# Tools for tomorrow: a scoping review of patient-facing tools for advance care planning

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***Abstract*:** Advance care planning (ACP) supports individuals in aligning their medical care with personal values and preferences in the face of serious illness. The variety of ACP tools available reflects diverse strategies intended to facilitate these critical conversations, yet evaluations of their effectiveness often show mixed results. Following the Arskey and O'Malley framework, this scoping review aims to synthesize the range of ACP tools targeted at patients and families, highlighting their characteristics and delivery methods to better understand their impact and development over time. Studies included focused on patient-facing ACP tools across all settings and mediums. Exclusions were applied to studies solely targeting healthcare providers or those only aiming at completion of advance directives without broader ACP discussions. Searches were conducted across PubMed, Embase, CINAHL, The Cochrane Library, and Web of Science. Data were extracted using a predesigned spreadsheet, capturing study population, setting, intervention modality, and intervention theme. Tools were categorized by delivery method and further analyzed through a year-wise distribution to track trends and developments. We identified 99 unique patient-facing tools, with those focusing on counseling (31) and video technologies (21) being the most prevalent while others incorporated online platforms, print materials, games, or some combination of different delivery methods. Over half the tools were designed for specific patient groups, especially for various diseases and racial or ethnic communities. Recent years showed a surge in tool variety and innovation, including integrated patient portals and psychological techniques. The review demonstrates a broad array of innovative ACP tools that facilitate personalized and effective ACP. Our findings contribute to an enhanced understanding of their utilization and potential impacts, offering valuable insights for future tool development and policy making in ACP.

## Plain language summary

### Scanning the landscape of tools to assist patients with advance care planning

This review investigates the variety of tools, programs, and interventions designed to help patients plan their healthcare in advance, a process known as advance care planning (ACP). ACP is crucial because it ensures individuals receive medical care aligned with their wishes, especially during serious illness or near the end of life. Our study gathered information from various sources, focusing on tools aimed directly at patients and their families. We found 99 unique tools that assist in ACP, including individual counseling sessions, video-based tools, and digital platforms. Some tools are designed specifically for certain patient groups, such as those with particular diseases or belonging to diverse racial and ethnic communities. Our review highlights the recent surge in the variety and innovation of these tools, such as integrated patient portals and methods incorporating psychological techniques, suggesting a growing effort to make ACP more accessible and tailored to individual needs. However, despite this variety, more research is needed to understand how these tools impact healthcare outcomes and how they can be effectively

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implemented in different care settings. Our findings aim to guide future development of ACP tools, improve their integration into healthcare practices, and ensure they meet the diverse needs of patients and families.

***Keywords:*** advance care planning, advance directives, attitudes on death, end-of-life care, surrogates

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## Introduction

Advance care planning (ACP) is a process that supports individuals at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care.[1] The goal of ACPs to help ensure that people receive medical care that is consistent with their values, goals, and preferences during serious and chronic illness. The complexity of these conversations necessitates supportive tools, interventions, and implementation strategies designed to facilitate discussions, enhance comprehension, and guide decision-making. Recent developments in ACP have led to the development of diverse tools and strategies, yet the evidence regarding their effectiveness remains variable and, at times, contradictory.[2]

Existing ACP tools span video-assisted discussions, group sessions, interactive online interventions, and beyond. A crucial aspect of ACP is the direct engagement of patients through patient-facing tools, which serve as essential instruments in guiding their care decisions. However, there are different perspectives on whether ACP should be patient-initiated, clinician-initiated, or through shared decision-making. Past reviews have focused on specific delivery methods of ACP tools[3] or a specific focus on tools to assist providers rather than patients and families,[4] while our review is the first to prioritize patient-facing tools of all types and mediums throughout all settings, highlighting their importance in the broader landscape of ACP. Recently, critics of ACP have highlighted various shortcomings, including hindered clinical implementation, inconsistent effects on patient quality of life, and decades of inconclusive evidence from ACP research concerning its use.[5] These critiques often overlook the potential value of specific ACP tools used and their variable implementation strategies. This variability in implementation strategies might be a significant driver of the conflicting evidence observed, as ACP is not a monolithic intervention, and the 'how' of its delivery is tightly linked to its effectiveness.

The development of tools to facilitate ACP has evolved over the past five decades from a focus on advance directives in the 1970s to the development of decision aids in the 2000s.[6–8] With advancements in technology, digital and interactive tools gained prominence, providing individuals with convenient access to ACP documents and educational resources.[9] Recent developments emphasize person-centered approaches that delve into an individual's values, goals, and priorities beyond medical decisions using personalized communication strategies that emphasize communicative competence.[1,10] The ongoing integration of ACP tools into healthcare systems aims to standardize practices and ensure consistent documentation and communication of individual and or family preferences.

This scoping review aimed to gather and synthesize the existing literature on ACP tools targeted at patients and families. Our primary aim was to catalog the existing tools, programs, and interventions that exist to support ACP. Our secondary aim was to evaluate the tool characteristics, delivery methods, targeted populations, innovative approaches, and trends in ACP tool development over time. The focus on these populations stems from our intention to comprehend how these tools directly empower patients and their families in making informed decisions, bridging a crucial gap between medical terminologies and lay understanding. This patient and family-centered approach is foundational to improving ACP implementation, as it equips individuals with the knowledge and confidence needed to initiate discussions and make choices that reflect their values and preferences. By mapping and categorizing the various approaches available, we aim to shed light on the prospective benefits and nuances

associated with the use of these tools in the ACP process, inform future development and/or adaptations, and ultimately aim to improve the effectiveness and efficiency of ACP implementation across various populations.

## Methods

This scoping review was conducted using the Arksey and O'Malley[11] five-stage framework of developing the research question, identifying relevant studies, selecting studies, charting the data, and summarizing and reporting the results. The review was guided by the following research question: What tools, programs, or interventions exist to support patients with ACP? We aimed to catalog the existing literature on ACP tools with patient-facing elements that target patients and families. This scoping review was not registered with a formal protocol.

### *Search strategy*

A research librarian (CV) developed a literature search strategy during November and December 2021 to retrieve studies that would answer the research question. The searches consisted of controlled vocabulary and keywords related to ACP, crossed with programs/interventions terms included, but were not limited to behavior therapy methods, psychosocial interventions, communication, and evaluation studies. Searches were completed between 1 December and 9 December 2022 using PubMed, Embase, The Cochrane Library (Wiley access), the Cumulative Index to Nursing and Allied Health (CINAHL) *via* EbscoHost, and Web of Science (Clarivate). All searches were limited to English language articles. Search results were updated on 14 March 2023 in the same five literature indexes as the original searches to ensure inclusion of the most recently published studies. The search strategy used can be found in Supplemental File 1.

### *Study selection*

All references were imported into Endnote and Covidence. After removing duplicates, title and abstracts were reviewed by two researchers (SR and KM) based on relevance to the research question. The researchers dually reviewed 20% of title and abstracts to guarantee inter-rater reliability before splitting the remaining 80% between them for solo review. Full texts were then dually reviewed by two researchers. Discrepancies were resolved by consensus.

Table 1 details the inclusion and exclusion criteria employed in our review. Studies were excluded if they did not include an intervention relevant to ACP, were not original empirical research, or were targeted for healthcare providers rather than patients. Notably, studies with an intervention aimed only at completing advance directives alone were not deemed comprehensive enough to be classified as an ACP strategy based on our inclusion criteria. While advance directive completion is an integral component of ACP, this delineation aligns with specific standards, such as billing requirements, which identify ACP as a more extensive process of ongoing communication.[12] Further, studies with interventions that were aimed specifically at training clinician communication, rather than for patient-facing interaction, were also excluded.

Studies were not excluded based on patient population parameters nor outcomes. A second round of study selection was conducted using articles identified in the updated search as well as by hand search of systematic or scoping reviews included in the original search. A Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist can be found in Supplemental File 2.

### *Analysis*

An Excel spreadsheet was developed for data extraction. The following data were extracted: study population, study setting, intervention modality, intervention theme, intervention target population, intervention target setting, study names, and general information on each study for tracking purposes (title, author, and year). Data were not extracted from systematic reviews, but data from studies identified by hand search were extracted from those studies. After data extraction was completed, studies were then grouped by study name to ensure the tools, programs, or interventions were unique and did not include duplicates.

We categorized interventions based on their delivery modes to better understand the diverse approaches to ACP. Individual counseling was defined as a tool that assisted a healthcare worker or social worker in interviewing or guiding the

**Table 1.** Inclusion and exclusion criteria.

| Criteria | Inclusion | Exclusion |
|---|---|---|
| Study design | Original empirical studies | Review articles, commentaries, editorials, and nonempirical literature |
| Intervention focus | Interventions relevant to advance care planning defined as the process that supports individuals at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. | Interventions solely focused on completing advance directives without broader ACP discussions. |
| Target audience | Tools, programs, or interventions with patient-facing components. | Interventions targeted for healthcare providers without direct patient engagement or aimed specifically at training clinician communication. |
| Population | All populations, without restriction based on specific patient groups or diseases. | No exclusions based on patient population parameters. |
| Outcomes | All outcomes related to ACP, including but not limited to engagement, comprehension, documentation, and implementation of ACP. | No exclusions based on study outcomes. |

ACP, advance care planning.

patient and potentially their surrogate/family caregiver through ACP in a one-on-one setting. Video-based tools involved the use of video-based tools to provide educational content, personal testimonials, or scenario-based discussions to aid patients in understanding and making informed ACP decisions. Hybrid delivery methods combine multiple delivery modes, such as counseling, digital tools, and print materials, to offer a multifaceted approach to ACP. Print materials included booklets, brochures, or pamphlets that provide instructions, questionaries, and/or vignettes. Web-based were any materials that were provided online or through digital technology only.

To assess the evolution of ACP tools over time, we conducted a year-wise distribution analysis of the included studies, categorizing them based on their publication year. Further, we systematically categorized the primary characteristics of the tools and interventions, such as delivery methods and specific adaptations, and tracked their frequency and variations over the study periods to highlight prevalent trends.

## Results

### *Study characteristics*

Searches of electronic databases initially identified 2542 articles. After de-duplication and the addition of articles identified by hand search, 2291 articles were screened at the title and abstract stage, of which, 2025 were excluded. Of the 266 articles assessed at the full text stage, 106 were excluded. The most predominant exclusion reason was interventions that did not meet our definition of ACP, where a majority of these were tools designed solely to aid in the completion of advance directives.

One hundred and sixty articles were included (Figure 1), including six systematic reviews, and were published between 2004 and 2023. Fifty-one studies focused on older adult populations, defined as 55 years of age and older. Ninety-eight studies focused on populations with some sort of chronic conditions, of which, 30 focused on patients living with cancer, 15 focused on persons living with dementia, 9 focused on persons living with cardiovascular diseases, and 6 focused on persons living with kidney disease. One hundred and sixteen studies took place in the United States, nine in Canada, five in Australia, five in Japan, and the rest in other parts of East Asia or Europe. Twelve studies enrolled predominantly or exclusively Black/African American populations, while three studies enrolled Chinese American populations, and three studies enrolled Hispanic populations. Six studies focused on adolescents or young adults, and four enrolled veterans.

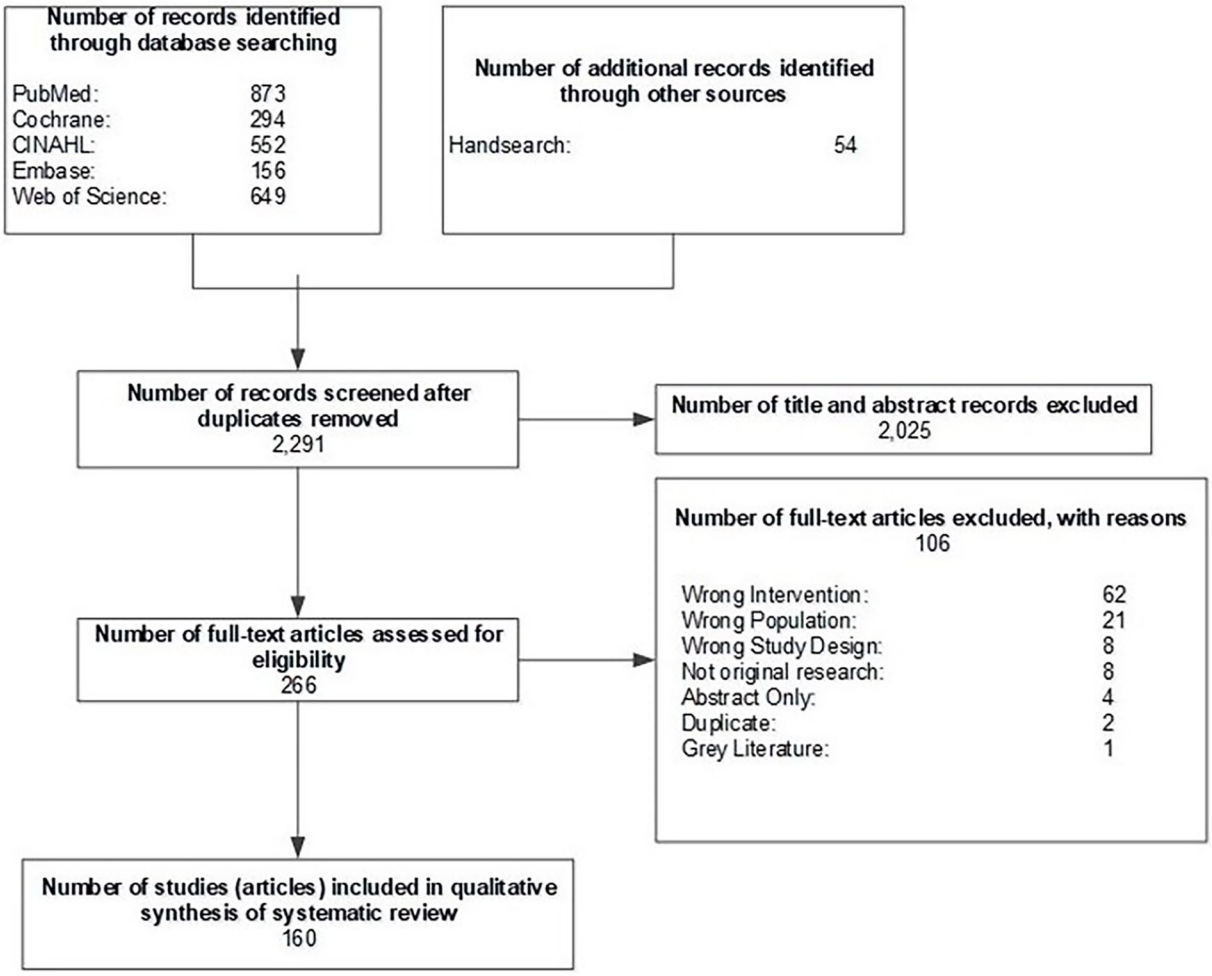


**Figure 1.** Flowchart of the inclusion and exclusion process.

### *Tools, programs, and interventions for ACP*

A total of 99 unique interventions were identified (Table 2). Intervention characteristics were analyzed thematically, with particular consideration given to the target populations or settings of each intervention. The most frequently used tools for ACP included in our review were PREPARE for Your Care, PROVEN, Hello Project (formerly My Gift of Grace), Making Your Wishes Known: Planning Your Medical Future, Patient-Centered Advance Care Planning (PC-ACP), and Sharing Patient's Illness Representation to Increase Trust (SPIRIT). The PREPARE for Your Care tool, used in 15 studies, innovatively incorporated a hybrid delivery method, offering adaptability across varying patient needs.[13–27] Conversely, tools such as PROVEN[28–33] and Hello Project[34–38] used video and game-based approaches respectively, illustrating the variety of delivery methods. The web-based tool, Making Your Wishes Known,[39–43] offers wide accessibility, while PC-ACP[44–48] and SPIRIT[49–53] highlight the significance of individual counseling in ACP. Respecting Choices, which was only explicitly included in two studies, was the seminal tool to help with ACP, and was a component of or was adapted into at least five more tools.[54–63] For example, the Family-Centered Advance Care Planning (FACE) tool is a combination of Respecting Choices and Five Wishes programs.[62,63]

### *Delivery methods*

Tools for ACP included in this review were categorized into seven different delivery methods. Thirty-one tools were delivered *via* individual counseling,[44–55,59–61,75,76,79,80,83,84,87,88–91,95,97–100,103,107,108,112,121–123,128,134,135,138,145,147] Twenty-one tools used video technology

**Table 2.** Intervention characteristics of included tools.

| Intervention or tool | Included studies | Delivery method | Target population or setting | Theme |
|---|---|---|---|---|
| PREPARE for Your Care[13–27] | 15 | Hybrid | Unspecified | Unspecified |
| PROVEN[28–33] | 6 | Video-based | Nursing home | Unspecified |
| Hello Project (formerly My Gift of Grace)[34–38] | 5 | Game | Community-based | Unspecified |
| Making Your Wishes Known: Planning Your Medical Future[39–43] | 5 | Web-based | Unspecified | Unspecified |
| Patient-Centered Advance Care Planning (PC-ACP)[44–48] | 5 | Individual counseling | Unspecified | Surrogate-focused |
| Sharing Patient's Illness Representation to Increase Trust (SPIRIT)[49–53] | 5 | Individual counseling | Dialysis patients | Surrogate-focused; disease-specific |
| Go Wish card game[64–67]* | 4 | Game | Unspecified | Unspecified |
| Sharing and Talking About My Preferences (STAMP)[68–71] | 4 | Hybrid | Unspecified | Unspecified |
| Aslakson *et al.*[72–74] tool | 3 | Video-based | Surgery | Disease-specific |
| ACP Intervention (ACP-I)[75,76] | 2 | Individual counseling | Hispanic; older adults | Culturally adapted |
| Advance Care Treatment-Plan (ACT-Plan)[77,78] | 2 | Group visits | Dementia; Black/African Americans; community-based | Culturally adapted; disease-specific |
| Family-Centered Advance Care Planning (FACE)[62,63] | 2 | Hybrid | Unspecified | Surrogate-focused |
| Family-Centered Advance Care Planning for Teens with Cancer (FACE-TC)[79,80] | 2 | Individual counseling | Adolescent; cancer | Age-specific; disease-specific |
| Respecting Choices[56,57]** | 2 | Hybrid | Unspecified | Culturally adapted |
| Respecting Patient Choices[60,61] | 2 | Individual counseling | Unspecified | Peer support |
| SHARING Choices[81,82] | 2 | Hybrid | Primary care | Surrogate-focused |
| SPIRIT – Modified for Dementia[83,84] | 2 | Individual counseling | Dementia | Disease-specific; surrogate-focused |
| The Conversation Project[85,86] | 2 | Video-based | Unspecified | Narrative-based |
| Voice Your Values[87,88] | 2 | Individual counseling | Dementia | Disease-specific |
| Voicing My CHOiCES[89,90] | 2 | Individual counseling | Cancer; adolescents | Age-specific |
| Bosisio *et al.*[91] tool | 1 | Individual counseling | Dementia | Adopted from advance care planning Medizinisch Begleitet[92]; disease-specific |

*(Continued)*

**Table 2.** (Continued)

| Intervention or tool | Included studies | Delivery method | Target population or setting | Theme |
|---|---|---|---|---|
| Advance Care Planning: Communicating with Outpatients for Vital Informed Decisions trial[93] | 1 | Hybrid | Unspecified | Pandemic-focused |
| Advanced Care Planning (title)[94] | 1 | Hybrid | Cancer | Disease-specific |
| Better tArgeting, Better outcomes for frail ELderly patients (BABEL)[95] | 1 | Individual counseling | Nursing homes | Surrogate-focused |
| De Panfilis *et al.* tool[96] | 1 | Web-based | Multiple sclerosis | Disease-specific |
| Benefits of Obtaining Ownership Systematically Together in pediatric ACP (BOOST pACP)[97] | 1 | Individual counseling | Adolescents | Age-specific |
| Brief Negotiated Interview – Emergency Department (BNI-ED)[98] | 1 | Individual counseling | Older adults; serious illness; emergency department | Unspecified |
| Communicating and Listening to Our Senior's voice about End-of-life (CLOSE), or 'the Hanoljigi' (in Korean)[99] | 1 | Individual counseling | Older adults; home healthcare | Unspecified |
| Deciding Together[100] | 1 | Individual counseling | Unspecified | Surrogate-focused |
| DECIsion-making about goals of care for hospitalized meDical patiEnts (DECIDE)[101] | 1 | Video-based | Hospital | Unspecified |
| Educational Video to Improve Nursing home Care in End-stage dementia (EVINCE)[102] | 1 | Video-based | Dementia; nursing home | Disease-specific |
| Engagement of Patients with Advanced Cancer (EPAC)[103] | 1 | Individual counseling | Cancer | Veteran-specific; disease-specific |
| Engaging in Advance Care Planning Talks (ENACT)[104] | 1 | Group visits | Unspecified | Unspecified |
| Engaging in Advance Care Planning Talks Mild Cognitive Impairment (MCI-ENACT)[105] | 1 | Group visits | Dementia | Disease-specific |
| Explore Your Preferences for Treatment and Care[106] | 1 | Web-based | Unspecified | Unspecified |
| Family/Adolescent-Centered Advance Care Planning (FACE)[107] | 1 | Individual counseling | Adolescent; HIV/AIDS | Culturally adapted; age-specific; disease-specific |
| Family-Centered Advance Care Planning-HIV (FACE-HIV)[108] | 1 | Individual counseling | HIV/AIDS | Disease-specific |
| Have a Say programme[109] | 1 | Hybrid | Dementia | Disease-specific; surrogate-focused |
| Heart to Heart Cards[110] | 1 | Game | Chinese American; community-based | Culturally adapted |
| Honoring Choices Minnesota[55] | 1 | Individual counseling | Unspecified | Adapted from Respecting Choices |

*(Continued)*

**Table 2.** (Continued)

| Intervention or tool | Included studies | Delivery method | Target population or setting | Theme |
|---|---|---|---|---|
| Honoring Choices Wisconsin[54] | 1 | Individual counseling | Unspecified | Adapted from Respecting Choices |
| Lay health worker Educates Engages and Activates Patients to Share (LEAPS)[111] | 1 | Booklet | Cancer; underrepresented racial/ethnic groups; low-income; community-based | Culturally adapted; disease-specific |
| Let Me Talk (modified for Chinese)[112] | 1 | Individual counseling | Chinese | Narrative-based; culturally adapted |
| More Good Days[113] | 1 | Video-based | Cancer | Disease-specific |
| Multi-modal Acceptance and Cognitive Therapy (M-ACT)[114] | 1 | Hybrid | Cancer; palliative medicine | Disease-specific |
| My Preferences[115] | 1 | Hybrid | Older adults | Unspecified |
| Normalization of Advance Care Planning (NACP); Used Making Your Wishes Known Brochure[116] | 1 | Hybrid | Unspecified | Unspecified |
| Our Memory Care Wishes (OMCW)[117] | 1 | Web-based | Dementia; nursing homes | Disease-specific |
| Person-Centered Oncologic Care and Choices (P-COCC)[118] | 1 | Hybrid | Cancer | Disease-specific |
| Plan Well Guide[119] | 1 | Web-based | Serious illness | Surrogate-focused |
| Lum *et al.*[120] tool | 1 | Electrtonic Health Record-based | Unspecified | Narrative-based |
| Preserving Identity and Planning for Advance Care (PIPAC)[121] | 1 | Individual counseling | Dementia | Surrogate-focused; disease-specific |
| Promoting Resilience in Stress Management –Advanced Cancer (PRISM-AC)[122] | 1 | Individual counseling | Adolescents; cancer | Age-specific; disease-specific |
| Respecting Choices + Motivational Interviewing[58] | 1 | Hybrid | Black/African Americans | Culturally adapted |
| Respecting Choices + Patient Care Connect Program[59] | 1 | Individual Counseling | Cancer | Peer Support; Disease-specific |
| The Support, Health, Activities, Resources and Education (SHARE) program[123] | 1 | Individual counseling | Dementia | Disease-specific; Surrogate-focused |
| SPIRIT – Heart Failure (SPIRIT-HF)[124] | 1 | Individual counseling | Heart failure | Disease-specific; surrogate-focused |
| Speak Up campaign[125] | 1 | Group visits | Canadian | Unspecified |
| Chiu Wu *et al.*[126] tool | 1 | Hybrid | Unspecified; community-based | Unspecified |
| Lai and Chan[127] tool | 1 | Video-based | Chinese | Culturally adapted |

*(Continued)*

**Table 2.** (Continued)

| Intervention or tool | Included studies | Delivery method | Target population or setting | Theme |
|---|---|---|---|---|
| Ko *et al.*[128] tool | 1 | Individual counseling | Unspecified | Unspecified |
| Volandes *et al.*[129] tool | 1 | Video-based | Older adults; dementia | Disease-specific |
| Volandes *et al.*[130] tool | 1 | Video-based | Unspecified; skilled nursing facilities | Unspecified |
| Kizawa *et al.*[131] tool | 1 | Video-based | Unspecified | CPR focus |
| Shuji *et al.*[132] tool | 1 | Hybrid | Unspecified | Unspecified |
| Lin *et al.*[133] tool | 1 | Video-based | Older adults | Narrative-based |
| Pajka *et al.*[134] tool | 1 | Individual counseling | Serious illness; emergency department | Unspecified |
| Michael *et al.*[135] tool | 1 | Individual counseling | Cancer | Disease-specific |
| Obama *et al.*[10] tool | 1 | Hybrid | Unspecified | Empathetic communication |
| Canny *et al.*[136] tool | 1 | Booklet | Cancer; primary Care | Disease-specific |
| Lin *et al.*[137] tool | 1 | Hybrid | Cancer | Culturally adapted; disease-specific |
| Patel *et al.*[138] tool | 1 | Individual counseling | Cancer | Health coaching; disease-specific |
| Mindfully Optimizing Delivery of End-of-Life Care (MODEL Care)[139] | 1 | Group visits | Cancer | Mindfulness; surrogate-focused; disease-specific |
| El-Jawahri *et al.*[140] tool | 1 | Video-based | Cancer | Disease-specific; Narrative-based |
| Michael *et al.*[141] tool | 1 | Video-based | Cancer | Surrogate-focused; disease-specific |
| Vogel *et al.*[142] tool | 1 | Web-based | Cancer | Disease-specific |
| Wong *et al.*[143] tool | 1 | Group Visits | Chinese | Culturally adapted |
| Dhingra *et al.*[144] tool | 1 | Hybrid | Chinese American | Culturally adapted |
| Menon *et al.*[145] tool | 1 | Individual counseling | Unspecified | Values inventory |
| Takada *et al.*[146] tool | 1 | Booklet | Heart failure | Disease-specific |
| Doorenbos *et al.*[147] tool | 1 | Individual counseling | Heart failure | Disease-specific |

*(Continued)*

**Table 2.** (Continued)

| Intervention or tool | Included studies | Delivery method | Target population or setting | Theme |
|---|---|---|---|---|
| Sadeghi *et al.*[148] tool | 1 | Video-based | Heart failure patients; hospital | Disease-specific |
| El-Jawahri *et al.*[149] tool | 1 | Video-based | Heart failure | Disease-specific |
| Leung *et al.*[150] tool | 1 | Video-based | Unspecified | Unspecified |
| Ufere *et al.*[151] tool | 1 | Video-based | Liver disease | Disease-specific |
| Sævareid *et al.*[152] tool | 1 | Group visits | Nursing home | Unspecified |
| Chan and Yu[153] tool | 1 | Group visits | Older adults | Social Work-based |
| Matsui[154] tool | 1 | Hybrid | Older adults; Japanese | Unspecified |
| Volandes *et al.*[155] tool | 1 | Video-based | Dementia; rural | Disease-specific |
| Hutson and Hankins[156] tool | 1 | Video-based | HIV/AIDS | Narrative-based; Disease-specific |
| Fink *et al.*[157] tool | 1 | Group visits | Rural; Hispanic; Community-based | Culturally adapted |
| Dierickx *et al.*[158] tool | 1 | Hybrid | Terminally ill | Unspecified |
| Barrison and Davidson[159] tool | 1 | Group Visits | University students | Unspecified |
| Values Discussion Guide[160] | 1 | Booklet | Unspecified | Unspecified |
| Video Images about Decisions for Ethical Outcomes in Kidney Disease (VIDEO-KD) trial[161] | 1 | Video-based | Kidney disease | Disease-specific |
| Video Images about Decisions for Ethical Outcomes (VIDEO) adaptation[162] | 1 | Video-based | Unspecified | Unspecified |
| Your Conversation Starter Kit[163] | 1 | Booklet | Dementia; community-based | Disease-specific |
| Your Life, Your Choices[164] | 1 | Booklet | Unspecified | Unspecified |

*One study for the Go Wish card game was a Swedish version and another was an Italian version.
**One study for Respecting Choices was a Dutch version.

to.[28–33,72–74,85,86,101,102,113,127,129–131,133,140,141,148–151,155,156,161,162] Twenty tools were classified as using hybrid delivery methods. For example, PREPARE for Your Care is a website that includes step-by-step instructions, questionnaires, and other interactive elements, alongside its core video content. Ten tools were delivered *via* group visits, workshops, or educational sessions.[77,78,104,105,125,139,143,152,153,157,159] Seven tools were delivered online or through a computer with some tools custom-designed for specific populations.[39–43,96,106,119,117,120,142] Six tools utilized print materials.[111,136,146,160,163,164] Other interventions were more interactive: three tools involved various sorts of games of sorts, most prominently card games such as the Go Wish, a play on the Go Fish card game.[34–38,64–67,110]

### *Disease-specific tools*

Fifty-four tools have been tailored for a specific population.[10,49–53,56–59,72–80,83,84,87–91,93,94,96,97,102,103,105,107–111,113,114,117,118,120–124,127,129,135–138,140–144,146–149,151,155,156,157,161,163] Of these 54, 42 focused on a

specific disease state.[49–53,59,72–74,77–80,83,84,87,88,91,94,96,102,103,105,108,109,113,114,117,118,121,123,124,129,135–142,146–149,151,155,156,161,163] Seventeen tools focused on patients living with cancer,[59,79,80,89,90,94,103,111,113,114,118,122,135–142] 12 tools on patients living with dementia,[77,78,83,84,87,88,91,102,105,109,117,121,123,129,155,163] 5 tools on patients living with heart failure,[124,146–149] 3 on patients living with HIV,[107,108,156] 2 tools on patients living with kidney disease,[49–53,161] and 1 tool each focused on surgery,[72–74] liver disease,[151] and multiple sclerosis patients.[96]

### *Culturally adapted tools*

Thirteen tools were culturally adapted for different racial or ethnic groups[56–58,75,76,107,110,112,127,143,144,157]: five for Chinese or Chinese American populations,[110,112,127,143,144] two for Hispanic populations living in the United States,[75,76,157] two for Black/African American populations,[58,77,78] and one tool was adapted for underrepresented racial/ethnic populations without a specific group in mind.[111] Five tools were designed or adapted for adolescents[79,80,89,90,97,107,122] and one tool for veterans.[103] One tool specifically targeted rural populations.[157] Three tools were translations of English-language tools: an Italian and Swedish translation of the Go Wish card game and one Dutch translation of PREPARE for Your Care.[56,96,67]

### *Setting-specific tools*

Fifteen tools were designed or adapted to be delivered in specific settings. Seven studies were designed for community-based settings such as community centers, six were designed for nursing homes or skilled nursing centers, and two were designed for primary care.

### *Approaches used for ACP delivery*

Several tools for ACP delivery included novel or unique approaches. Some focused on creative use of technology. The computer-tailored intervention component of the Sharing and Talking About My Preferences (STAMP) study provides personalized feedback reports on individual's readiness to participate in ACP behaviors, decisional balance, values/beliefs, and processes of change.[68–71] This tool uniquely provides dynamic, individualized feedback by tracking longitudinal changes and tailoring suggestions to foster active engagement in ACP behaviors based on the person's readiness stage. The Lum *et al.*[120] tool integrates a number of components to assist with ACP into the patient portal, including access to educational resources (PREPARE for Your Care, The Conversation Project, etc.), a support line to call, and an online messaging portal for asking questions of ACP experts. The tool also links with patients' medical durable power of attorney form.

Other tools included a variety of psychological techniques. The Mindfully Optimizing Delivery of End-of-Life Care (MODEL Care) tool brings mindfulness-based stress reduction program into ACP delivery for patients living with advanced cancer.[139] This approach aids in fostering self-regulation, self-awareness, and self-transcendence, potentially enhancing quality of life by encouraging acceptance of medical realities, thus reducing distress, avoidant coping, and delays in ACP. Similarly, the Obama *et al.*[10] tool introduces empathic communication to improve ACP engagement.

### *Current trends*

Within the past decade, there has been a marked increase in both the number and variety of studies on ACP tools. Our review included an average of two studies in the first 5 years (2004–2009) and an average of 21 studies in the last five full years (2018–2022). This research has brought forth a broader range of delivery methods and innovative approaches to ACP, demonstrating adaptability to specific populations. Similarly, there has been an evolution in delivery methods, shifting from primarily booklets and individual counseling to now integrating more video-based and web-based technologies as well as hybrid tools including components of multiple different delivery methods. There has also been an increase in population-specific adaptations, such as cultural- and dementia-specific tools. This growth and diversification signify an ongoing commitment to enhance and personalize ACP, adapting to the individualized needs of patients and families.

## Discussion

### *Main findings*

Our scoping review identified 99 unique ACP tools, demonstrating a variety of delivery methods and applications across diverse populations and

settings. The tools encompassed a range of delivery methods including individual counseling, video technology, and hybrid models. These were frequently adapted to specific populations such as those living with chronic conditions such as cancer or dementia, as well as those such as culturally diverse racial/ethnic groups. The past decade has seen a significant increase in the volume and diversity of studies using ACP tools, indicating a growing commitment to enhancing and personalizing ACP. This expansion in research also reflects an increase in innovative approaches, with tools incorporating dynamic feedback, mindfulness techniques, and integration with patient portals.

The broad variations in delivery methods for ACP tools reflects the evolving and dynamic nature of ACP itself, signaling a shift from passive recipient- or primarily healthcare provider-focused models to more interactive, patient-facing approaches. With the integration of innovative delivery methods such as video technology and hybrid models, ACP is aligning with contemporary societal and technological advancements, accommodating various learning styles, health literacy levels, and cultural contexts. This, in turn, highlights the ACP's movement away from a static, one-time conversation to a continuous, adaptable process. Moreover, the increasing trend of innovative approaches to ACP, including digital interfaces and gamification, further exemplifies the field's commitment to enhancing and personalizing ACP. This is of particular importance after the increased acceptance of virtual activity and death and dying experienced faced during the coronavirus pandemic.[165] The future of ACP should emphasize developing and implementing these flexible, adaptable tools to further embrace the individuality and variability of patient and family needs and preferences.

Our scoping review builds on the findings of preceding systematic reviews, which similarly aim to synthesize the empirical literature on ACP.[3,4] While Dupont *et al.*[3] and Myers *et al.*[4] provide more specific insight into the effectiveness of ACP, our review provides a more comprehensive look at the vast diversity of ACP tools and their trends over time. Our review focuses on all types of tools across different settings, with a focus on the patient, who is often overlooked when considering ACP tools.

### *Implications for policy and practice*

In the larger context over the recent debate over the effectiveness and utility of ACP, our findings illustrate the evolving nature of ACP tools and hence demonstrate that concerns based on data from ACP in the past may not be reflective of ACP today. Critics overlook the dynamic nature of ACP as reflected in the wide range of delivery methods and innovative approaches in the field. Given the right population adaptations and delivery methods, ACP has the potential to achieve the value-based care critics say is lacking. More research on the efficacy and utility of these newly emerging population-specific, patient-facing tools is needed. One of their central arguments is that patient decision-making is not static, and our findings reveal that ACP tools can themselves be dynamic and can be adapted to encourage changes in decision-making or updates in distinct populations through innovative approaches. These findings support the case for ACP as a nuanced, adaptable, and essential tool for end-of-life care planning, thereby challenging the critics' assertion.

The increasing diversity and sophistication of ACP tools hold substantial implications for both clinical practice and future research. With a variety of delivery methods tailored to individual needs, clinicians are now able to facilitate ACP in a manner that aligns with a patient's comfort, learning style, and cultural background. Particularly, the emergence of innovative, population-specific tools allows for a more personalized and inclusive approach to ACP, creating an environment where various patient populations feel acknowledged in their end-of-life care planning *versus* a 'one size fits all' approach. On the research front, these developments emphasize that ACP is an evolving field, requiring innovative measures of effectiveness beyond traditional metrics. Future studies should focus on patients' understanding, satisfaction, and alignment of care with personal values, along with the optimal implementation of these tools in different settings. This could also include the innovative approaches that maximize the ability for individuals and families to learn from the experiences of others who have been in similar circumstances. Continued exploration of these facets, guided by patients' and families' needs and preferences, is vital for realizing the full potential of ACP.[166]

While the tools and interventions identified in this review have undeniably made strides in addressing

individual and population-specific needs, our review highlights crucial gaps that persist. A glaring deficiency is the dearth of tools that specifically target populations that traditionally experience health disparities, particularly Black/African American and rural residents. Black/African American people often have lower rates of ACP completion and face disproportionate end-of-life care challenges due to socioeconomic factors, mistrust in the healthcare system, and cultural beliefs.[167,168] Similarly, rural populations often encounter a lack of access to healthcare services, including palliative and end-of-life care.[169] Additionally, specific caregiving scenarios such as for individuals living with dementia also benefit from the individualized, nuanced approaches to ACP. Inadequate ACP in such populations can exacerbate existing health disparities and result in care that is incongruent with patients' values and preferences. Future ACP tools must aim to address these disparities, developing interventions tailored to address the unique needs, preferences, and contexts of these underserved populations, including in community-based settings.

### *Strengths and limitations*

As with all reviews, there is a possibility that our review missed relevant studies. To help to mitigate this, we employed a broad search strategy across multiple databases. In addition, our review did not assess the quality of the studies included, which is consistent with the scoping nature of our review. Moreover, our review did not consider gray literature, nonempirical literature, or websites. This may have led to the underreporting of even newer or more novel tools, yet we remain convinced that our findings reflect the overarching trends that are likely to continue into this literature. Our review also did not consider tools that exclusively assist with advance directive completion, rather than ACP, creating the potential for the exclusion of relevant tools due to the considerable overlap between the two. However, this allowed us to provide a clearer and more consistent sample, relevant for healthcare providers. These interventions are complex, and it is possible that we may have missed certain nuances. We attempted to mitigate this limitation with dual review and frequent consensus building on complicated cases. Finally, publication bias may have been present, as studies with positive findings are often more likely to be published. This could potentially skew our understanding of the effectiveness and acceptance of the available tools. Despite this limitation, the findings from this review provide valuable insights into the evolving landscape of ACP tools.

## Conclusion

Our scoping review reveals an evolving landscape of ACP tools, marked by increasing diversity in delivery methods and a trend toward personalized, adaptable resources. The integration of technology and patient- and family-centered approaches signifies promising progress in end-of-life care, offering new paths for engagement with patients and families. Critics questioning the utility of ACP may need to revisit their perspectives in light of these innovative developments. Our findings highlight the need for further research on the effective implementation and integration of these tools as well as other unique approaches into healthcare systems and community-based settings. Ultimately, the continual advancement of these tools may reshape health services research, leading to more patient- and family-centered care and improving end-of-life decision-making processes outcomes for all people thereby promoting health equity.

## Declarations

### *Ethics approval and consent to participate*

Ethical approval was not required due to the type of review.

### *Consent for publication*

All authors consent to publication.

### *Author contributions*

**Sean R. Riley:** Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Project administration; Resources; Software; Supervision; Validation; Visualization; Writing – original draft; Writing – review & editing.

**Christiane Voisin:** Data curation; Methodology; Writing – review & editing.

**Erin E. Stevens:** Supervision; Writing – review & editing.

**Seuli Bose-Brill:** Funding acquisition; Supervision; Writing – review & editing.

**Karen O. Moss:** Conceptualization; Data curation; Formal analysis; Funding acquisition; Investigation; Supervision; Validation; Writing – original draft; Writing – review & editing.

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*Competing interests*

The authors declare that there is no conflict of interest.

*Availability of data and materials*

Available upon request to the corresponding author.

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**Supplemental material**

Supplemental material for this article is available online.

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