Review Article

Volunteer Involvement in Advance Care Planning: A Scoping Review

Marcus Sellars, BBSc, PGDipPsych, Jamie Simpson, BHlthSc, Master of Health Promotion, Helana Kelly, BApplSc, MSc, Olivia Chung, BS, BA (Hons), Linda Nolte, BHSc (Nut&Diet), Postgraduate Diploma in Health Services Management, Julien Tran, BPsych (Hons), MPH, and Karen Detering, MBBS, Masters in Health Ethics

Advance Care Planning Australia (M.S., J.S., H.K., O.C., L.N., J.T., K.D.), Austin Health, Melbourne; Sydney Medical School (M.S.), The University of Sydney, Sydney; and Faculty of Medicine (K.D.), Dentistry and Health Sciences, Melbourne University, Parkville, Victoria

Abstract

Context. Volunteer involvement may support organizations to initiate and operationalize complex interventions such as advance care planning (ACP).

Objectives. A scoping review was conducted to map existing research on volunteer involvement in ACP and to identify gaps in current knowledge base.

Methods. We followed the PRISMA extension for Scoping Reviews (PRISMA-ScR) guidelines. The review included studies of any design reporting original research. ACP was defined as any intervention aimed at supporting people to consider and communicate their current and future health treatment goals in the context of their own preferences and values. Studies were included if they reported data relating to volunteers at any stage in the delivery of ACP.

Results. Of 11 studies identified, nine different ACP models (initiatives to improve uptake of ACP) were described. Most of the models involved volunteers facilitating ACP conversations or advance care directive completion ($n = 6$); and three focused on ACP education, training, and support. However, a framework for volunteer involvement in ACP was not described; the studies often provided limited detail of the scope of volunteers' roles in ACP, and in three of the models, volunteers delivered ACP initiatives in addition to undertaking other tasks, in their primary role as a volunteer navigator. Increased frequency of ACP conversation or documentation was most commonly used to evaluate the effectiveness of the studies, with most showing a trend toward improvement.

Conclusions. Current literature on volunteer involvement in ACP is lacking a systematic approach to implementation. We suggest future research should focus on person-centered outcomes related to ACP to evaluate the effectiveness of volunteer involvement. J Pain Symptom Manage 2019;57:1166–1175.

Key Words

advance care plan, volunteer, peer, advance directive, systematic review, scoping review

Background

Advance care planning (ACP) supports people to consider and communicate their future health treatment preferences in the context of their own goals and values.[1] It is an ongoing process in which a person may complete an advance care directive (ACD), a document which can be used to appoint a substitute decision-maker or health care proxy and record their values and preferences for care.

Evidence regarding the type of health care resources required to deliver a comprehensive and effective ACP program that incorporates promotion,

Address correspondence to: Marcus Sellars, BBSc, PGDipPsych, Advance Care Planning Australia, Austin Health, PO Box 5555, Heidelberg, Victoria 3084, Australia. E-mail: marcus.sellars@austin.org.au

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education of staff, patients, and family, facilitation, and governance of ACP is currently unclear.[2,3] One potential mechanism to support the delivery of ACP is to introduce the involvement of volunteers. Volunteers may be able to deliver effective interventions such as ACP, especially in organizations that are restricted in their ability to initiate and operationalize ACP with existing resources.[4] It has also been suggested that some people may prefer to interact with other patients (peers) or lay people over health professionals regarding ACP.[5]

In other health settings relevant to ACP, such as hospice services in the UK[6] and end-of-life care internationally,[7] volunteers play a significant role in supporting the delivery of health care services. However, the role of volunteers can vary considerably and depends on the context of the organization, in which they are operating.[7,8] Volunteer involvement may be consistent with a "whole-community" approach to ACP,[9] to introduce and discuss the topic early before a person becomes acutely unwell, and to reduce reliance on the health care system to deliver all the stages of implementation.

Volunteer involvement in ACP has not been clearly described in the literature. This study aims to map research on volunteer involvement in ACP, identify outcomes associated with ACP volunteer models, and determine gaps in existing knowledge. The results obtained will help to inform strategies that will maximize volunteer effectiveness and performance monitoring in ACP delivery.

Method

We followed the PRISMA extension for Scoping Reviews (PRISMA-ScR) guidelines.[10] Scoping reviews are used to synthesize knowledge to answer broad questions about interventions, such as those regarding the nature of the evidence or what is currently known about the concept.

Selection Criteria

Original research studies (both quantitative and qualitative) that described volunteer involvement at any stage of an ACP intervention were included. We included studies where volunteers played either a central or minor role in delivering an ACP intervention or studies where ACP was one component of a larger intervention (i.e., palliative care) but still involved volunteers. In addition, studies reporting participant outcomes (i.e., patient or health professional) who had participated in an ACP intervention involving volunteers were also included. Studies that discussed volunteer involvement in palliative or end-of-life care without the inclusion of ACP were excluded. Conference abstracts and non-English articles were also excluded. ACP was defined as any intervention aimed at supporting people to consider and communicate their current and future health treatment goals in the context of their own preferences and values.[1]

Selection of Sources and Evidence

The search strategies are provided in Supplemental Table S1. We searched CINAHL, MEDLINE, PsycINFO, and Embase from inception until September 4, 2018. Google Scholar, PubMed, and reference lists of relevant articles were also searched, as were two gray literature databases; CareSearch and the New York Academy of Medicine Grey Literature Report. Three authors (J. S., O. C., and J. T.) independently screened the titles and abstracts of articles, reviewed the full text of articles after the initial screening, and then resolved discrepancies through discussion. If necessary, a fourth co-author was consulted (M. S.) until agreement was reached. If terminology was unclear as to whether a study included volunteers (e.g., lay workers), authors were contacted via e-mail to determine eligibility.

Data Charting Process

For each study, descriptive data were extracted including author, year, study location, components and purpose of ACP volunteering model, study populations, aims of the study, methodology, and reported outcomes relevant to ACP. Following this, data and text under the background/aims, results/findings, or conclusion/discussion sections for each study were imported into NVivo, version 10. One investigator (M. S.) performed line-by-line coding of the data and text from studies generated by the database search, conceptualized the data, and inductively identified concepts. Text was then coded into existing concepts or a new concept was created as required. Similar concepts were grouped into themes.

The resulting themes coded included reasons for volunteers' involvement in ACP, role titles for volunteers, models of ACP (e.g., facilitation, education, and support), participant outcomes (e.g., ACP knowledge and comfort and completion of ACP conversations and ACDs), volunteer outcomes (e.g., self-efficacy and comfort), health system outcomes, and barriers and facilitators to implementation.

Results

Literature Search

From 1348 articles identified in the search, we included 11 published articles (Figure 1). The characteristics of the 11 studies are summarized in Table 1. Most studies were from the U.S. ($n = 8$) and used

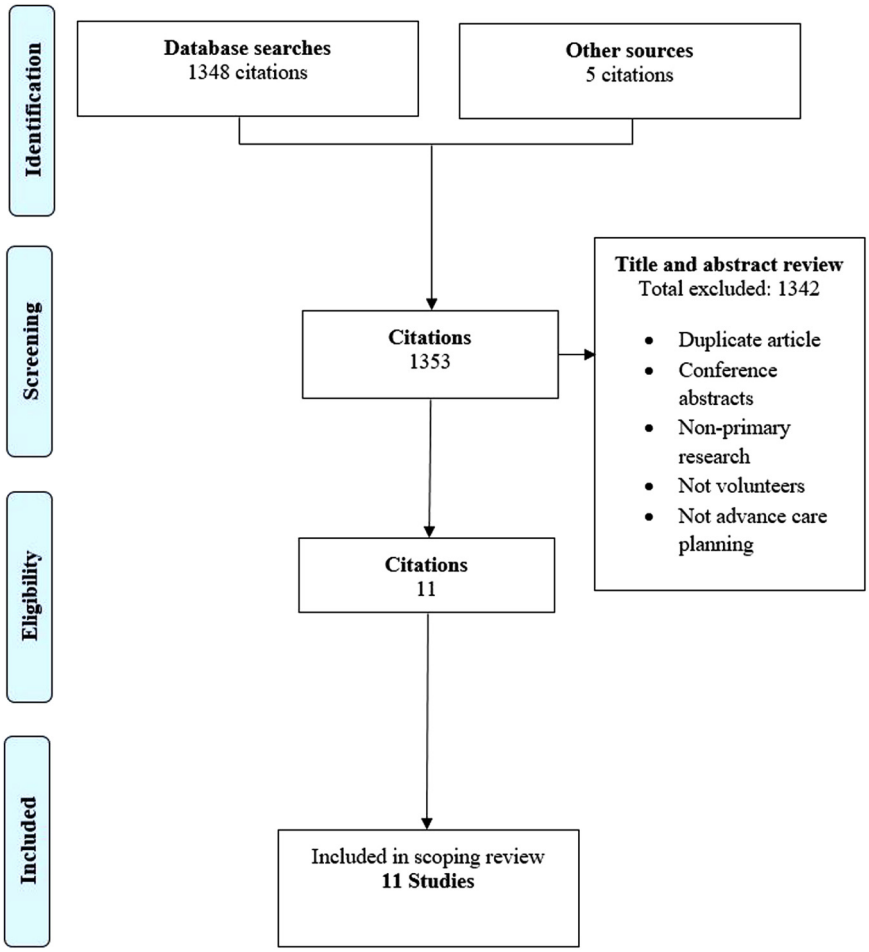

Fig. 1. Search results.

either quantitative or mixed research methods ($n = 10$). Of the quantitative studies, only one was a randomized controlled trial[11] and three were uncontrolled trials.[12–14] The included studies were published between 1991 and 2018, with three studies published in 2018, suggesting increasing research interest in this topic.

Table 1
Characteristics of Included Studies ($N = 11$)

Characteristics	Number of Studies (%)	Contributing Studies
Country of origin		
US	8 (73)	11–15,17,19,20
UK	2 (18)	5,18
Canada	1 (9)	16
Research method		
Qualitative	1 (9)	
Semistructured interviews ($n = 1$)		15
Quantitative	5 (45)	
Randomized controlled trial ($n = 1$)		11
Uncontrolled trial ($n = 3$)		12–14
Program evaluation ($n = 1$)		19
Mixed methods	5 (45)	5,16–18,20

Reasons Volunteers Have Been Incorporated in Models of ACP

Most of the included studies (nine of 11) described a rationale(s) for volunteer involvement in ACP. These included the likelihood of volunteers being effective in some elements of ACP program delivery, given their involvement in other similar health settings and interventions (such as palliative care or cancer care),[11,13,15–17] recognition that some people may prefer to interact with other patients (peers) or lay people over health professionals regarding ACP,[5] volunteers may benefit personally from participating in ACP program delivery,[5,18] and that volunteers may provide additional resources to support ACP programs that are under-resourced.[15–17,19,20]

Role Titles for Volunteers

In our review, we identified eight different titles for volunteers in the delivery of ACP. The most common title or term was Navigator, either Peer,[20] or Lay,[15,17] or Volunteer.[16] Other titles included Peer Mentor,[11] Simulated Patient,[12] Advance Directive Volunteer,[14] Peer Educator,[5,18] and Lay Counselor.[13]

Models of ACP

Of the 11 studies identified, nine different ACP models (or initiatives to improve uptake of ACP) involving volunteers were described. Most of the models involved volunteers facilitating ACP conversations or ACD completion ($n = 6$),[11,13–15,17,19,20] whereas three focused on ACP education, training, and support led by volunteers for people in the community or health professionals.[5,12,16,18] In three of the models, volunteers provided either ACP facilitation[15,17,20] or ACP education, training, and support,[16] in addition to undertaking other tasks in their primary role as a navigator, such as supporting them to navigate the health system more broadly.

Table 2 lists the studies by model design (facilitation of ACP conversation and documentation and ACP education, training, and support) and provides reported information about the location of the study, components of the model (name, type of volunteer, population, and training), purpose of the model, and outcomes. Outcomes are categorized as either participant outcomes, volunteer outcomes, or health system outcomes (Table 2). In addition, a graphic depiction of a conceptual framework of the stages of ACP implementation[21] and the broad evidence base and evidence gaps in volunteer involvement in ACP are included in Fig. 2.

Models to Facilitate ACP. Six ACP facilitation models were described in seven studies.[11,13–15,17,19,20] Three used lay volunteers (nonprofessionals who were trained),[13–15] and three used peers (patients who were trained).[11,19,20] Interventions aimed to facilitate ACP with populations including people with Alzheimer's disease,[13] advanced cancer,[15,17,20] chronic kidney disease,[11] attending a geriatric clinic,[14] or admitted to hospital.[19] Four of the facilitation studies[11,17,19,20] described the ACP training provided to volunteers (Table 2).

Models to Provide ACP Education, Training, and Support. There were three ACP education, training, and support models described in four studies.[5,12,16,18] Two of the ACP models focused on older people in the community, including older people,[5,18] one concentrated on people living at home with advanced chronic illness,[16] and another involved training medical residents to facilitate ACP through role play with volunteers.[12] In the two interventions where volunteers provided education and support in the community, volunteers were trained during three-day workshops.[16,18]

Participant Outcomes

ACP Knowledge and Comfort Among Participants. In the only study measuring ACP knowledge among participants,[12] doctors who participated in simulated ACP discussions with volunteers showed an increase in self-reported ACP knowledge, as well as greater comfort raising the topic with patients, with most (96%) having described the overall experience as positive. In another study, chronic kidney disease patients who participated in a volunteer-led discussion about the value of ACDs felt significantly more comfortable discussing ACDs compared with patients who only received written materials about ACDs or who were in a control group.[11]

Completion of ACP Conversations and ACDs. Five of the seven ACP facilitation studies[11,13,14,17,20] measured ACP conversations or ACD completion rate, with all showing a trend toward greater completion rate following the ACP volunteer intervention. In an 18-month U.S. evaluation study involving 50 volunteers trained to facilitate ACP conversations across 12 cancer centers, lay navigators initiated 1319 (15% of total patients) ACP conversations, with 481 of these patients completing an ACP conversation.[17] By the conclusion of this study, 12 volunteers had completed 10 or more ACP conversations. In the only study that included a control group,[11] patients with chronic kidney disease who received a peer-mentoring ACP intervention were four times more likely to complete an ACD ("Five Wishes Advance Directive") compared with participants who received printed materials only or who received neither peer mentoring or printed materials.

Two facilitation studies using lay volunteers to "counsel" either people with Alzheimer's disease ($n = 64$)[13] or people attending a geriatric clinic ($n = 34$),[14] whom had not previously completed ACP, reported that the majority of people (between 52%–71%) went on to complete a document to either record preferences and instructions or to appoint a "health care proxy." In another study[20] of 11 patients with cancer who did not have an ACD at the beginning of an ACP facilitation intervention, five (45%) had completed an ACD by the end of the study.

Volunteer Outcomes

ACP Self-efficacy Among Volunteers. One ACP facilitation intervention examined competency of volunteers,[17] showing that compared with baseline (pre-training) volunteers who had attended ACP facilitator training scored significantly higher on four of five domains of a self-efficacy survey relating to ACP discussions. In addition, volunteers who had more experience facilitating ACP (>10 conversations) showed a trend toward greater self-efficacy scores, compared with those with less experience (<10 conversations), and reported significantly higher levels of support from their organization.

Table 2
Characteristics of Models of ACP Involving Volunteers and Their Purpose

Studies to Facilitate ACP				
Study	Location of the Study	Components of the Model	Purpose	Reported Outcomes Relevant to ACP
Bekelman et al. (2018)[20]	U.S.	Name: Stepped peer navigator and social work intervention Type of volunteer: Peer navigators Population: Veterans with advanced cancer Training provided to volunteers: one-on-one with a social worker	Improve palliative care outcomes	PO: most were satisfied with the intervention and 45% ($n = 5$) of total sample completed an advance care directive by completion of the study
Luptak & Boult (1994)[14]	U.S.	Name: An incremental, episodic, interdisciplinary intervention Type of volunteer: Lay volunteers Population: Elderly people Training provided to volunteers: Not stated	To assist elderly people to record advance care directives	PO: most (71%) completed an advance care directive ($n = 24$)
Marin et al. (1999)[13]	U.S.	Name: Healthcare Proxy Counselling Program Type of volunteer: Lay counselor Population: People with Alzheimer's disease Training provided to volunteers: Not stated	Assist people with Alzheimer's disease to complete a health care proxy document	PO: most patients without a health care proxy document ($n = 64$) completed one (89%)
Niranjan et al. (2018)[15]; Rocque et al. (2017)[17]	U.S.	Name: Patient Care Connect Type of volunteer: Lay navigators Population: Medicare beneficiaries diagnosed with cancer Training provided to volunteers: Respecting choices	To support older patients with cancer from diagnosis through survivorship and end of life, including volunteer-led ACP	PO: over 1.5 years 1319 (15% total patients) ACP conversations initiated, with 481 completing ACP ACP conversations completed with 481 patients (36%) VO: preparedness in conducting ACP conversations significantly increased after training Facilitators of ACP conversations included patients' prior ACP experience, clinical staff buy-in, patient readiness, and follow-up consistency Barriers included timing of conversation (unsure of when best to start conversation), discomfort in talking about death, lack of resources (time and space), and negative perceptions of navigators HSO: patients who participated in ACP had fewer hospitalizations and lower trends in chemotherapy use, ICU admissions, and ER visits
Perry et al. (2005)[11]	U.S.	Name: Peer mentoring Type of volunteer: Peers, dialysis patients Population: Dialysis patients Training provided to volunteers: a single workshop, where volunteers were provided with ACP resources and watched a video describing the benefits of ACP and legal implications of advance care directives	Peer-led ACP for patients on dialysis	PO: advance care directive completion was higher among patients in the peer mentor intervention group (35%) than in a printed material (12%) and a control group (10%) Desire to complete advance care directive higher in the peer mentor intervention group (68%) than printed material (41%) and control groups (38%) Peer mentor intervention had significantly greater comfort discussing advance care directives with staff than printed material and control group

Wirpsa & Elpern (2016)[19]	U.S.	Name: A volunteer-based advance care directive team Type of volunteer: Volunteers who met requirements of the role description were identified and recruited by the director of the volunteer program. Interested volunteers were screened and interviewed by the pastoral services program administrator. Population: Inpatients Training provided to volunteers: Orientation and training materials were compiled, and training was completed one-on-one by a chaplain experienced in facilitating ACP	To improve responses to patient requests for information about advance care directives and to provide expert assistance to patients in completing advance care directives.	PO: an increase in advance care directive enquiries attended to from 2011 (14%) to 2015 (86%) HSO: cost-saving of U.S. $21,000 estimated by multiplying the estimated number of hours volunteers contributed over a year

Studies to Provide Education, Training, and Support

Study	Location of the Study	Components of the Model	Purpose	Reported Outcomes
Gordon et al. (1991)[12]	U.S.	Name: Simulated ACP conversation to teach medical residents Type of volunteer: Volunteer simulated patients from the community Population: Medical residents Training provided to volunteers: Volunteers attended a meeting and were told the goal of the exercise to help physicians improve their ability to communicate with patients about advance care directives	To improve physician's ACP knowledge and awareness and communication skills about ACP to patients	PO: most felt positive about the sessions (96%) and showed improvements on eight items related to ACP skills, knowledge, and attitudes post-training compared with pre-training
Pesut et al. (2018)[16]	Canada	Name: A compassionate community approach to early palliative care Type of volunteer: Volunteer navigators Population: People aged 55 years or older with advanced chronic illness living in the community Training provided to volunteers: Three-day workshop	To provide health system navigation support through home visits, including about ACP	ACP outcomes not reported
Sanders et al. (2006)[5]; Seymour et al. (2011)[18]	UK	Name: The peer education training programme Type of volunteer: People recruited primarily from community groups Population: Older people Training provided to volunteers: Three-day training course	To assist older people with their end-of-life treatment and care choices	VO: at four-month follow-up, ($n = 24$), 88% of the volunteers had initiated a one-to-one discussion about ACP/end-of-life care, 29% had given or planned to give a presentation, and two had worked together to arrange an information day At 12- to 18-month follow-up increased knowledge of ACP and comfort in discussing ACP was reported

PO = participant outcomes; VO = volunteer outcomes; HSO, health system outcomes; ACP = advance care planning.

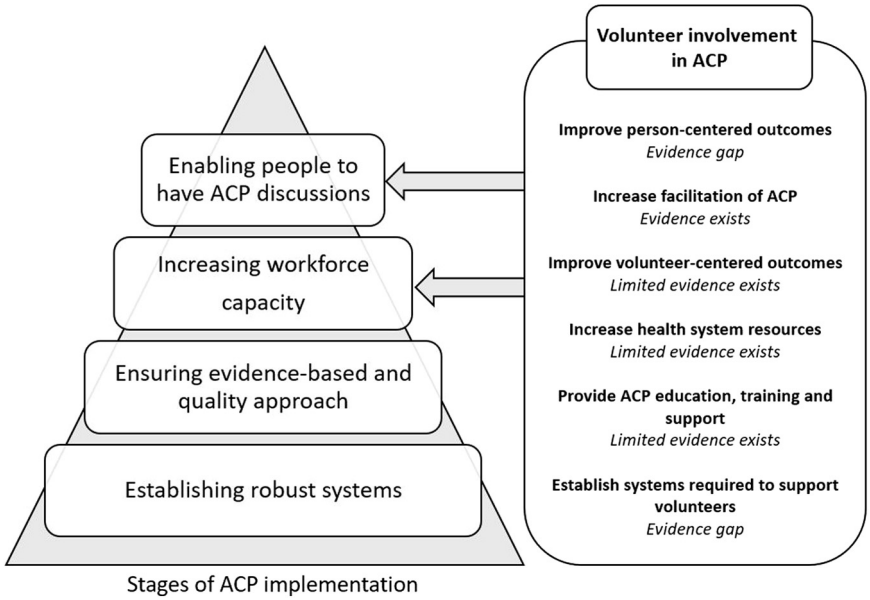

Fig. 2. Graphic representation of a conceptual framework of advance care planning (ACP) implementation and the evidence base and research gaps for volunteer involvement.

Health System Outcomes

Two studies reported health care savings following involvement of volunteers in ACP. One study estimated a cost-saving of $21,000 (USD) following an ACP facilitation intervention in an academic medical center in the U.S. This was done by multiplying the estimated number of hours volunteers contributed over a year (2000 hours) by the minimum wage per hour in that region (USD $10.50).[19] However, the exact number of volunteer hours was not available and cost estimates did not account for other health system resources incurred, such as costs involved in volunteer recruitment, training, and support. Another study in the U.S. reported significantly fewer hospitalizations (46% vs. 56%) and trends toward fewer emergency room and intensive care unit visits within the last 30 days of life for patients who participated in volunteer-led, facilitated ACP than those who declined.[17] However, the total mean cost of care was not available to compare between the two groups.

Barriers and Facilitators to Volunteer Involvement in ACP

Barriers and facilitators to volunteer ACP involvement was described at the patient level, volunteer level, and system level in two ACP facilitation studies[15,17] and one ACP education and support[18] studies.

Patient level. Volunteers perceived that lower health literacy, fear, and a lack of illness acceptance contributed to a patient's unwillingness to engage with ACP.[15,17] In contrast, having past experience with ACP or "end of life" and higher health literacy were perceived as enhancing patient readiness to engage in an ACP discussion facilitated by a volunteer.[15,17]

Volunteer level. Some volunteers reflected that they needed to overcome their "own reserv[ations]"[17] about ACP and end of life before feeling able to facilitate ACP conversations. One volunteer reflected that they perceived their own discomfort with the topic, which had made patients feel "awkward" during an ACP conversation,[15] and one volunteer felt uncomfortable facilitating ACP because they struggled "visualis[ing] what end of life would be like for a patient."[15] Moreover, some volunteers felt anxious before attending ACP training because of their own experience with death; however, the course appeared to give the volunteers greater confidence to discuss ACP and end of life.[18] Volunteers who had personal experience with ACP appeared more comfortable in their role. Volunteers also reflected that facilitating ACP was more successful if they had opportunities to "build a rapport"[15] with the patient over time, to develop a relationship with them over their health care journey and waiting until the patient had become ready to discuss ACP.[15,17]

System level. Some ACP facilitators appeared to struggle to integrate themselves within their organizations, with some feeling that the validity of their role in facilitating ACP was questioned by other health care staff given their "nonmedical"[15] background, some being unable to find a location to facilitate ACP or because the culture of the organization was not aligned with

ACP.[15] Having engagement and support from clinicians improved patient buy-in and volunteers effectiveness in facilitating ACP because they could ask questions about patient treatment outcomes.[17]

Discussion

Difficulties initiating and operationalizing complex interventions such as ACP serve as an antecedent for the creation of volunteer roles, to assist in the ongoing delivery of such initiatives. In this scoping review, we identified 11 primary studies describing nine different ACP models (initiatives to improve uptake of ACP) involving volunteers across various health system settings. Our findings indicate a paucity of research focusing on volunteer involvement in ACP and a lack of a systematic approach to implementation. A further issue is that the included studies often lacked sufficient detail regarding the scope of volunteers' roles in ACP. Despite these limitations, our analysis of the studies identified two principle roles for volunteer involvement in ACP; facilitation of ACP conversations and advance care directive completion; and provision of ACP education, training, and support.

Although we identified two primary roles for volunteers in ACP, the degree of volunteer involvement varied across the studies and was sometimes unclear due to a lack of detail provided within the papers regarding the scope and limits of their role. In three models,[15–17,20] volunteer navigators delivered ACP initiatives in addition to undertaking other tasks as part of their role. In two of these (one ACP education and one ACP facilitation), we were unable to determine what volunteer involvement consisted of in delivery of ACP.[16,20] This was because the degree of overlap with clinician roles in facilitating ACP documentation was not clear[20] or because supporting people to engage with ACP was not the primary role of the volunteers; thus minimal detail regarding the ACP component of the intervention was provided.[16]

In this review, none of the studies provided a detailed framework for explaining the scope and dimensions of volunteer involvement in ACP at an organizational level, which may explain why some volunteers involved in ACP facilitation experienced difficulty integrating themselves within their organizations. Some volunteers perceived a lack of acceptance to facilitate ACP in their organization because they were "nonmedical," they were unable to find a location to facilitate ACP, or they felt the culture of organization was not supportive of ACP.[15] This finding is consistent with other qualitative studies of ACP implementation in hospital and aged care settings, which suggests that a nonsystematic approach to ACP can lead to a lack of shared understanding and vision for integrating ACP into care[22,23] and act as a barrier to cultural acceptance of ACP within the organization.[24]

A positive finding from this review was that most of the volunteer-led ACP facilitation programs reported improvements in the frequency of completion of ACP conversations or ACDs, compared with having no ACP initiative in place. In addition, volunteers in both facilitation and education roles became more comfortable discussing ACP as they became more experienced in their role. However, few studies identified in this review evaluated whether or not contributing to an ACP program had a significant positive impact on volunteers (i.e., "volunteer-centered" outcomes). This was despite two studies describing personal benefits to volunteers as one of the reasons for incorporating them in ACP.[5,18] In other related settings, such as palliative care, volunteers' willingness to contribute to health services has been described as contingent on their own goals and whether or not volunteering can fulfill them.[8] In addition, volunteer involvement in end-of-life care may impart to volunteers what is perceived as "valuable life skills."[7]

The articles identified in this review provide an equivocal picture of the potential risks of having volunteers involved in ACP. This was in terms of risks to patients and family members (and consequently to health care organizations) and also to the volunteers themselves. Past research shows that even when facilitated by a health professional, people can become distressed by ACP and misinterpret the intent of discussion to signify the immediate death of the patient, if ACP is initiated or introduced without giving sufficient context or sensitivity.[25,26] Similarly, in our review, some volunteers felt uncomfortable facilitating ACP because they struggled to visualize what end of life would be like for a patient[15] and some felt uncertain about discussing treatment outcomes with patients.[17] Risk management processes, including robust screening methods, clear role definition and scope, support and governance processes, and follow-up of volunteers,[21] may help to mitigate some of these concerns. However, these concepts were not explored in-depth in any of the included studies and only one study considered instances in which ACP program delivery may be inappropriate for volunteers to complete and a process for identifying and referring distressed patients to a health professional.[20]

Furthermore, although models of ACP implementation are broad, it is widely acknowledged that organizational leadership, leading to adequately trained health and care staff across the organization who are supported in their roles, is required to promoting and widespread change.[27] In our review, we identified a tension between the need to increase health system resources and recognition that ACP conversations are technically and emotionally challenging. In describing

their rationale for involving volunteers in ACP facilitation, Rocque et al. (2017) indicated that "delegat[ing]" the task of ACP facilitation to nonclinical volunteers was a potential solution to increasing ACP uptake because ACP is too "time-consuming" for health professionals to complete.[17] Yet this fails not only to consider the potential risks of involving volunteers in challenging conversations such as ACP but also the flow-on effect of delegating ACP to an external program, such as health care staff being less likely to engage with ACP.[24]

Given that maximizing health system resources was a central reason for volunteer involvement in this review, evaluating effectiveness and cost-effectiveness of ACP initiatives involving volunteers is needed to determine whether the benefits of this approach outweigh the costs. In our review, two studies reported cost-savings following implementation of ACP involving volunteers.[17,19] Yet neither study presented mean costs per-patient associated with health care utilization at end of life or mean costs per-patient associated with the ACP intervention, and thus, the impact of volunteer involvement in ACP on cost-effectiveness is not currently known. This finding is similar to past reviews examining the economic evidence for ACP[28,29] showing that the costs required to deliver an effective ACP program are relatively unknown because of a lack of high-quality randomized controlled trials.

Our scoping review has some limitations. To develop a comprehensive understanding of the extent and nature of volunteer involvement in ACP, we included all studies describing volunteer involvement at any stage in the delivery of ACP (i.e., any intervention aimed at supporting people to consider and communicate their current and future treatment goals in the context of their own preferences and values). As a result, a wide heterogeneity of models of ACP involving volunteers was identified and three models included ACP initiatives as part of a broader role for volunteers. However, we only charted data related to the ACP component of studies and were able to use this information to develop a comprehensive understanding of ways in which volunteers have been involved in ACP to date. In addition, we excluded articles that were not published in English and most studies were from the U.S.; thus, the transferability of the findings to other populations is unclear.

Similar to research on other models of ACP,[30] none of the studies identified in this review examined the perspectives of participants following ACP facilitation or other person-centered outcomes, such as the quality of the ACP discussions or document completion, whether such documents were accessible when needed or whether people received care consistent with their preferences.[31] Rather, most of the studies focused on ACP completion as the primary outcome or barriers and facilitators to implementation as perceived by the volunteers, and thus, the extent to which volunteers can effectively perform a role in ACP remains uncertain.

Future research should aim to evaluate the effectiveness of volunteers in ACP, both in terms of the impact on volunteer-centered outcomes and on person-centered outcomes, such as acceptability of the program and whether it leads to greater adherence to a person's treatment preferences, as well as defining the scope of a volunteer role in ACP. In addition, future economic evaluations of volunteers in ACP should measure person benefits alongside cost-savings and consider the costs of setup and running volunteer programs. Finally, we also suggest future trials consider existing volunteering frameworks[32] in defining the scope and involvement of volunteers in ACP programs, such as the magnitude of volunteer involvement in ACP, how this involvement contributes to the organizations' overall work and mission, the status of the volunteers within the organization (i.e., how they will be integrated within existing systems and structures), and what support and escalation procedures are in place for them if required.

Conclusion

This scoping review has identified the emerging literature on volunteer involvement in ACP, demonstrating a lack of systematic approach to implementation, with the included studies often providing limited detail in the scope of volunteers' roles in ACP. Future research should aim to evaluate the effectiveness of volunteers in ACP, both in terms of the impact on volunteers and on person-centered outcomes, such as acceptability of the program and whether it leads to greater adherence to a person's health treatment preferences. In addition, future models should consider existing frameworks for volunteer involvement in organizations in defining the scope of volunteers' role in ACP.

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Appendix

Supplemental Table S1
Search Strategy

Number	Searches
1	"advance? care plan*"
2	"advance? care directive*"
3	"advance? health plan*"
4	"advance? healthcare plan*"
5	"advance? health care plan*"
6	"advance? health care directive*"
7	"advance? healthcare directive*"
8	"advance? directive*"
9	“living will*”
10	Volunteer*
11	ambassador*
12	Lay
13	Navigator*
14	Unpaid
15	Peer*
16	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 (abstract)
17	10 or 11 or 12 or 13 or 14 or 15 (abstract)
18	16 and 17