registry of advance-care plans (Australian Health Ministers’ Advisory Council 2011). Participants in our study indicated their willingness to enhance their ACP knowledge

and skills through involvement in training workshops, mentorships and watching an ACP discussion.

In terms of resources, availability of a private, quiet location is ideal to facilitate ACP discussions (Simon *et al.* 2015). It is encouraging that several practice nurses in our study had indicated that there were such facilities in practices. However, the participants identified lack of Medicare payments and funding linked in with ACP as a significant barrier to their involvement in ACP. Another important gap participants mentioned was the lack of availability of patient educational material on ACP. This is despite the work on ACP that has been ongoing by various websites (e.g. <http://advancecareplanning.org.au> and <http://start2talk.org.au>, accessed 26 February 2016). More recently, Australian Government funding has enabled a palliative and ACP project 'Decision Assist' to provide healthcare providers with resources through various listed educational programs, recommended resources and telephone assistance (Decision Assist 2015). Informing practice nurses of these resources could potentially address this barrier.

Limitations

It was not possible to determine the exact number of nurses who received an invitation email and the exact response rate because the nursing organisations used a wide variety of online platforms to share the invitation to participate. It was not possible to verify whether the participants who responded were actual practice nurses who worked in New South Wales. However, given that there are ~2791 practice nurses in New South Wales (Australian Medicare Local Alliance 2012), the sample size of this survey would be 5% and thus fairly small. The topic may have attracted participants who are interested in ACP or EOL issues, thus adding to the possibility of self-selection bias. The survey involved self-reporting, which could have introduced responder bias and problems with the accuracy of recalled information. Our online study would have also excluded participants who might prefer responding on paper-based questionnaires. Therefore, our results would need to be interpreted with caution because of the possible limited generalisability.

Conclusions

In summary, the present study highlighted the positive attitudes and willingness of New South Wales practice nurses to initiate and conduct ACP discussions with patients. The participants felt that they have an important role in ACP and reported a generally high level of confidence in leading ACP discussions, especially with practice patients that they are familiar with. The confidence of nurses decreased as their familiarity with the patients decreased. Although participants reported several barriers, including general lack of resources and specific remuneration for ACP, most reported adequate space and time to conduct the discussions. The open-ended responses from nurses disclosed various system lapses in communication around ACP and EOL care. Therefore, a program of ACP involving practice nurses should include training programs designed to improve their skills in discussing with patients and also to improve clarity around legal and ethical matters.

Conflicts of interest

None declared.

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