

Review Article

Understanding the Outcomes of Supplementary Support Services in Palliative Care for Older People. A Scoping Review and Mapping Exercise



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Abstract

Context. Supplementary support services in palliative care for older people are increasingly common, but with neither recommended tools to measure outcomes nor reviews synthesizing anticipated outcomes. Common clinically focused tools may be less appropriate.

Objectives. To identify stakeholder perceptions of key outcomes from supplementary palliative care support services, then map these onto outcome measurement tools to assess relevance and item redundancy.

Methods. A scoping review using the design by Arksey and O'Malley. EMBASE, CINAHL, MEDLINE, and PSYCHinfo searched using terms relating to palliative care, qualitative research, and supplementary support interventions. Articles were imported into Endnote™, and Covidence™ was used by two reviewers to assess against inclusion criteria. Included articles were imported into NVivo™ and thematically coded to identify key concepts underpinning outcomes. Each item within contender outcome measurement tools was assessed against each concept.

Results. Sixty included articles focused on advance care planning, guided conversations, and volunteer befriending services. Four concepts were identified: enriching relationships; greater autonomy and perceived control; knowing more; and improved mental health. Mapping concepts to contender tool items revealed issues of relevance and redundancy. Some tools had no redundant items but mapped only to two of four outcome themes; others mapped to all concepts, but with many redundant questions. Tools such as ICECAP-Supportive Care Measure and McGill Quality of Life had high relevance and low redundancy.

Conclusion. Pertinent outcome concepts for these services and population are not well represented in commonly used outcome measurement tools, and this may have implications in appropriately measuring outcomes. This review and mapping method may have utility in fields where selecting appropriate outcome tools can be challenging. *J Pain Symptom Manage* 2020;60:449–459. © 2020 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Key Words

Aged, aged 80 and older, frail elderly, palliative care, patient-reported outcome measures, systematic review

Key Message

Four concepts can be expected as outcomes from nonclinical palliative care services: enriching relationships; greater autonomy and perceived control;

knowing more; and improved mental health. These concepts are not well represented in typically used outcome measurement tools, so policymakers should pay attention to ensure that outcomes of such services are appropriately measured.

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Accepted for publication: March 12, 2020.

Introduction

Robust ways of measuring the outcomes of novel services for older people are critically important. This helps in understanding whether there is benefit to such services and to make investment decisions.¹ Outcome measurement is acknowledged to be particularly challenging in some fields, including palliative and end-of-life care for older people.² It is recommended that outcome measures should be brief (to avoid burden), multidimensional (to recognize the multiple needs and holistic nature of palliative care), psychometrically sound and validated for the population under study, and suited to the clinical task.² There are also challenges associated with assessing outcomes during a time of deteriorating health, such that declining outcome scores can be appropriately interpreted.³

In palliative and end-of-life care for older people (hereafter, end-of-life care, used here to mean care in the last 12–18 months of life), supplementary care is increasingly provided outside usual health and social care providers. Public health and compassionate community approaches have inspired services or interventions provided by volunteers, community networks, and nonclinical charitable providers,^{4–6} although few feature in reviews of service models.⁷ For the purposes of this review, we call these supplementary support services, with a wide definition given that the composition of these services will differ depending on the context. Examples of such supplementary support services include those provided by volunteers or other community members or charitably provided services where the support staff are not required to have clinical, social, or spiritual care qualifications to fulfill their role. Such support is, however, likely to focus on practical, psychosocial, and spiritual needs. This may include future care conversations. There are many types of future care planning, some of which are clinically mediated (e.g., do-not-resuscitate orders), others involve wider ranging, less formal, conversations.⁸ Some of the expected outcomes of these supplementary support services may differ from clinically provided services. For example, symptom burden is likely to be at the forefront of clinical care, whereas an impact on issues, such as loneliness, belonging, or social support perhaps more anticipated from supplementary support services.^{9–11} It may be that typically recommended palliative care outcome measurement tools are not the most relevant in these situations.

In choosing an outcome tool, an implicit decision is made regarding what constitutes a successful outcome from a given intervention. It is important that the construct to be measured is clearly identified.^{12,13} There is no agreed core outcome set for

supplementary, community, or volunteer-provided interventions toward the end of life. Understanding key concepts underpinning likely outcomes is an important first step to then appraising existing tools to understand which may address these areas. We therefore report a scoping review of qualitative research designed to understand stakeholder perspectives on supplementary or volunteer services for older people toward the end of life. We present how the key concepts from this review enable an appraisal of the relevance of existing outcome measurement tools to facilitate appropriate tool choice.

Methods

A scoping review design was chosen as this addresses an exploratory research question, enabling mapping of key concepts using a systematic approach.^{14–16} They are commonly used where a large and diverse body of literature needs to be broadly understood in an understudied field. It is reported here using the Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews checklist extension for scoping studies.¹⁷ As recommended, the study followed the framework stages by Arksey and O'Malley¹⁵ for the conduct of scoping reviews combined with the enhancements by Levac et al.:¹⁶ identifying the research question, identifying relevant studies, study selection, charting the data, and collating results.¹⁴ A formal assessment of methodological quality of included studies is usually not performed.^{15,18} After identification of key concepts, these were compared with the questions asked in commonly used generic outcome measurement tools.

Review Question

What are the key concepts underpinning anticipated outcomes of supplementary or volunteer end-of-life interventions for older people, as perceived by older people, their family carers, or health and social care professionals?

Mapping Question

Are the key concepts underpinning outcomes of supplementary or volunteer end-of-life interventions for older people as determined by the scoping review assessed in potentially relevant outcome measurement tools?

The output of the review is a list of key concepts underpinning outcomes of supplementary or volunteer end-of-life interventions that can be used to appraise and choose from contender outcome measurement tools potentially used in research or service evaluation.

Inclusion and Exclusion Criteria

As the aim is to understand perceptions of actual or anticipated intervention outcomes, we focused on identifying qualitative research that described or interpreted perceived outcomes from a range of supplementary or volunteer services or interventions provided toward the end of life for older people. This could include befriending or support interventions, public health, or compassionate community initiatives. We also included studies exploring advance care planning (ACP) or guided future care conversations, as these were known components of some supplementary support services.^{8,19} Quantitative research predefines outcomes, and hence it was out of scope, although mixed-method studies where the qualitative component could be separately extracted were included. This concept and context guided our inclusion and exclusion criteria (Table 1).

Search Strategy

Key terms from existing robust reviews of palliative care or related interventions were used as the basis to construct search strings for palliative care combined with terms for supplementary support interventions and qualitative research. If possible, filters for older people were used (Appendix Table 1). We focused database searches on the largest and most comprehensive databases likely to include relevant studies (EMBASE, CINAHL, MEDLINE, and PSYCHinfo) from inception to March 2018. As scoping reviews are iterative, given the very large number of relevant studies found, a decision was made to neither expand the search to other databases, gray literature, nor hand searching.

Data Extraction and Analysis

Titles and abstracts were screened by two reviewers (S. R. D. and C. E. W.) against inclusion criteria using the Covidence™ (Covidence, Melbourne, Australia) program to manage the process of agreement and flag discrepancies. Articles were included if only some of the article explored supplementary services or interventions with older people, and if these data could be disaggregated. Disagreements were resolved after discussion. Agreed full texts were imported into NVivo™ (QSR International, Daresbury, Cheshire, Australia), and attributes assigned on the study characteristics reported in the supplementary table data. The full text of each article was carefully read by S. R. D. or C. E. W. to identify data that could reasonably be understood to refer to something that was a consequence of, or benefit from, the intervention received, and these data iteratively coded within NVivo. Disagreements were resolved through team discussion. NVivo was used to manage the process, including inductive qualitative content analysis. These codes were iteratively compared and contrasted to identify areas of similarity, identify key concepts, and create the analytic framework for the review. Data on these key concepts and core attributes of the article were then extracted.

Mapping Key Concepts to Outcome Tools

There are a large number of potential palliative and end-of-life care outcome measurement tools. For example, reviews of outcome measurement in palliative care have identified more than 500 potential outcome instruments available.^{20,21} We therefore not only chose contender tools primarily from the most comprehensive publicly available palliative care

Table 1
Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
1. Reports qualitative findings, including those qualitative data that could be extracted from studies also reporting quantitative data	1. Concerns people with dementia, as advanced dementia toward the end of life may preclude articulation of service impacts
2. Contains data from older people or describes services for older people (defined as 65+), which could be extracted from studies also including a wider adult population	2. Published in a language other than English
3. Contains data on outcomes from the perspective of the older person, their family/carer, or staff.	3. Studies of pediatric populations
4. Concerns outcomes from supplementary support or volunteer services or interventions (e.g., guided conversations, advance care planning, needs assessment, public health or compassionate community initiatives, befriending, and support interventions)	
5. The population includes people who could be in their last year of life (e.g., adult cancer patients with incurable disease (defined by tumor staging), or adults with a progressive life threatening disease (e.g., as defined by New York Heart Association Class) and may include patients classed in the literature as frail elderly if receiving a palliative care-focused intervention)	

instrument library²² but also assessed newer tools and those commonly used with older people. This was not intended to be comprehensive but as an exemplar of how others could use the found concepts to appraise other tools. Contender tools were those which were brief (defined as ≤ 30 items for the purpose of this study), multidimensional (e.g., not just focused on a single outcome such as depression), and suitable for use across all diagnoses (e.g., not just for those with cancer). Tools that met these criteria were tabulated. For each individual question within the tool, a

judgment was made on whether the question addressed one of the key concepts identified from the scoping review. This allowed an understanding of what proportion of questions mapped on to at least one key concept, and how many key concepts were addressed within an individual measurement tool.

Results

Sixty articles were included in the scoping review (Fig. 1).

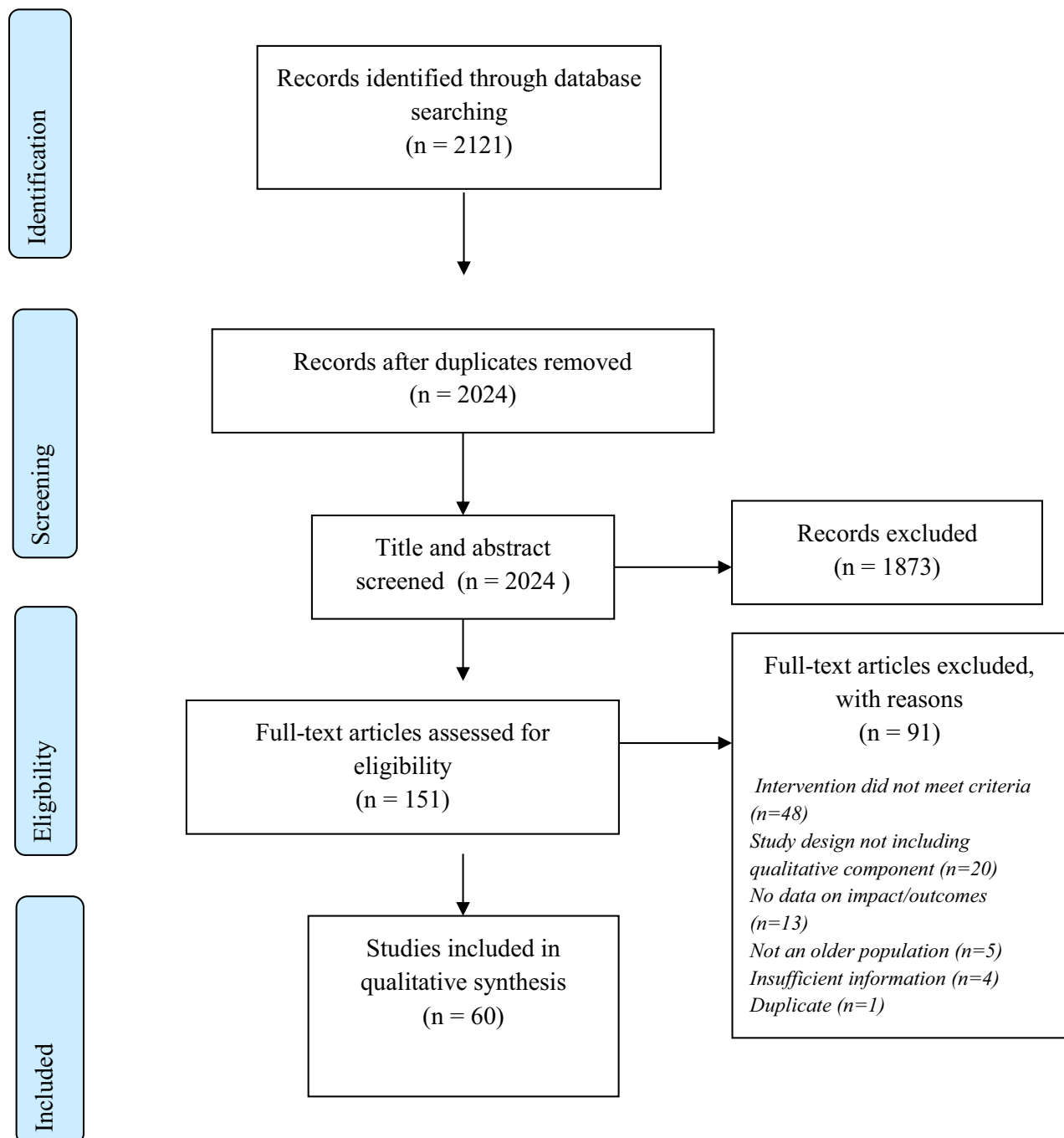


Fig. 1. Process of searching for the literature.

Articles were from 11 countries (with the bulk from the U.K. ($n = 15$), U.S. ($n = 12$), Australia ($n = 11$), and Canada ($n = 7$). Interventions or services reported included ACP interventions ($n = 31$), volunteer-provided services ($n = 9$), and different forms of community-provided services ($n = 8$). Details of articles included in the review are shown in [Appendix Table 2](#).

Four key concepts were identified from the included qualitative articles reviewed:

- **Enriching relationships:** Relationships engendered feelings of being more cared for, respected, loved, and secure.
- **Greater autonomy and perceived control:** People felt more empowered, understood, and consulted.
- **Knowing more:** More involved and informed. The intervention promoted a greater level of engagement and knowledge in the patient about their condition.
- **Improved mental health:** People felt less anxious or stressed. They could also be more confident, more independent, and more assertive.

Although presented separately, there is overlap in these concepts, particularly as they relate to both impacts that are more process oriented (e.g., relationships and a sense of autonomy) and those that have more of an outcome orientation (e.g., knowledge and improved mental health).

Enriching Relationships

Central to the perceived utility of the services and interventions provided was the less tangible relational dynamics that created enriching relationships. Although this is complex, it can be encapsulated in the enduring feeling of being cared for and having someone there for them. These go well beyond physical needs to encompass personhood to have a sense of humanity:

They cared about my life, my son, not just my body^{23(p117)}

Together with input from clinical professionals, the interpersonal work of staff and volunteers provided a sense of holistic care, encompassing a greater range of the patient's needs than would be possible for clinical services alone. There was a sense that services that sit out with the norm of clinical services may have an advantage in facilitating such relationships; they can be supportive, noninstrumental with permission to engage in mundane, but important conversations. The chance to engage in small talk of this sort could be especially valuable for patients approaching the end of life if they lacked other opportunities for normal conversations:

I think the thing with a volunteer is, you're actually out of the illness and out of the problem, so therefore patients can come and talk to you knowing you're not actually a nurse and knowing you're not actually a family member and actually just ... have a laugh ... you're just like a listening ear (Susan)^{24(p629)}

Attentive, skillful, and empathic listening was key to these outcomes, providing an opportunity for the patient to share the psychological burdens of their situation. The feeling of being listened to was accentuated by a perception that the worker/volunteer was easily accessible and had time for conversation. In some cases, the feeling of being carefully listened to was an outcome in its own right:

Before erm I was stuck indoors and when friends or family came to visit they're all very well meant and very pleasant etc but in the great majority anybody that came felt it was their duty to sit down and talk at me, talk at me, talk at me, but I got that from the radio and the television you know [...] and erm [befriending volunteer] is very prepared to listen^{25(p161)}

At one extreme, normal everyday talk allowed the patient to be themselves and be free of the guilt associated with the disease. At the other end of the spectrum, interactions could have more profound effects, serving to confirmed one's personal identity or the meaning of one's existence through the telling of significant life events^{26(p71)}

People felt they were part of a continuous, reliable, and ongoing relationship. These bonds increased confidence in those providing care:

I felt that because she knew me right more or less from the beginning, that it was very easy to talk to her about it all... you build up quite a bond^{27(p1398)}

They [volunteers] were described as "friends but not quite friends" and their capacity to engage with deeper issues that family members felt uncomfortable talking about was important^{28(p8)}

The notion of a quasi-friendship role expresses many of the advantages and outcomes of this sort of intervention because these are processes and outcomes one would associate with a supportive friendship, such as listening, small talk, continuity, reliability, and a feeling of being cared for. Positive changes in state of mind could be mediated through the knowledge that someone cared for them, rather than through tasks or roles. Important examples of this included greater self-esteem and self-respect, born of the knowledge that the patient was cared for and listened to as part of an ongoing relationship.

The existence of relationships themselves could be described as a form of impact.

Greater Autonomy and Perceived Control

Much of the included literature explored the experiences of, and outcomes from, ACP, where there is a focus on enhancing autonomous choice and perceived control. People value the opportunity to establish their wishes, but it was not always the case that they began with a wish to discuss or consider their care preferences. It was often through structured conversations that patients felt more comfortable about discussing topics that would otherwise have been considered taboo or too difficult to consider. The effect of interventions was critical in enabling patients to express key priorities, such as to be free of pain, not be short of breath, to be free from anxiety, and to die in a place of their own choice. Where wishes can be asserted, there is hope that these will be met:

... wanted to know their preferences and that this would influence not only how they were treated but also the outcomes of that treatment. This was a powerful stimulus to engage in ACP [advance care planning]^{29(p1025)}

Such a sense of autonomous decision making could reduce anxiety and stress as people felt reassured that their wishes for the future would be respected:

One participant was worried about his loss of memory and saw the recording of his wishes as protecting his autonomy^{30(p176)}

People felt that an ability to establish their wishes protected dignity, prevented unwanted treatment, or changes in place of care. This gave a sense of control, especially where there were concerns that wishes might otherwise not be met:

One of the reasons I want to have everything written out is because I have a very strong willed family member and it is either her way or the highway and she has this way of twisting around things so that it ends up her way^{31(p120)}

Maintaining one's own priorities could be viewed by patients as a way of ensuring that their interpretation of their situation remained primary, and was not overridden, by others such as those influenced by a culture of life at all costs. Knowing that one's wishes will be respected could allow patients to turn their attention to other matters and make them feel respected and listened to.

Impacts relating to growths in patient autonomy and control relied on input from the worker or volunteer that supported patient capacities. In one article, this was explained as an increase in patient voice or agency, requiring a commensurate and proportional

diminution in professional power over the situation. In other cases, the role was theorized more simply as advocacy, in which the worker/volunteer acted as a sounding board and conduit for patient wishes.

Knowing More

This is related to issues of autonomy and control, as, for example, to engage in ACP it is necessary that people contemplate the reality of their illness and mortality and to know something about the process of death and dying. Knowing more can lead people to greater acceptance of their situation, potentially with benefits of enabling patients to process the reality of death or lose some of their fear. By knowing more patients could become emboldened to choose for themselves, reassured that they were making the right decision. In other cases, it was simply the opportunity for discussion that led people to consider difficult choices rather than avoid them and put them off. In such cases, the sharing of information and experiences can increase comfort and ease in relation to discussing death, sometimes through dispelling unfounded fears. Here, participation in a community support group (circles of care) facilitated openness:

I want others to know my need so they can better understand my needs. Circles of Care members are now more like family members. The more people you know the better your support^{32(p6)}

Information was not only a mechanism to bring about other outcomes but also an outcome in itself, insofar as people often wanted to be aware of more information so they could make informed decisions:

Most patients wanted more information Having this information was seen as vital in maintaining their ability to hope. This was achieved by relieving fears and by helping control the day to day aspects of life^{33(p2)}

Improved Mental Health

People expressed benefits relating to reduced anxiety, stress, and depression from the caring and relational emotional support offered. Many patients could also benefit psychologically from growing peace of mind about their future care. In addition, for some patients being party to the relationship helping to address the distress they suffered as a consequence of loneliness and neglect:

There's no comparison. I mean, before I had them I was depressed, lonely and [...] it's the very knowledge that people care. No, no it's changed my life^{25(p161)}

Following advance care planning, some patients felt relieved from depression and indecision regarding

Table 2
Mapping Review Concepts Onto Contender Outcome Measurement Tools

Tool Name and Description	FACIT-Pal-14 ⁴⁵	EQ-5D ⁴⁶	The McGill QOL ^{36,47}	MVQOLI, 15 Item Version ⁴⁸	The MOS Social Support Survey ⁴⁹	The OPQoL-Brief ⁵⁰	POS ⁵¹	PQLI ⁴¹	QUAL-E ⁵²	The WEMWBS ⁵³	WHO QOL-BREF ⁵⁴	ICECAP-SCM ⁴⁰
Number of key concepts mapped	2	1	3	1	3	2	3	4	4	2	4	4
Questions on improved mental health	6/14	1/5	4/17	0/15	0/20	5/14	3/11	1/7	726	12/13	2/26	1/7
Questions on enriching relationships	3/14	0/5	2/17	2/15	6/20	2/14	1/11	1/7	3/26	1/13	2/26	1/7
Questions on greater autonomy and control	0/14	0/5	2/17	0/15	3/20	0/14	1/11	1/7	2/26	0/13	1/26	2/7
Questions on knowing more	0/14	0/5	0/17	0/15	1/20	0/14	0/11	1/7	2/26	0/13	1/26	0/7
Relevance	9/14 Items relevant in two concepts	1/5 Items relevant in one concept	8/17 Items relevant in three concepts	2/15 Items relevant in one concept	9/20 Items relevant in three concepts	7/14 Items relevant in two concepts	4/11 Items relevant in three concepts	4/7 Items relevant in four concepts	14/26 Items relevant in four concepts	13/13 Items relevant in two concepts	4/26 Items relevant in four concepts	4/7 items relevant in four concepts

FACIT-Pal-14 = Functional Assessment of Chronic Illness Therapy—Palliative Care 14-Item Version; EQ-5D = EuroQoL Five Dimensions Questionnaire; QOL = quality of life; MVQOLI = Missoula-Vitas Quality of Life Index; MOS = Medical Outcomes Study; OPQoL = Older People's Quality of Life Questionnaire; POS = Palliative Care Outcome Scale; PQLI = Palliative Care QOL Instrument; QUAL-E = Quality of Life at End of Life; WEMWBS = Warwick-Edinburgh Mental Well-being Scale; WHOQOL-BREF = WHO Quality of Life-BREF; ICECAP-SCM = The ICECAP Supportive Care Measure.

the burden of dialysis, uncertainties about their illness, and eventual death. Thus, they felt able to “make a choice,” “move on,” and “live the rest of their life as positively as possible”^{34(p3)}

Interwoven, again, is the importance of a sense of being listened to, that someone has a personal friend-like interest in yourself and your well-being.

Mapping Key Concepts on to Outcome Tools

We mapped the four key concepts identified in the scoping review onto 12 exemplar outcome measurement tools. These are tabulated (Table 2) and an indication given of how many of the questions within these tools were considered to address the four key concepts from the scoping review.

Some tools have multiple redundant items, where there are questions that do not map on to the identified concepts. This may cause unwanted burden in those toward the end of life. An example is the World Health Organization Quality of Life-BREF, where only four of 26 questions were considered to address key concepts identified in the scoping review. Some tools have no or few redundant items, but the items within the tool only map onto one or two outcome concepts. An example is the Warwick-Edinburgh Mental Well-being Scale, where all 13 items were considered relevant but only mapped on to two of the key concepts. There are also tools that both have redundant questions that do not map onto our key concepts and where relevant questions do not map on to all concepts. An example is the Older People’s Quality of Life Questionnaire-Brief, where only half of the questions (7 of 14) appear relevant, and these are only across two concepts.

Tools where more than 50% of the items mapped onto at least one of the key concepts were the Functional Assessment of Chronic Illness Therapy—Palliative Care, McGill Quality of Life Questionnaire (McGill QOL), Older People’s Quality of Life Questionnaire-Brief, Palliative Care Quality of Life Instrument (PQLI), Quality of Life at End of Life (QUAL-E), Warwick-Edinburgh Mental Well-being Scale, and ICECAP-Supportive Care Measure (ICECAP-SCM). Tools that mapped onto three and/or more concepts were the McGill QOL, Medical Outcomes Study Social Support Survey, Palliative Care Outcome Scale, PQLI, QUAL-E, World Health Organization Quality of Life-BREF, and ICECAP-SCM. The tools that therefore that have high relevancy with low redundancy are the McGill QOL^{35,36} (17-item questionnaire, with eight mapping on to three concepts), ICECAP-SCM^{37–40} (seven-item questionnaire, with five items mapping onto all four concepts), the PQLI⁴¹ (with four items mapping on to all four

concepts), and the QUAL-E⁴² (with 14 items mapping on to all four concepts).

Discussion

When older people and other key stakeholders talk about what matters to those receiving supplementary or volunteer services or interventions toward the end of life, they talk about four main concepts: enriching relationships, greater autonomy and perceived control, knowing more, and improved mental health. These are not concepts exclusive to supplementary support services but are clearly benefits from such care. These are not, however, necessarily the concepts assessed as outcomes in commonly used outcome measurement tools with older people and those toward the end of their lives. For example, outcome measurement tools, when assessed against these concepts, often have high numbers of redundant items or do not assess against each of these concepts. Measuring the outcomes of supplementary support services therefore, using most existing tools, risks increasing respondent burden with redundant items or measuring inappropriate concepts.

The tools that were identified as exemplars as potentially having the highest relevancy with low redundancy were the McGill QOL, ICECAP-SCM, PQLI, and QUAL-E. It may be that providers and researchers of supplementary support services may wish to consider using these tools. Other factors however will also come into play before a choice of tool for a specific purpose should be made. First, who completes the tool? Some tools are designed for the person themselves (patient and service user) to complete (e.g., the McGill QOL); other tools for an interviewer to administer (e.g., the QUAL-E). Second, the length of time over which the respondent is asked to recall. The QUAL-E, for example, asks for recall during the last month, whereas the McGill QOL asks for recall during the past two days. Third, tools also vary in the estimated length of time to complete and their total number of items. It is not advised to only use the elements from a tool that map onto the concepts identified in this review, as this would not then be a valid measure. Other areas of consideration include whether the tool is validated for a particular population of interest or translated into particular languages. It is critically important that before a tool is used for a particular purpose or population that there are checks made that it has been tested in that population and found to be valid and reliable.

Challenges will remain, however, in using such outcome tools; however relevant they appear, to measure service outcomes where they are less tangible, prone to individual variation, and in a situation where

decline is expected. Some of these issues are conceptual, with questions about whether measurement of the concepts identified from the review such as enriching relationships is even possible. In addition, determining differences between concepts such as autonomy and knowing more may be challenging. Others are pragmatic, about understanding impact for a particular person in a situation of decline over time, and where response shift is likely to occur.^{43,44} Ways of understanding benefit that do not purely rely on outcome measurement tools are likely to remain important. In addition, benefit from interventions may be particularly felt when people lack other resources, social support or other networks, and tools do not identify these contextual issues.

Strengths and Limitations of the Review

This was a transparent and robust review with a clear audit trail and quality control procedures. However, because of the very large number of articles found across a wide range of journals, we did not enlarge the pool of databases searched, hand-searched journals, and the gray literature. Given the large number of included studies and clear themes across studies, this limitation is unlikely to have impacted on the findings of the review. Given the relatively large proportion of studies of ACP, this may have influenced the articulation of the knowing more theme, whereas a study testing these as theoretical propositions within a study of a supplementary support service found that future care planning, and hence knowing more, occurred less than anticipated.¹⁹ We did not map concepts onto all contender tools, given the large number of available tools, but offer this as an exemplar for readers to appraise other tools they may consider using in this field.

Conclusions

Analysis of qualitative research enabled identification of four main perceived care outcomes from supplementary palliative care support services. It was possible to then identify whether these concepts were included in exemplar existing outcome measurement tools. This enables an informed choice of existing outcome measurement tools for research and practice, understanding better the areas of relevance and redundancy/burden. This method may lead to fewer new tools being developed, given the plethora of existing tools, unless there is explicit need. Caution is, however, required, as the concepts of interest may be best understood qualitatively.

Disclosures and Acknowledgments

This work was supported by Age UK. The authors declare no conflicts of interest.

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Appendix

Appendix Table 1
Search Strategy

Database	Terms/Headings for Palliative Care	Terms/Headings for Related Interventions	Terms for Qualitative Research	Filters for Older People (EMBASE Only)
EMBASE (via Ovid)	palliative therapy OR hospice care/or hospice/ or hospice patient/ OR bereavement/ OR death/ OR terminally ill patient/ OR (palliat* or terminal* or hospice* or "chronic disease" or end-stage or advanced-stage or late- stage or final-stage or bereavement* or "end-of- life" or "life-limit*" or dying).ab,ti.	volunteer/ OR advance care planning/ OR counseling/ OR patient advocacy/ OR ("advance care plan*" or volunteer* or counseling or advocacy or care- coordination).ab,ti.	interview.tw. or exp health care organization/or experiences.tw.	aged/ elderly care/or geriatrics/ (aged or elderly or "older person*" or geriatric* or OAP* or pensioner*).ab,ti.
CINAHL (via EBSCO host)	(DE "Palliative Care") OR (DE "Terminal Care") OR (DE "Hospice Care") OR (DE "Terminally Ill Patients") OR TI (palliat* OR terminal* OR hospice* OR "chronic disease" OR end-stage OR advanced- stage OR late-stage OR final-stage OR bereavement* OR "end of life" OR life-limit* OR dying) OR AB (palliat* OR terminal* OR hospice* OR "chronic disease" OR end-stage OR advanced-stage OR late-stage OR final-stage OR bereavement* OR "end of life" OR life- limit* OR dying)	TI ("advance care plan*" OR volunteer* OR friend* OR community OR counseling OR advocacy OR "care- coordination") OR AB ("advance care plan*" OR volunteer* OR friend* OR community OR counseling OR advocacy OR "care- coordination") OR (DE "Death Counseling") OR (DE "Volunteer Workers") OR (DE "Volunteer Experiences") OR (DE "Patient Advocacy") OR (DE "Advance Care Planning")	TX interview OR MH audiorecording OR MH qualitative stud* OR (MH "Qualitative Studies")	
MEDLINE (via EBSCO host)	(DE "Hospice Care") OR (DE "Terminal Care") OR (DE "Palliative Care")	TI ("advance care plan*" OR volunteer* OR friend* OR community OR counseling OR advocacy OR "care- coordination") OR AB ("advance care plan*" OR volunteer* OR	((("semi-structured" or semistructured or unstructured or informal or "in-depth" or indepth or "face-to-face" or structured or guide) adj3 (interview* or discussion* or	

(Continued)

Appendix Table 1
Continued

Database	Terms/Headings for Palliative Care	Terms/Headings for Related Interventions	Terms for Qualitative Research	Filters for Older People (EMBASE Only)
PsycINFO (via EBSCO host)	<p>OR</p> <p>TI (palliat* OR terminal* OR hospice* OR "chronic disease" OR end-stage OR advanced-stage OR late-stage OR final-stage OR bereavement* OR "end of life" OR life-limit* OR dying) OR AB (palliat* OR terminal* OR hospice* OR "chronic disease" OR end-stage OR advanced-stage OR late-stage OR final-stage OR bereavement* OR "end of life" OR life-limit* OR dying)</p> <p>(DE "Palliative Care") OR (DE "Hospice") OR (DE "Bereavement") OR (DE "Death and Dying") OR (DE "Terminally Ill Patients")</p>	<p>friend* OR community OR counseling OR advocacy OR "care-coordination")</p> <p>OR</p> <p>(DE "Advance Care Planning") OR (DE "Hospital Volunteers") OR (DE "Volunteers") OR (DE "Counseling") OR (DE "Patient Advocacy")</p> <p>TI ("advance care plan*" OR volunteer* OR friend* OR community OR counseling OR advocacy OR "care-coordination") OR AB ("advance care plan*" OR volunteer* OR friend* OR community OR counseling OR advocacy OR "care-coordination")</p> <p>OR</p> <p>DE "Volunteers"</p>	<p>questionnaire*))) .ti,ab. or (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant").ti,ab. or interviews as topic/or focus groups/or narration/or qualitative research/</p> <p>OR</p> <p>(DE "Interview") OR (DE "Qualitative Research") OR (DE "Focus Groups")</p> <p>TI (((("semi-structured" or unstructured or informal or "in-depth" or "face-to-face" or structured or guide*) N3 (interview* or discussion* or questionnaire*)) or (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant")))</p> <p>OR AB (((("semi-structured" or unstructured or informal or "in-depth" or "face-to-face" or structured or guide*) N3 (interview* or discussion* or questionnaire*)) or (focus group* or qualitative or ethnograph* or fieldwork or "field work" or "key informant")))</p> <p>OR</p> <p>((DE "Qualitative Research") OR (DE "Interviews")) OR (DE "Group Discussion") NOT (DE "Literature Review")</p>	
	<p>TI (palliat* OR terminal* OR hospice* OR "chronic disease" OR end-stage OR advanced-stage OR late-stage OR final-stage OR bereavement* OR "end of life" OR life-limit* OR dying) OR AB (palliat* OR terminal* OR hospice* OR "chronic disease" OR end-stage OR advanced-stage OR late-stage OR final-stage OR bereavement* OR "end of life" OR life-limit* OR dying)</p>			

Appendix Table 2
Studies Included in the Review

Author Names	Research Question/Aim	Design/Methods	Sample Group	Sample Characteristics	Setting	Intervention	Conclusions/Key Findings
Bollig et al. ⁷	Explore the views of cognitively able residents and relatives from Norwegian nursing homes on ACP, decision making, and end-of-life care	Qualitative semistructured in-depth interviews with nursing home residents and focus group interviews with relatives of nursing home residents	Norway Nursing home residents	25 interviews with nursing home residents. 18 relatives participated in focus groups. Mean age residents 87 (66–100) and relatives 68 (41–91) yrs	Nursing homes	ACP	Besides planning for end of life, ACP helps the residents to prepare for death and can reduce moral distress for the relatives. ACP has a positive impact on quality of end-of-life care
Song et al. ⁵¹	Explore the perspectives of the bereaved surrogates of dialysis patients on the process and impact of an ACP intervention	Qualitative interviews and thematic analysis	U.S. 24 bereaved surrogates of patients from outpatient dialysis centers	Surrogates were 59 yrs (SD 14.0). Most were women (70.8%) and spouses of the deceased patients (41.7%)	Unclear	ACP	ACP provided a welcome opportunity to think about and discuss topics (e.g., death, life-sustaining treatments, acceptable or unacceptable outcomes, and end-of-life preferences). Most participants valued the opportunity to discuss these neglected topics ACP strengthened relationships by increasing communication.
Sellars et al. ⁴⁹	To describe the perspectives and attitudes of patients with ESRD and their caregivers toward ACP	Qualitative semistructured interviews	Australia Patients with ESRD (<i>n</i> = 24) and their caregivers (<i>n</i> = 15) aged 36–91 yrs at various stages of ACP	Patients were aged 55–91 (median 67), and 16 (41%) were men. Caregivers were aged 36–78 (median 62) yrs, and 6 (40%) were men	Interviews were conducted in person in the renal service	ACP	Five major themes were identified: <ul style="list-style-type: none"> • Articulating core values • Confronting conversations • Negotiating mutual understanding • Challenging patient autonomy—decisional disempowerment
Ingleton ²⁷	An evaluation of a community service assess satisfaction with the service and assess its impact	Formative qualitative evaluation. A multimodal approach: <ul style="list-style-type: none"> • A questionnaire survey of patients and carers during a six-week period • Nonparticipant observation • In-depth interviews • Document analysis 	U.K. Patients and carer service users	Survey: patient sample 14 males & 14 females The carer questionnaire completed by 17 people (five carers were males and 12 were females)	Unclear	The service provides respite beds, day care, community care, bereavement care, educational provision, and a welfare rights service	High levels of satisfaction were expressed by patients and carers

Davison ¹⁴	Determine the perspectives of patients with ESRD of the salient elements of ACP discussions	An ethnographic, qualitative, in-depth interview study was conducted of outpatients of a university-affiliated nephrology program	Canada Patients with ESRD	24 patients from a renal program. Participants were stratified by age, gender, and dialysis modality	Unclear	ACP	Participants found value in ACP in that it addressed fears; helped prepare them for death; strengthened interpersonal relationships; allowed them to achieve control over their life. Individual participants prioritized these issues differently
Sanders et al. ⁴⁷	A qualitative evaluation of a lay-led self-management course, adapted in some cases for people who are HIV positive	In-depth interviews with course participants	U.K. 31 Participants selected from the population enrolled in an RCT evaluation study of the EPP course	Purposive sampling to reflect age and gender Most respondents were women ($n = 23$) with a mean age of 50 yrs (range 28–75)	Home (generic course) or voluntary center (HIV adapted course)	U.K. EPP that provides self-management training for those with long-term conditions	Important to consider the biographical context of illness experience and the construction of narratives in aiding adjustment to living with illness. These aspects influence death awareness for people with chronic and life-threatening conditions, with implications for the implementation of this form of community education
Michael et al. ³⁷	To examine patients' and caregivers' perspectives about the use of the VT integrating clinical scenarios, as a tool for facilitating ACP discussions	Secondary analysis of data from three studies that incorporated the VT, focusing on statements specific to use of the VT and using a qualitative descriptive design informed by grounded theory	Australia Participants were recruited from the inpatient and ambulatory setting of a large metropolitan tertiary cancer center	85 Participants including 42 patients with Stage III–IV cancer (25 males), mean age 59.2 yrs (range 32–79) and 43 caregivers (13 males), mean age 52.9 yrs (range 29–79)	A large metropolitan tertiary cancer center	Vignette videos as a way of introducing ACP	The VT can be used to extend conceptualization and participation in ACP. Confronting vignettes should be avoided at sensitive times, and repeated offers are inappropriate for those distressed by the topic or who reject discussions. Findings recommend VT usage with skilled facilitators qualified to discuss patients' potential illness trajectories and with time to fully explore concerns
Luijckx and Schols ³³	Assess the impact of volunteer support from the perspective of family caregivers	Four components: focus groups; a survey; individual interviews; and an Internet panel	The Netherlands Focus group participants comprise family members of deceased persons.	Three focus groups with those who received volunteer support ($n = 13$), no volunteer support ($n = 9$), primarily female	Unclear	Volunteer support to patients and their families	Volunteers play a valuable role in palliative care. They provide practical and emotional support. Volunteer support is highly valued by family

(Continued)

Appendix Table 2
Continued

Author Names	Research Question/Aim	Design/Methods	Sample Group	Sample Characteristics	Setting	Intervention	Conclusions/Key Findings
			Individual interviews were carried out with six family caregivers	sample, age range 34–84			caregivers. Because of volunteers, family caregivers could rest, and patients could stay at home longer. Volunteers have more time to interact with terminally ill patients and their family members than other palliative caregivers do, and this gives their clients the opportunity to articulate their feelings and concerns
Winsett ⁵⁵	Explore patients' views on prognosis, end-of-life care, and hope	Qualitative study using in-depth interviews	Canada Patients with ESRD	19 patients 44–88 yrs (mean age 64 yrs, 58% women) with ESRD	Unclear	ACP	In patients with ESRD, facilitated ACP positively enhanced hope. Hope was sustained by information provided by HPs; relationships with HPs, family, and friends; and a role in the wider community
Davison and Simpson ¹⁴	To understand hope in the context of ACP from the perspective of patients with ESRD	Qualitative in-depth interview study	Canada Patients with ESRD	19 Patients from a renal program	Outpatient department of a university-affiliated nephrology program	ACP	Participants identified hope as central to the process of ACP in that hope helped them to determine future goals of care and provided insight into the perceived benefits of ACP and their willingness to engage in end-of-life discussions. More information earlier in the course of the illness focusing on the impact on daily life, along with empowerment of the patient and enhancing professional and personal relationships, were key factors in sustaining patients' ability to hope

Barnes et al. ⁵		Qualitative analysis of interview transcripts from ACP discussions	U.K. Patients with recurrent progressive cancer	40 Patients completed one or more ACP discussions Female (<i>n</i> = 19), male (<i>n</i> = 21); 36 white; one black Caribbean; three other. Median age 60.8 yrs (42–78)	In a place of patient's choosing	ACP	Patient concerns related to experiencing distressing symptoms or worrying how family members would cope. Some patients wished for more accurate information and were unaware of their options for care
Stewart et al. ⁵²	To explore views on ACP in care homes for older people	Qualitative exploration of views from care home staff and the family of residents in care homes for older people	U.K. Staff (care managers, nurses, and care assistants), community nurses, and families	Staff from 34 care homes, 16 care homes residential (two employing nurses), 10 nursing, and 8 dual-registered 38 care home managers	Care homes for older people in two London boroughs	ACP	Staff and families spoke positively about ACP. Staff felt ACP promoted respect for residents' wishes and aided their treatment decisions. In contrast, the son of a resident whose father had died a few weeks before the interview felt that participating in such a discussion had provided no real benefit for his father
Andersson and Ohlen ⁴	What it means to be a hospice volunteer in a country without a tradition of hospice or palliative volunteer care services	Ten volunteers from three different hospices in Sweden were interviewed. Their narratives were interpreted with a phenomenological hermeneutic method	Sweden Ten volunteers drawn from three hospices in central and western parts of Sweden	Nine women and one man. All aged 30–70. Three retired & remaining six were active in their professions	Within the volunteer's respective hospices	The work of hospice volunteers in general	The experience of being a volunteer to a large extent depends on how the volunteers are received into fellowship in the hospice and to what extent assignments are felt to be charitable and meaningful. Positive encounters with the hospice are closely related to personal growth
Beresford et al. ⁶	To explore what service users want from specialist palliative care social work	Qualitative individual or group interviews	U.K. Palliative social work service users, both bereaved people and people with life-limiting conditions	111 service users: 61 bereaved, 52 life-limiting illnesses and conditions; 39 men and 72 women; 9% identified themselves as black and/or members of minority ethnic groups	Unclear	Palliative care social work	What service users seemed to value from social work practice was that it was truly psychosocial; that is to say, it addressed both individual personal and psychological needs and the broader social circumstances and worlds people lived in and faced. These two were seen as inextricable.

(Continued)

Appendix Table 2
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Author Names	Research Question/Aim	Design/Methods	Sample Group	Sample Characteristics	Setting	Intervention	Conclusions/Key Findings
Burge et al. ⁹	To evaluate the introduction of a structured group ACP information session from the perspective of participants in pulmonary rehabilitation and maintenance programs	Prospective qualitative study with semistructured interview transcripts analyzed using iterative thematic analysis	Australia Participants in pulmonary rehabilitation & maintenance programs at a tertiary metropolitan hospital and two affiliated community sites	Sixty-seven participants with a range of chronic lung diseases were interviewed with ages ranging from 39 to 88 yrs	A tertiary metropolitan hospital and two affiliated community sites	ACP	The combination of practical help and support, with a relationship and friendship, was what so often were seen as valuable and unique Participants valued the ACP information. The group education format was well accepted and perceived to have advantages over individual sessions. Participants were happy to receive the information from a nonmedical facilitator
Chan et al. ¹⁰	To report on the effectiveness of an eight-week palliative care program in Hong Kong	A pretest/post-test design and semistructured interviews were adopted	Hong Kong After eight-week program, a convenient subsample of patients asked to provide feedback about perceptions of intervention through a semistructured interview	Characteristics of subsample of 14 interviewees are not made clear	Patient's homes	An eight-week home-based palliative care program with three components	In qualitative interview, four major themes were identified: 1. Improvement in the communication of treatment plans and after-death arrangements 2. Symptom management 3. Emotional support 4. Suggested areas of improvement
Crump ¹²	Explore African American seniors' perspectives on building skills to support ethnically diverse families of patients who are seriously ill and unable to speak	A community-based participatory research (with focus groups) approach was used to produce knowledge with participants from one Midwestern urban community	U.S. African American seniors living in one urban Midwestern metropolitan area	African Americans, aged 60 yrs or older	The nine focus groups were held at three community centers, two churches, and two homes	ACP	Themes were divided into five primary categories—those thought to be directly linked to the actual writing of an AD: trust, fear of death, relationships, lack of information and knowledge, and procrastination
Romøren et al. ⁴⁵	Nursing home doctors' descriptions of how the autonomy of the patient is taken into account in end-of-life decisions	Ten focus groups with 46 nursing home doctors	Norway Nursing home doctors	30 men and 16 women (aged 26–66 and working experience one to 38 yrs)	Unclear	ACP; aspects of decisions on life-prolonging treatment, and conflict with next of kin	Many end-of-life decisions appear arbitrary or influenced by factors independent of the individual patient's values and interests

Almack et al. ³	This study explores with patients, carers, and health care professionals if, when, and how ACP conversations about patients' preferences for place of care (and death) were facilitated and documented	Exploratory case study design using qualitative interviews	U.K. Patients, relatives, and clinical professionals	18 cases made up of patients ($N = 18$; 10 men and eight women; median age 75); nominated relatives ($N = 11$; seven women and four men; median age 65), and health care professionals ($N = 15$) caring for the patient	Unclear	ACP	and are not based on systematic ethical reflections. To protect patient autonomy in nursing homes, stronger emphasis on legal and ethical knowledge among nursing home doctors is needed The full potential of ACP is not being fulfilled. This study provides insights into the risks inherent in the process of having conversations where mortality must be acknowledged. Future research is needed to examine how to develop interventions to help initiate conversations to develop person-centered plans to manage the end of life
Johnson et al. ³⁰	To explore HPs' perceptions and experiences of ACDs and ACP in Australian palliative care services	A nationwide survey of 105 palliative care services was conducted. A qualitative analysis of open responses about ACP was undertaken	Australia Clinicians nominated by palliative care service directors (Palliative Care Outcomes Collaboration)	Most participants were female nurses, 40 yrs or older, and from metropolitan services. Participants had spent a mean of 12 yrs working in palliative care	N/A	The categories identified were grouped into four key themes: the ACD; the process of developing ACDs; the process of using ACDs; and the consequences of having ACDs	This article highlights the role of ACDs in facilitating communication, decision making, and providing care for dying patients. ACDs promoted greater understanding between family, friends and staff, and reduced distrust and conflict
Pesut et al. ⁴¹	The goal was to improve quality of life by developing independence, engagement, and community connections	Mixed-method evaluation data were collected from clients, volunteer navigators, the nurse navigator, and other stakeholders	Canada Clients/family, volunteer/nurse navigators, and other stakeholders	Volunteer demographics ($n = 7$) Age range (53–70); mean (60.0); and gender (male [$n = 0$]; female [$n = 70$]) Client demographics ($n = 18$) Age range (56–85); mean (70.0); and gender (male [$n = 8$]; female [$n = 10$]) Primary chronic condition: Cancer ($n = 7$) and other	Unclear	In-home visits by trained volunteers to provide navigation support. Volunteers were supported by a nurse navigator who provided an oversight and mentoring role	Clients and family rated the service as highly important to their care because of how the volunteer helped to make the difficult experiences of aging and advanced chronic illness more livable. Significant benefits cited by clients were making good decisions for both now and in the future; having a surrogate social safety

(Continued)

Appendix Table 2
Continued

Author Names	Research Question/Aim	Design/Methods	Sample Group	Sample Characteristics	Setting	Intervention	Conclusions/Key Findings
				(n = 11)			net; supporting engagement with life; and ultimately, transforming the experience of living with illness
Pesut et al. ⁴²	To pilot a nurse-led navigation service to provide early palliative support for rural older adults and their families living at home with advancing chronic illness	Twenty-five older adults and 11 family members living with advancing chronic illness	Canada Participants were 25 older adults living with advanced chronic illness	11 women and 14 men Age range (57–93) Mean (SD) 74.12 (10.27) Participant primary diagnosis: cancer: n = 13; heart failure: n = 4; COPD: n = 1; neurodegenerative: n = 1; other: n = 6	Unclear	Individuals living with advanced chronic illness received in-home visits by a nurse who performed a supportive navigation role	Research questions for this pilot study were aimed at evaluating feasibility, acceptability, and preliminary outcomes. The service was feasible, acceptable, and effective in meeting the needs of this population. Preliminary outcomes indicated that health care utilization was minimal and appropriate, client satisfaction was high
Field-Richards and Arthur ¹⁷	To explore the nurse-volunteer relationship in a day hospice	Underpinned by an interpretive approach, face-to-face semistructured interviews were conducted	U.K. 12 day hospice volunteers	12 self-selecting participants; two males and 10 females aged between 18 and 73 yrs. Participants volunteered at the hospice for 6–7 yrs (mean 16 months)	Hospice	Hospice volunteering	Volunteers see their role as becoming increasingly formalized partly as a response to increasing administrative demands on hospice nurses. The willingness of volunteers to take on new roles is variable
Fried et al. ¹⁹	To understand the perspectives of both patients and the person who would make medical decisions for them if they were unable (surrogates) on their participation in ACP	Qualitative cross-sectional study. This study examined ACP as a dyadic activity by conducting joint interviews with both veterans and their surrogates	U.K. Thirty-one veterans aged 55 yrs and older and their surrogates	31 Veteran-surrogate dyads. Approximately one-third of veterans were aged 55–59 and one-third were aged 70 and older. One-third of veterans were women, whereas three-quarters of surrogates were women. Approximately one-fourth of both were nonwhite	Telephone interview	ACP	The findings of the study illustrate the importance of the surrogate in the process of ACP. Although several of the barriers and facilitators were specific to the patient, many others either directly involved interactions between patient and surrogate or highlighted the ways in which the surrogate can influence ACP engagement

Froggatt et al. ²¹	The aim of this study was to describe current ACP practice in English care homes for older people	This study describes current ACP practice in care homes for older people drawing on data from a questionnaire survey (<i>n</i> = 213) of, and interviews (<i>n</i> = 15) with, care home managers	U.K. Home managers (<i>n</i> = 15)	15 Managers purposively selected from care homes where ACP was actively undertaken & ≥50% residents completed an ACP. Representation was sought in respect to size of home, chain, & ownership type	Unclear—presumably at their place of work	ACP	A priority is placed on older people being supported to remain in their own homes, even when very frail. Consequently, the move into a care home now occurs when people are older and frailer when their communication and cognitive abilities may be profoundly compromised. It could be too late postadmission to ascertain residents' and choices about future care
Allen et al. ¹	To describe the experience of recruiting, training, and retaining RSVs as interventionists delivering a reminiscence and creative activity intervention to community-dwelling palliative care patients and their caregivers	A community-based participatory research framework. Qualitative descriptive analysis identified themes arising from recruitment/feedback groups with potential RSV interventionists and individual interviews with RSVs who delivered the intervention	U.S. RSVs	Of the 12 RSVs who participated, 10 were women (four Caucasian, six African American, and two were African American men)	Unclear feedback groups at unspecified location	A reminiscence and creative activity intervention to community-dwelling palliative care patients	The intervention effects achieved by RSVs working with individuals with advanced chronic illness and their family caregivers were comparable to those achieved in the initial efficacy trial with professional interventionists. The themes identified by RSVs participating as LIFE interventionists reveal potential characteristics needed to be successful and mechanisms associated with positive short-term outcomes for the RSV that could result in long-term health benefits such as reduced risk of dementia
Hack et al. ²³	Explore dignity therapy via transcripts of the edited therapy session	In this qualitative study, 50 dignity therapy transcripts were randomly drawn and independently coded and analyzed by three investigators using a	Canada and Australia Transcripts randomly drawn for 50 terminally ill patients from	The mean age of participants was 64.3 yrs (range 36–95; SD 14.5), and 26 (52.0%) were women	Patient's hospital/residence	Dignity therapy	Dignity therapy serves to provide a safe therapeutic environment for patients to review the most meaningful aspects of their lives in

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Appendix Table 2
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Author Names	Research Question/Aim	Design/Methods	Sample Group	Sample Characteristics	Setting	Intervention	Conclusions/Key Findings
		grounded theory approach	palliative inpatient care programs at tertiary cancer centers and community hospitals in Canada (<i>n</i> = 17) or Australia (<i>n</i> = 33)				such a manner that their core values become apparent
Hajizadeh et al. ²⁴	We sought to gain general insights into the current practice of SDM and attitudes about patient involvement, as well as gain specific insights into experience with, and attitudes about, SDM for ACP	Qualitative analysis of face-to-face semistructured interviews	U.S. Eleven of 52 patients who were approached and met inclusion criteria for the study agreed to participate	The median age for patient participants' was 60 yrs (range 23–73)	A New York city public hospital	This process of informing and preference elicitation to assist with decision making is known as SDM and has become the standard model of collaboration between patients & their doctors to make health decisions	Although patients described participation in decision making, many deferred the final decision to their doctors. Doctors indicated a preference for SDM but expressed barriers including perceived lack of patient understanding and lack of patient empowerment
Horne et al. ²⁶	To develop and pilot an ACP intervention for lung cancer nurses to use in discussing end-of-life preferences and choices for care with patients diagnosed with inoperable lung cancer	A prospective qualitative design with semistructured individual patient interviews. A grounded theory approach was used for the analysis	U.K. 15 Patients took part in ACP discussions with their nurse, and nine agreed to be interviewed by a researcher about their perceptions of the intervention	Of the nine patients who took part in an interview with the researcher, three were males and six were females. They ranged in age from 52 to 87 yrs	Seven patients were interviewed in their own home and two patients in hospital	ACP	Patients' welcomed the recording of their wishes and appreciated the courage of the nurses in bringing up the subject of future care Further research is needed to determine the components of ACP and the training needs of staff
Brown et al. ⁸	To explore issues relating to end-of-life decisions with 15 individuals and their carers living in the community who had severe COPD	Qualitative in-depth interviews with participants and their carers to explore their need for services and support and included discussions about ACP	Australia 15 Participants and their carers (where relevant) participated in two in-depth interviews in their home at six-monthly intervals	Patients: nine males and six females Age range 50–79; mean 67 No carer details available	In patient's home	ACP with COPD patients	Patients and carers would welcome the opportunity to discuss end-of-life decisions, but almost no conversation about care planning had been initiated by HPs with any of the participants. Professional support is

Jack et al. ²⁸	To evaluate the impact of a community volunteer program to train volunteers to help by providing support to patients in their own homes	Semistructured digitally recorded individual, group, and focus group interviews, at the Hospice Africa Uganda sites with patients, the hospice staff, and CVWs	Uganda 21 Patients, 32 CVWs, 11 hospice clinical teams	Kampala CVWs: four males and six females; range 33–48 yrs; mean age 39 yrs Patients: three males and seven females; range 29–65 yrs; mean age 41 yrs Hoima CVWs: nine males, 11 females; range 28–52 yrs, mean age 39 yrs Patients: three males, eight females. Approximately 29–48 yrs (several patients were unsure of their age)	All interviews took place at the hospices and one selected community village hall location	Community volunteer program	required to assist with ACP and the completion of the legal AD documents The results included how the CVWs acted as a bridge to the hospice in identifying patients. Developing financial challenges that are emerging which could potentially impact on the program were reported. The community volunteer program appears to be having a positive impact on patients, families, and the hospice team
Jeong et al. ²⁹	Explore the phenomenon of ACP and advanced care directives in residential care settings in Australia	Case study research: participant observation, field notes, semistructured interviews, and document analysis. Data collected included semistructured interviews involving three residents and 11 family members	Australia Unclear. Data collected included semistructured interviews involving three residents and 11 family members	Unclear	Unclear (in the case of the participant observation, it was collected in the facility)	ACP	The participants' early experiences with ACP were expressed in unpleasant, hostile, and negative ways. However, those emotions and concerns were transformed to more stable, amenable, and positive attitudes and feelings as issues were resolved. The factors that enhanced or inhibited the transition were described
De Vleminck et al. ¹⁵	To explore how GPs conceptualize ACP, based on their experiences with ACP in their practice	Five focus groups were held with 36 GPs. Discussions were analyzed using a constant comparative method	Belgium Five focus groups were held with a total of 36 GPs ($n = 9$, $n = 11$, $n = 4$, $n = 5$, and $n = 7$)	Characteristics of participating GPs: males—27, females—9 Age: younger than 29 yrs: one; 30–39: five; 40–49: 13; 50–59: nine; and 60–69: eight	The focus groups were conducted in Flanders, Belgium in 2012	ACP	Four overarching themes were discerned: the organization of professional care required to meet patients' needs; the process of preparing for death and discussing palliative care options; the discussion of care goals and treatment decisions; and the completion of ADs

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Author Names	Research Question/Aim	Design/Methods	Sample Group	Sample Characteristics	Setting	Intervention	Conclusions/Key Findings
Menkin ³⁶	Explore the impacts of The Go Wish card game—an ACP tool developed by Coda Alliance to help people have conversations about end-of-life care	U.S. Methods underspecified				Go Wish: a tool for end-of-life care conversations	The cards focus the conversations, provide important vocabulary to give voice to patients' needs and concerns, and offer a means for sharing those ideas
Montross et al. ³⁸	To offer information about the pragmatic aspects of implementing dignity therapy for patients receiving hospice care	Referral and enrollment procedures as well as the logistics of therapy implementation were monitored. Patients' legacy transcripts were also qualitatively analyzed to measure emergent themes	U.S. Patients receiving dignity therapy	The 27 patients who fully completed dignity therapy as a clinical service had a mean age of 69 yrs, with a range from 33 to 98 yrs	N/A—qualitative analysis of legacy transcripts	Dignity therapy	The most commonly discussed topics among patients were (in rank order): autobiographical information, love, lessons learned in life, defining roles in vocations or hobbies, accomplishments, character traits, unfinished business, hopes and dreams, catalysts, overcoming challenges, and guidance for others
Low et al. ³²	To explore the experiences of people involved in U.K. PCDS and identify the important outcomes of this service	Focus groups were carried out separately with patients, informal carers, and volunteers from four purposively selected palliative care day units and with day unit managers from 11 units	U.K. 18 Patients, 12 carers, 22 day unit volunteers, 11 PCDS managers	Patients: mainly females with a median age of 60 yrs and predominantly white British (16 of 18) Carers: median age of 69 yrs predominantly white British, middle class females	Within each of the sites	PCDS	Patients benefited from both the support of PCDS professionals and social support of fellow PCDS patients, which contributed to a perceived improvement in their quality of life. Carers appreciated both the respite and support from PCDS but acknowledged that they still had a poor quality of life
Wright et al. ⁵⁶	Explore the process and therapeutic outcomes of meaning-centered dream work with hospice patients	CQR method	U.S. Seven hospice patients (five women)	Most participants ($n = 5$) were females, and the average age was 69.9 yrs (SD 14.7)	Within the hospice	A meaning-centered variation of the cognitive-experiential model of dream work	Participants described dream-work sessions as meaningful, comforting, and helpful. High scores on a measure of gains from dream interpretation were reported, consistent

Murray et al. ³⁹	We aimed to investigate caregiver perspectives on the acceptability and impact of ACP, documented in a letter format, for patients with motor neuron disease and caregivers	This is a qualitative cross-sectional study. Data were analyzed by a narrative synthesis approach. Structured interviews were held with 18 former caregivers of deceased patients with motor neuron disease	Australia 18 Former caregivers of deceased patients with motor neuron disease	Most participants were females (72%), older than 60 yrs (mean age 62 yrs), and were spouses of the deceased patients (78%). Two of the participants were children and one a sibling	Unclear	ACP in motor neuron disease	with qualitative findings. No adverse effects were reported or indicated by assessments A total of four global themes emerged: readiness for death, empowerment, connections, and clarifying decisions and choices. Many felt the letter of future care was or would be beneficial, engendering autonomy and respect for patients, easing difficult decision making and enhancing communication within families
Allen et al. ²	To examine the effectiveness of RSVs in delivering a reminiscence and creative activity intervention aimed at alleviating palliative care patient and caregiver distress	Qualitative content analysis	U.S. 45 Dyads of patient and carer	Of the 45 dyads that completed baseline, 28 completed postintervention and 24 completed follow-up	Other than patient screening instruments, patient and caregiver assessments were completed in the patient's home at baseline, postintervention, and follow-up	Reminiscence and creative activity interventions	Little qualitative data
McMahan et al. ³⁵	To understand what steps best prepare patients and surrogates for decision making	We conducted 13 English/Spanish focus groups with participants from a Veterans Affairs and county hospital and the community. Semistructured focus groups asked what activities best prepared participants for decision making	U.S. 38 Patients and 31 surrogates, who reported making serious medical decisions	Mean patient age was 78.8 yrs, and 61% were nonwhite. Mean surrogate age was 57.10 yrs, and 91% were nonwhite	Veterans Affairs and county hospital and the community	ACP beyond ADs	Qualitative analysis identified four overarching themes about how to best prepare for decision making: identify values based on past experiences and quality of life; choose surrogates wisely and verify they understand their role; decide whether to grant leeway in surrogate decision making; and inform other family and friends of one's wishes to prevent conflict
Hanson et al. ²⁵	To implement and evaluate new volunteer	Unstructured interviews	U.S. 130 Volunteers	Support team volunteers characteristics	Unclear where qualitative	Peer support	Lack of qualitative data

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Author Names	Research Question/Aim	Design/Methods	Sample Group	Sample Characteristics	Setting	Intervention	Conclusions/Key Findings
	support teams for African Americans with advanced cancer		and 25 African American patients	(<i>N</i> = 130) Age: 21–30 (16); 31–40 (11); 41–50 (34); 51–60 (28); 61–70 (33); 71 or older (4) Gender: female—107; male—23 Race/ethnicity Caucasian—8; African American—113; Other—5 Patient characteristics Age: younger than 41 yrs (3); 41–50 (7); 51–60 (19); and 61 and older (18) Gender: female—40; male—8	data were collected		
Noble et al. ⁴⁰	An evaluation of The MMSPCS	Mixed methods: a retrospective analysis of secondary care use in the last year of life; financial evaluation of the MMSPCS using an activity-based costing approach; qualitative interviews with patients, carers, health and social care staff, and MMSPCS staff and volunteers; a postal survey of general practices; and a postal survey of bereaved caregivers using the MMSPCS	U.K. 30 Interviews were carried out with Midhurst service staff & volunteers 21 Interviews with patients (11) & carers (10). 18 interviews with external staff	Unclear	Unclear	A medical consultant-led multidisciplinary team aiming to provide round-the-clock advice and care, including specialist interventions, in the home, community hospitals and care homes	Patients and carers reported positive experiences of support, linked to the flexible way the service worked
Rhee and Zwar ⁴⁴	Explore how ACP is conceptualized by stakeholder organizations and clinicians involved in aged care and end-of-life care in Australia	Qualitative descriptive analysis of semistructured telephone interviews	Australia 23 Participants including expert clinicians and representatives of government organizations, professional societies, consumer groups,	23 Participants (14 females and nine males), ages ranging between 34 and 65 (mean 52). Twelve were clinicians, two had clinical backgrounds but were no longer practicing, whereas nine were from a nonclinical	Telephone interview	ACP	Most participants viewed ACP as an ongoing process aimed at enhancing an individual's autonomy and ensuring good end-of-life care. Some viewed ACP as a process undertaken by patients to define and communicate their

			and other organizations involved in aged care and end-of-life care	background			treatment preferences. Others viewed ACP as discussions undertaken by HPs to gain a better understanding of the patient's values and goals to provide good care
Friis and Forde ²⁰	We wished to test systematic ACP discussions on an acute geriatric ward and investigate how patients felt about such discussions	An internationally tested tool was used as a basis for discussion with willing patients	Norway 58 Patients interviewed: 54 wanted full information about their health condition and four wanted limited information	Unclear	Hospital ward	ACP	Most took a very positive view of an ACP discussion of this type. Only one had a negative attitude. The patients were overwhelmingly positive with regard to ACP discussions. They have important messages to convey about information, the involvement of their families, and the intensity of end-of-life treatment
Duggleby et al. ¹⁶	Evaluate the effectiveness of a psychosocial supportive intervention called the LWHP in increasing hope and quality of life for older adult, community-living, terminally ill cancer patients	Qualitative data using open-ended hope questions were collected from the treatment group	Canada 61 Elderly advanced cancer patients receiving services from palliative home care in three western Canadian health regions participated in this study	The mean age of the participants was 74.97 yrs (SD 8.97). There were 28 males (46.7%) and 32 females (53.3%). Most were Caucasian (58 [96.7%])	In the patient's homes	A psychosocial supportive intervention called the LWHP	Most (61.5%) patients in the treatment group reported that the LWHP increased their hope. This preliminary evaluation of the effectiveness of the LWHP suggests that it may increase hope and quality of life for older terminally ill cancer patients at home
Pollock et al. ⁴³	Investigate the impact of the keyworker role in a three-year cancer supportive community care project to identify and provide for the needs of patients with a diagnosis of noncurative cancer	A qualitative study incorporating face-to-face interviews and focus groups with 19 health care professionals and 25 patients and carers and a thematic analysis of qualitative interview and focus group transcripts	U.K. 19 Health care professionals and 25 patients	The average age of those interviewed was 65, with a range between 49 and 84. The patient sample is not representative in terms of gender. Of the 43 eligible cases, 24 were women and 19 men. However, nine of the patient participants were men	In the patient's homes	The Supportive Care Project aimed to identify the needs of patients with noncurative diagnosis, about which little is known, and establish how they might best be met	In contrast to widespread professional assumptions about patients' need for counseling, many patients preferred to turn to their friends and families for support, and to adopt a stance of emotional and personal self-reliance as a strategy for coping with their predicament. The study highlights the continuing orientation of services around

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Author Names	Research Question/Aim	Design/Methods	Sample Group	Sample Characteristics	Setting	Intervention	Conclusions/Key Findings
Singer et al. ⁵⁰	To examine traditional academic assumptions by exploring ACP from the perspective of patients actively participating in the planning process	Forty-eight patients who were undergoing hemodialysis were interviewed six months after receiving an AD form	Canada 48 Patients	30 Men and 18 women with a mean age of 48.3 yrs. The mean age of participants was 48.3 yrs (age range 20–80)	During a scheduled dialysis session	ACP	professional, rather than patient, agendas The participants said that their purpose in ACP was to prepare for death and dying, and their underlying goals included the exercise of control and an attempt to relieve burdens placed on loved ones. ACP was viewed as a social process, and completing a written AD form was often regarded as unnecessary
Rydholm et al. ⁴⁶	How do faith community nurses support quality of life in older adults and caregivers?	This mixed-method study used both quantitative and qualitative strategies to attempt to discern the nature and impact of faith community nurse interventions on community-dwelling older adults	U.S. Faith community nurses	1061 Notes regarding 713 older adults were retrieved from 75 faith community nurses	Unclear—diaries	Faith community nursing	The nurses solicited help from blended networks, procured assistive devices, cued family members, made environments safe, reengaged those who were despairing, calmed those who were anxious, facilitated recovery aftercare, advocated for those who were neglected, and helped caregivers navigate end-of life decisions
Litzelman et al. ³¹	Report how CHWs used GW R cards and what values and preferences emerged as patients' highest priorities	15 Semistructured interviews. A team of four reviewers used immersion and crystallization techniques to identify and assimilate like comments into thematic categories	U.S. 15 Patients who had been served by CCAs	The mean age of the 15 patients interviewed was 71.8 yrs (SD 4.0); 73% were women, 46.7% African American, 46.7% Caucasian, and 6.7% other	Unclear	CHWs use of GW R cards with patients	After analyses of the 15 interviews by the reviewing team, three thematic categories emerged: the importance of ACP conversations and how their CCAs facilitated these conversations, the usability of the GW cards, and their feelings toward their CCA. The following expands on each of

Stone et al. ⁵³	This study explored experiences of initiating and completing ACP discussions in homes undertaking the gold standards framework in care homes	After an ACP discussion, 28 semistructured interviews were conducted with the resident, a family member, and the staff member who undertook the ACP. Content analysis was then conducted	U.K. 28 Interviews were undertaken with 11 residents, six family members, and six staff	Unclear	Within one of three NCHs	ACP	those categories, highlighting the majority opinion Three main categories of findings emerged: understanding ACP, undertaking ACP discussions, and impact of and reactions to ACP discussions. Staff understanding of ACP varied, affecting the depth of their discussions
Gardiner and Barnes ³²	Explore the mechanisms by which befriending facilitates well-being in older people at the end of life	Semistructured interviews	U.K. 12 Recipients and family of a U.K. befriending service for older people at the end of life	Gender: male—3; female—8 Age: mean—71; range—51–91 yrs Diagnosis: cancer—3; noncancer—8	Unclear	Befriending	The befriending service had a multidimensional impact on a range of outcomes, including emotional and psychological well-being and reduced social isolation. Other outcomes included practical support and family carer support
Fisher et al. ¹⁸	The key aim of this study was to explore patients' experiences of palliative day care in a Western Australian context	An in-depth qualitative research design with semistructured interviews was used for this study. A constructivist framework and interpretivist methodology guided this study	Australia Eight patients (two males and six females) with ages ranging from 44 to 82 yrs were interviewed	Eight patients (two males and six females) with ages ranging from 44 to 82 yrs	Day center	Palliative day care	Four broad themes emerged from the data, related to patients' experiences: being bounded physically; temporally; and socially; and the role of palliative day care in supporting patients. This study highlighted the potential for palliative day care to provide a therapeutic community space
Venkatasalu et al. ⁵⁴	To explore and critically examine stakeholders' views and perceptions concerning a nurse-led palliative care discharge service	A pluralistic evaluation design using qualitative methods was used	U.K. 12 Participants (five bereaved carers and seven HPs) participated in the evaluation	Carers: three males and two females. Their ages ranged from 52 to 84 yrs. Of the seven HPs interviewed, all were females	Four interviews were carried out at participants' homes and one at the hospital—as chosen by participants. Locations of HP interviews are unclear	Nurse-led palliative care discharge service	Four key themes emerged relating to the role of the discharge facilitator service: achieving preferred place of care; the discharge facilitator as the conduit between hospital and community settings; delays in hospital discharge and stakeholders' perceptions of the way

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Author Names	Research Question/Aim	Design/Methods	Sample Group	Sample Characteristics	Setting	Intervention	Conclusions/Key Findings
Seal ⁴⁸	Explain the role of patient advocacy in the ACP (ACPing) process	Focus groups	Australia Preintervention focus group sessions were evenly attended by a total of 18 nurses. The six month postintervention focus group was attended by three enrolled nurses	Unclear	Selected wards in an acute care public hospital in South Australia	The RPCP improves AD utilization through providing a supportive framework for ACP and primarily equipping nurses as RPC consultants	forward for the service Focus group participants shared that it used to be hard to advocate for patients, but now they could act legitimately and felt ethically comfortable about ensuing end-of-life-care
McMahan et al. ³⁴	To understand diverse older patients' and surrogates' experiences with decision making for serious illness	We conducted 13 English- and Spanish-speaking focus groups with participants from San Francisco VA and county hospitals. Semistructured interviews asked about decision-making experiences and what best prepared participants	U.S. Patients who reported making serious medical decisions and surrogate decision makers	Seven groups included patients (<i>n</i> = 38), aged older than 65 yrs. Six groups included surrogate decision makers (<i>n</i> = 31), aged older than 18 yrs. Mean patient age was 78.8 yrs, and 61% were nonwhite. Mean surrogate age was 57.10 yrs, and 91% were nonwhite	Unclear	Beyond ADs	Five additional ACP steps, beyond ADs, may better prepare patients and surrogates for complex medical decisions. To be effective, ACP needs to expand beyond asking patients to make decisions about life-sustaining treatment and must also focus on preparation for medical decision making
Cheung et al. ¹¹	To describe nurses' perspectives on their role and challenges of ACP in the dialysis setting	Face-to-face semistructured interviews. Results were based on grounded theory and thematic analysis	Australia 26 dialysis nurses	Median age 55 (range 32–72)	Unclear	ACP	We identified five themes: advocating for patients; dispersed knowledge; navigating family like relationships; juxtaposition of frailty and resilience; and community of nurses

ACP = advance care planning; ESRD = end-stage renal disease; RCT = randomized controlled trial; EPP = Expert Patients Program; VT = vignette technique; HPs = health professionals; ACDs = advance care directives; N/A = not available; COPD = chronic obstructive pulmonary disease; RSVs = retired senior volunteers; LIFE = legacy intervention family enactment; SDM = shared decision making; CVWs = community volunteer workers; GPs = general practitioners; PCDS = palliative care day services; CQR = consensual qualitative research; MMSPCS = Midhurst Macmillan Specialist Palliative Care Service; LWHP = Living with Hope Program; CHWs = community health workers; GW R = Go Wish R; CCAs = care community assistants; NCHs = nursing care homes; RPCP = Respecting Patient Choices Program; AD = advance directive; VA = Veteran Affairs.

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