Year: 2021

Advance care planning evaluation: a scoping review of best research practice

Gloeckler, Sophie ; Krones, Tanja ; Biller-Andorno, Nikola

Abstract: Various indicators have been used to evaluate advance care planning, including completion rates, type of care received, and satisfaction. Recent consensus suggests, though, that receiving care consistent with one's goals is the primary outcome of advance care planning and assessment should capture this metric. Goal concordant care is challenging to measure, and there is little clarity about how best to do so. The aim of this scoping review is to explore what methods have been used to measure goal concordant care in the evaluation of advance care planning. PubMed, Embase, PsycINFO, CINAHL and Cochrane were searched in September 2020 to identify studies that aimed to track whether advance care planning affected the likelihood of patients receiving care that matched their preferred care. 135 original studies were included for review. Studies used retrospective chart review (36%, n=49), questionnaire (36%, n=48) and interview (31%, n=42), focusing on both patients and proxies. Studies considered both actual care received (55%, n=74) and hypothetical scenarios anticipating possible future care (49%, n=66); some studies did both. While the reviewed studies demonstrate the possibility of working towards a solid methodology, there were significant weaknesses. Notably, studies often lacked enough reporting clarity to be reproducible and, relatedly, key concepts, such as end-of-life or preferred care, were left undefined. The recommendations that follow from these findings inform future research approaches, supporting the development of a strong evidence base to guide advance care planning implementation in practice.

DOI: <https://doi.org/10.1136/bmjspcare-2021-003193>

Posted at the Zurich Open Repository and Archive, University of Zurich

ZORA URL: <https://doi.org/10.5167/uzh-207985>

Journal Article

Accepted Version

The following work is licensed under a Creative Commons: Attribution-NonCommercial 4.0 International (CC BY-NC 4.0) License.

Originally published at:

Gloeckler, Sophie; Krones, Tanja; Biller-Andorno, Nikola (2021). Advance care planning evaluation: a scoping review of best research practice. *BMJ Supportive Palliative Care*:Epub ahead of print.

DOI: <https://doi.org/10.1136/bmjspcare-2021-003193>

**How to Evaluate Advance Care Planning:
A Scoping Review to Inform Best Research Practice on Measuring Goal Concordant Care**

Sophie Gloeckler,^{1,2} Tanja Krones,^{3,4} Nikola Biller-Andorno¹

¹Institute of Biomedical Ethics and History of Medicine, University of Zürich, Zürich,
Switzerland

²Columbia University School of Nursing, New York, New York, United States

³Universität Spital Zurich, Bioethics Clinical Ethics, Zurich, Switzerland

⁴Universität Zurich Lehrstuhl für Medizingeschichte, Bioethik und Medizingeschichte Zurich,
Switzerland

Correspondence concerning this article should be addressed to Nikola Biller-Andorno, MD,
PhD; University of Zürich, Institute of Biomedical Ethics and History of Medicine,
Winterthurerstrasse 30, 8006 Zürich; Email: biller-andorno@ibme.uzh.ch

Word Count: 4,112

ABSTRACT

Various indicators have been used to evaluate advance care planning, including completion rates, type of care received, and satisfaction. Recent consensus suggests, though, that receiving care consistent with one's goals is the primary outcome of advance care planning, and assessment should capture this metric. Goal concordant care is challenging to measure, and there is little clarity about how best to do so. The aim of this scoping review is to explore what methods have been used to measure goal concordant care in the evaluation of advance care planning. Pubmed, Embase, PsycINFO, CINAHL, and Cochrane were searched in September 2020 to identify studies that aimed to track whether advance care planning affected the likelihood of patients receiving care that matched their preferred care. 135 original studies were included for review. Studies used retrospective chart review (36%, $n = 49$), questionnaire (36%, $n = 48$), and interview (31%, $n = 42$), focusing on both patients and proxies. Studies considered both actual care received (55%, $n = 74$) and hypothetical scenarios anticipating possible future care (49%, $n = 66$); some studies did both. While the reviewed studies demonstrate the possibility of working towards a solid methodology, there were significant weaknesses. Notably, studies often lacked enough reporting clarity to be reproducible and, relatedly, key concepts, such as end-of-life or preferred care, were left undefined. The recommendations that follow from these findings inform future research approaches, supporting the development of a strong evidence base to guide advance care planning implementation in practice.

Keywords: Clinical Decisions; Communication; End of Life Care < Ethics; Methodological Research; Quality of Life; Ethics

KEY MESSAGE BOX

1. What was already known?
 - Goal concordant care is a primary outcome of advance care planning
 - This is challenging to measure
2. What are the new findings?
 - Studies have used chart review, survey, and interview
 - Current methodology is flawed: often not reproducible and concepts poorly defined
3. What is their significance?
 - A) Clinical
 - Support establishing a strong evidence base guiding implementation
 - B) Research
 - Recommendations for improving methodology inform future research

INTRODUCTION

Advance care planning (ACP) is an effort to consider and communicate one's values, goals, and preferences as they relate to future healthcare decisions[1]. ACP can produce many forms of preference expression, including advance directives, living wills, physician orders for life-sustaining treatment (POLST), designation of a surrogate decision maker, conversations with one's healthcare providers, do not hospitalize orders, and more. Best viewed as a process, something to be revisited and reconsidered over time, the hope is that ACP in any of these forms will guide healthcare staff and loved ones in making decisions when one is incapable of consenting, refusing, or requesting services for oneself[2]. The assumption is that ACP supports others in meaningfully inferring a patient's preferences.

Despite growing acceptance of the value of ACP and its role in quality care, there has been a lack of clarity around how best to evaluate the effectiveness of ACP[2-4]. Consensus around how to assess the impact of ACP is needed in order to establish a strong foundation of evidence to support its implementation. Reviews of ACP effectiveness indicate that those looking to assess ACP have done so from many disparate angles as described below.

In evaluating ACP, some have looked to track the components necessary for ACP, including awareness of ACP; self-efficacy to engage in ACP; readiness to engage in ACP; identification of values and preferences; communication of values and preferences; documentation of values and preferences; revision of values and preferences over time; and accessibility of relevant documents[5-8]. These are the elements necessary to produce and reference advance care plans. This focus on process engagement and completion, though, falls short of evaluating whether the process has had an impact. The presence of ACP or the efficacy of efforts to motivate ACP is not a measure of the utility of that ACP.

Some have looked to track how ACP influences the care received, measuring outcomes such as length of intensive care unit (ICU) stays; rate of ICU admission; use of life sustaining treatments; costs; use of palliative care services; rate of hospice enrollment; and rate of unplanned hospital admissions[5- 7, 9, 10]. A concern with an emphasis on this kind of outcome measure is that the goal of ACP is not for patients to meet some objective idea of expedient or preferred care. While these evaluations measure associations between ACP and certain kinds of care or absence of care, they fall short of capturing whether that care aligned with what the patient wanted; some patients' ACP includes explicit requests *for* life-sustaining care. This way of evaluating ACP is problematic without clarity that what is being measured is not patient centered.

Other ACP evaluation efforts have, though, focused on patient and family centered outcomes such as satisfaction with care and quality of life. These studies have measured outcomes such as quality of communication with providers; patient satisfaction with care; surrogate or family satisfaction with the process of death and dying; rates of concern about the future; presence of a sense of peace or hope; and rates of negative emotions such as stress, anxiety, and depression[6-9, 11, 12]. These outcomes are relevant to quality end-of-life care, but they do not necessarily touch on the primary goal of ACP, which is to inform decision making when the person is unable to make decisions for him or herself.

Given that standardized outcomes defining successful ACP were lacking, a large, multidisciplinary Delphi panel convened in 2017 and determined top ACP outcome constructs, taking into consideration those mentioned above and others. The consensus, increasingly widely recognized in the field, is that “care consistent with goals” is the primary outcome of ACP[2]. The challenge remains, though, how to effectively measure this outcome. As those undertaking

the Delphi study note, “there is still no standardized, valid, or reliable method to measure this outcome [goal concordant care], especially across serious illness populations when preferences may vary over time”[2].

The aim of this literature review is to capture how goal concordant care, the recognized primary aim of ACP, has been measured in practice. Studies have been undertaken to assess whether ACP leads to patients receiving care that is consistent with their preferences, and the central question of this scoping review is what methods those studies have used. Understanding what indicators have been used to track goal concordant care allows for an evaluation of the strengths and limitations of existing approaches in order to hopefully guide the process of refining a gold standard for capturing this elusive outcome.

METHODS

Literature Search and Study Selection

A search of the literature was conducted in September 2020. The search included the databases Pubmed, Embase, PsycINFO, CINAHL, and Cochrane. The database searches were supplemented by hand searching the reference lists of reviews focused on ACP to identify additional, potentially relevant articles. The literature search included terms for ACP defined broadly combined with terms relevant to concordance, and, for feasibility, the search was limited to studies conducted in English in the last ten years. Since the aim was to review methodologies that have been used in completed studies, only published articles were included; no grey literature search was necessary. The search strategy was developed under the guidance of a Columbia University research librarian. Details of the search strategy are presented in the Appendix. A review protocol was not registered.

The returned search results were screened for duplicates. Titles and abstracts were then screened for relevancy. A second reviewer screened a random sample of ten percent of the studies to establish inter-rater reliability. Articles were included if they measured whether advance care planning, defined broadly to consider components such as advance directives, use of proxies, living wills, discussions, POLSTs, etc., led to goal concordant care. Goal concordant care could be the explicit focus of the study or simply one aspect of data collection. Studies had to take into account patient preferences; for example, studies that tracked place of death had to track not only where the patient died, but if that location aligned with the patient's wishes regarding place of death. Studies were excluded if they were not original research or were a study protocol of a not-yet published study. Since the aim was to better understand all possible approaches for tracking goal concordant care, no study was excluded based on population or study design.

Data Extraction

Each article was assessed to determine if tracking goal concordant care was a primary objective of the study and if the study included an evaluation of a tool or aid. Studies were coded according to whether they were reflecting on care received or considering hypothetical scenarios for future care. The type of ACP reviewed and the study design were both noted. Common methods, which included chart review, interview, and survey, were tracked, and finer analysis was conducted to identify quality indicators such as establishment of inter-rater reliability or use of validated scales and whom the survey or interview engaged. Finally, studies were described according to the type of congruence measured such as proxy-patient agreement, doctor's ability to accurately identify patients' preferences hypothetically, place of death, and others. Results were synthesized and summarized by reporting frequency and percentage statistics.

Risk of bias

Since this study was aimed at cataloguing methods used as opposed to demonstrating the impact of ACP or estimating intervention effects, evaluating individual studies for risk of bias was not relevant. That said, when considering common methods used such as chart review and survey, some quality indicators were tracked.

RESULTS

Study Screening

There were 2,101 original articles identified in the databases after 1,405 duplicates were removed. Two articles were added from the reference lists of relevant reviews. After screening titles and abstracts, 227 possibly relevant articles remained. A second reviewer screened 10% of all included articles ($n = 211$) to establish inter-rater reliability. There were 24 conflicts between the two reviewers, leading to 89% rate of agreement. After full text review, 135 articles were ultimately included. See Figure 1, *PRISMA Flow Diagram*, for the breakdown of study screening.

Study Aims and Focus

The included studies were split fairly evenly between those that were reflecting on care received (55%, $n = 74$) and those that were dealing with hypothetical scenarios anticipating possible future care (49%, $n = 66$); some studies did both. Many of the studies (41%, $n = 56$) stated that measuring goal concordant care was the objective. For example, as one study describes, the aim was “to examine the effectiveness of an advance care planning intervention in facilitating concordance between cancer patients' preferred and received life-sustaining treatment”[13]. Some of the studies (14%, $n = 19$) were evaluating specific ACP tools. For example, one such study describes the objective as “determin[ing] if a video aimed at educating

and engaging hospitalised patients on a standardised ACP order set can improve ... concordance between a patient's expressed and chart-documented care preferences"[14]. By design, the included studies covered a spectrum of ACP interventions. See Table 1 for a breakdown of ACP type evaluated. Some studies included more than one ACP intervention, for example both the use of a proxy and an advance directive, so the totals sum to more than 100%.

Table 1

Advance Care Planning (ACP) Elements Evaluated

Type of ACP Evaluated	%	<i>n</i>
Surrogate Decision Makers	29	39
Specific ACP Templates ^a	23	31
Advanced Directives	22	30
ACP Conversations	17	23
Life Sustaining Treatment Preferences	16	22
Multiple Elements of ACP	15	21
Do Not Hospitalize Orders	2	3
Psychiatric Advance Directives	1	2

^aRespecting Choice (*n* = 8), Family CEntered (FACE) Advance Care Planning (*n* = 4), What Matters Most (*n* = 2), Making Your Wishes Known (*n* = 2), Serious Illness Care Program (*n* = 2), Life Priorities Scale (*n* = 2), Community-Based Palliative Network Care Plan (*n* = 1), Kidney Supportive Care (KSC) Program (*n* = 1), Five Wishes (*n* = 1), Proactive Elderly Advance Care (PEACE) (*n* = 1), My Preferences (*n* = 1), Deciding Together (*n* = 1), Personal Values Report (*n* = 1), Vague (*n* = 7).

Table Legend: *Type of Advance Care Planning (ACP) Evaluated* captures the frequency of the various forms of ACP investigated in the included studies.

Study Design

There were three common methods used: retrospective chart review (36%, *n* = 49), questionnaire (36%, *n* = 48), and interview (31%, *n* = 42), with some studies using a combination of these methods. Many of the interviews or questionnaires made use of case vignettes (20% of interviews or questionnaires, *n* = 18). Where study design was specified, the majority of studies were random controlled trials (23%, *n* = 31). Other designs included prospective cohort study (6%, *n* = 8), retrospective cohort study (4%, *n* = 6), cross sectional sample (2%, *n* = 3), longitudinal observational study (1%, *n* = 2), and case-control (1%, *n* = 1).

Retrospective chart review was used in 66% ($n = 49$) of the studies that reflected on care received. The following is a straightforward example of this method: “Consistency with the PTOs [Physician Treatment Orders] was assessed from the medical records. If a treatment was provided despite the presence of an order specifying no treatment, the treatment was considered inconsistent”[15]. Sometimes, retrospective chart review was combined with consultation of loved ones or doctors (24% of retrospective chart review studies, $n = 12$) as in this example: “Data on the receipt of the aforementioned 6 LSTs [cardiopulmonary resuscitation, intensive care unit care, chest compression, intubation with mechanical ventilation, nasogastric tube feeding, and intravenous nutrition] in patients’ last month of life were retrieved from medical records and supplemented by caregivers’ reports during bereavement follow-ups”[16]. This example specifies that the review was of care received in the last month of life, but studies relying on retrospective chart review did not consistently specify the window of treatment time considered. Some studies were transparent around assumptions made, such as “we assumed that patients with full or modified code status preferred care in all domains and that patients with DNR code status preferred care in all domains except for CPR and defibrillation...We assumed that partial treatment preferences included dialysis unless otherwise specified and excluded cardioversion or defibrillation, which would be explicitly requested along with CPR,”[17] but this detailing was uncommon. More often, the methods were vague, simply stating something along the lines of, “compliance with wishes was determined by two researchers (KMD, WS), who reviewed the medical records of deceased patients”[18]. Using more than one reviewer and tracking inter-rater reliability is a quality indicator that was described in the methodology of 29% ($n = 14$) of the retrospective chart reviews.

The use of questionnaires was as common as retrospective chart review (36%, $n = 48$). Targeted participants varied, although most common was to include both patients and caregivers (40% of questionnaires, $n = 19$). Some studies focused only on patients (33% of questionnaires, $n = 16$), some included clinicians (31% of questionnaires, $n = 15$), and some targeted just caregivers (8% of questionnaires, $n = 4$). One questionnaire that appeared in multiple studies was the Decisional Conflict Scale (15% of studies with questionnaire, $n = 7$). Nearly half of all studies with questionnaires specified the use of instruments that had been validated (48%, $n = 23$).

The other commonly used method was interview (31%, $n = 42$). The majority of interviews were with both patient and caregiver (40% of interviews, $n = 17$) as in this example: “elders and their identified family caregivers were interviewed separately... questions [were] designed to explore the perceived challenges and concerns of the participants, their end-of-life preferences, and the extent to which they had discussed these issues with family members”[19]. The other commonly conducted interviews were with loved ones after the patient’s death (33% of interviews, $n = 14$) as in this example: “If the patient had died within six months of study enrollment, the family member was interviewed at about three months after the date of death about the quality of death and compliance with known end of life wishes”[11]. Some studies included only the patient (19% of interviews, $n = 8$) and some included or focused on clinicians (17% of interviews, $n = 7$).

Types of Congruence

The studies measured varying kinds of congruence, and some evaluated more than one of the following, so totals sum to greater than 100%. The most common type of congruence measured was an explicit assessment of whether the care received matched preferred care (55%,

$n = 74$). These studies all had a retrospective component as in the following example: “Using the Health and Retirement Study, which is a nationally representative, longitudinal cohort of adults over age 50, we sampled decedents whose family completed the 2014 post death interview. Families reported frequency of GCC [goal concordant care] at the EOL [end of life]”[20]. One indicator that was used in 20% ($n = 15$) of these studies was whether actual place of death matched preferred place of death.

Many studies evaluated proxy-patient concordance (27%, $n = 37$); these studies looked at proxies’ ability to accurately identify the preferences of those they represented. An example of this is a study where “participants chose between three unlabeled care scenarios ... Respondents selected (1) most-preferred and (2) least-preferred scenarios within each question. SPs [support persons] answered the same questions but from patient's perspective” to see how well the two aligned[21]. Another type of similar concordance measured was clinicians’ accuracy identifying patients’ preferences hypothetically (14%, $n = 19$). These studies evaluated how reliably ACP informs doctors’ ability to predict patients’ preferences as in the following example: “A ‘consensus physician response’ was generated for each treatment decision...This consensus response was shared with the patient whose advance directive had been reviewed, and she/he was then asked to indicate how well the physician translated his/her wishes into clinical decisions”[22].

There were other less commonly used methods as well that served as indicators for ACP’s influence on goal concordant care. Some studies evaluated patients’ self-consistency (9%, $n = 12$). These studies reviewed the stability and coherence of patients’ preferences over time or within one document as a way of investigating how well ACP indicates actual preferences; if the ACP documents are internally contradictory or unstable over time, then following them less

reliably leads to goal concordant care. The following is an example of how patient self-consistency was measured: “Subjects sorted the [goals of care] cards into Very Important, Somewhat Important, and Not Important piles. Subjects then rank ordered their top 10 cards from the Very Important pile. Two weeks later the participants repeated the sorting process”[23]. Another method indirectly measuring goal concordant care was to track rates of conflict and regret, which was evaluated in 11% ($n = 15$) of studies. Less commonly, studies reflected on whether documentation matched the ACP conversations that took place (4%, $n = 6$). These studies evaluated how accurately a written document captured a discussion as in the following example: “Conversations were audiotaped. Two researchers independently compared audio recordings with the corresponding documentation in an electronic health record (EHR) template and free-text progress notes, and rated the degree of concordance and adherence”[24]. Finally, family and clinician concordance was measured in a few studies (2%, $n = 3$) that compared the doctor’s interpretation of the patient’s wishes and the family’s interpretation of those wishes.

DISCUSSION

The present scoping review highlights both that various methods for measuring goal concordant care do exist and also that increased rigor is needed. The Delphi study identifying goal concordant care as the primary outcome of ACP flagged the concern that this metric is challenging to capture in practice[2]. While the reviewed studies demonstrate the possibility of working towards a solid methodology for tracking whether ACP leads to patients receiving their preferred care, weaknesses suggest that there is still much work to be done to refine best practice. This scoping review provides a basis for recommendations to guide future research methodology.

Part of the challenge in evaluating goal concordant care is that concepts are poorly defined. Fundamentally, the term goal concordant care remains vague: Does it refer to declared goals, presumed goals, or both? Is primacy given to predetermined wishes declared in advance or wishes articulated retrospectively of what would have been preferred? It would be helpful to refine the concept of goal concordant care in order to guide the approach to measuring it. Even if goal concordant care is well defined, though, the best methods may not always be feasible. For example, not all patients are ultimately able to offer reflective input on whether their preferences were met. Moreover, depending on the definition, goal concordant care may or may not indicate that ACP was useful. For example, if there is a conflict between the two, is goal concordant care the care that heeds preferences in the moment of a person who may exhibit varying degrees of capacity or care that is loyal to the goals stated in advance when the person had full decisional capacity? If the former, goal concordant care becomes a less helpful proxy for effective ACP.

Relatedly, a significant shortcoming of the methods reported in the reviewed studies was a frequent lack of clarity either due to deficits of reporting or because complex constructs were not well considered. For those studies concerned with end-of-life care, for example, are researchers considering the person's last hours, weeks, month, or some other time frame? In such studies, what end-of-life encompasses should be made explicit such that authors indicate the window of time their study considers. Perhaps more challenging, authors should consider, define, and communicate their construction of concordance. Must someone receive only their preferred care to fit this criterion or is there a threshold? Moreover, many stated preferences do not ever become relevant since there are many issues that do *not* arise and no decision needs to be made; how should these preferences be taken into account in evaluation? It is also worth reflecting on whether the aim is to track concordance with expressed wishes around specific medical

interventions, such as dialysis or resuscitation, or something more abstract such as concordance with expressed general goals of care. It would be advisable to be mindful of the distinction between these two and, where relevant, explicitly pre-define and report which medical interventions are being assessed. Reproducibility is a central tenant of the scientific method, and more clarity is needed from many of the current studies evaluating goal concordant care in order to concretize concepts and, on a basic level, make it possible for other researchers to follow the study protocol.

Some of the reviewed studies lacked measures that would reduce error and bias, such as use of two reviewers or use of validated scales. Certain quality indicators should be considered and reported, especially if researchers are working towards high quality retrospective chart review. When carrying out chart review, it seems advisable that data collectors be qualified with some medical research expertise and/or have been trained in how to perform the data collection; studies should consider this and report whether or not it is the case. Since chart review is prone to bias and error, researchers should also mention whether or not there was more than one reviewer for reliability; the validity of findings would be sounder if studies consistently had more than one reviewer. Finally, many studies only reviewed those documents available in the medical record. While perhaps not always feasible, it would be worthwhile to make an effort to determine if documents not in the medical record existed and/or influenced decision making.

Chart review is only one arena where possible shortcomings exist. In the use of case vignettes, for example, there may be limited generalizability given the broad array of potential clinical scenarios and given that vignettes isolate decisions that in real life are influenced by multiple factors. This reflects a more general aspect of ACP: if ACP is not a broad effort to develop individualized goals of care over time, ACP may have limited application depending on

how closely the preferences described fit the intricacies of the presenting, clinical scenario. Another possible concern with interview and survey studies is that patients are approached at a specific point during their disease, and it is probable that preferences and perhaps also concordance between patients and proxies evolves over the course of the disease's progression. This is a challenge not only in studies, but in ensuring high quality ACP itself where declared preferences are meant to be revisited and reconsidered over time. Tracking stability of patient preferences over time is one way to inform understanding of the need for ACP to be evolving and the need for ACP evaluation to consider timing. Other challenges relate to efforts to ascertain preferences through the reports of surrogates and doctors. When engaging surrogates to relay whether patients' wishes were met as occurs in post-death interviews carried out with a patient's loved ones, to what extent is it valid to assume that the surrogate's interpretations represent the patient's wish? To address this, some studies have looked explicitly at the question of how well proxies or doctors can identify the patient's preferences. While the above concerns are relevant and demand reflection, they do not invalidate the use of vignettes, survey, and interviews.

Some of the above concerns are at the heart of the debate over the utility of ACP more broadly. Concerns, including that patients may be limited in their ability to future forecast; that clinical scenarios may be too complex and statements of preference too open to divergent opinion to be relevant or directive; that patient preferences are too mutable over time; that designated proxies may not be the ones with the best insight into the patient's true preferences; and others have been recognized by earlier researchers and thinkers as, for example, explored in an early article from 1991 by Wolf et al. The current, standing definition of ACP takes these concerns into account by defining ACP not as a single event or form, such as one conversation

with a healthcare provider or the one-time completion of an advance directive, but rather an ongoing effort that enables individuals to define, discuss, potentially record, and refine goals and preferences for future medical care with family and providers over time[25]. Ongoing reflection and exchange are essential. The scope of this paper is not to address concerns about the utility, feasibility, and validity of ACP, but rather to refine an understanding of sound methodology to track goal concordant care. As such, some recommendations to further the field's efforts to track goal concordant care are listed below:

- Attend to reproducibility: define time frames being reviewed, medical interventions being tracked, thresholds for concordance, etc.
- In the case of chart review, reducing bias and error means having trained data collectors and using more than one reviewer
- There is value in supplementing chart review with interview of loved ones or clinicians, but do keep in mind the limitations of these proxies' ability to truly know the patients' preferences
- Consider concrete, positively stated wishes such as preferred place of death
- Consider validated scales such as the Decisional Conflict Scale applied to a well-defined clinical situation
- Be deliberate about when in the disease progression data is being collected

LIMITATIONS

The main limitation of this scoping review is that only one main investigator screened the majority of studies and extracted data; although inter-rater reliability was high, it is preferable to have two reviewers for the entire volume of studies. Moreover, it was not possible to include studies published in languages other than English, introducing possible bias.

FUTURE RESEARCH

Further research is needed to assess the feasibility of the above recommendations in research practice. Hopefully these contributions pave the way towards a better understanding of the impact of ACP based on studies that have investigated goal concordant care. Drawing on more rigorous guidelines for assessing goal concordant care, it would also be meaningful to conduct studies that allow for comparison between the differential impact of various forms of advance care planning – including innovative approaches such as AI-based tools[26, 27]– in various settings to determine if certain approaches are more effective.

DECLARATIONS

Availability of data and materials

The datasets used during the current study are available from the corresponding author on reasonable request.

Competing Interests

The authors declare that they have no competing interests. Funding for this work comes from SG's PhD funding.

Author's Contributions

SG was involved in conceptualizing the study, developing the methodology, performing analysis, and writing the original draft. NB was involved in supervising and conceptualizing the study as well as in the review and editing of the writing. TK was involved in conceptualizing the study as well as in the review and editing of the writing.

Acknowledgements

The authors acknowledge the contribution of Daniel Drewniak in methodology and Rasita Vinay in article review.

Figure Legend and Abbreviation

Figure 1, *PRISMA Flow Diagram*, tracks the process of identifying, screening, and excluding, and including articles for the scoping review; 135 articles were ultimately reviewed. The abbreviation ACP is used throughout the text and refers to advance care planning.

References

01. Howard M, Bernard C, Tan A, Slaven M, Klein D, Heyland DK. Advance care planning: Let's start sooner. *Can Fam Physician*. 2015;61(8):663-5.
02. Sudore RL, Lum HD, You JJ, Hanson LC, Meier DE, Pantilat SZ, et al. Defining Advance Care Planning for Adults: A Consensus Definition From a Multidisciplinary Delphi Panel. *J Pain Symptom Manage*. 2017;53(5):821-32.e1.
03. Biondo PD, Lee LD, Davison SN, Simon JE, CRIO) ACPCRaIOPA. How healthcare systems evaluate their advance care planning initiatives: Results from a systematic review. *Palliat Med*. 2016;30(8):720-9.
04. Johnson SB, Butow PN, Kerridge I, Bell ML, Tattersall MHN. How Well Do Current Measures Assess the Impact of Advance Care Planning on Concordance Between Patient Preferences for End-of-Life Care and the Care Received: A Methodological Review. *J Pain Symptom Manage*. 2018;55(2):480-95.
05. Evans N, Bausewein C, MeOaca A, Andrew EV, Higginson IJ, Harding R, et al. A critical review of advance directives in Germany: attitudes, use and healthcare professionals' compliance. *Patient Educ Couns*. 2012;87(3):277-88.
06. Kelly AJ, Lockett T, Clayton JM, Gabb L, Kochovska S, Agar M. Advance care planning in different settings for people with dementia: A systematic review and narrative synthesis. *Palliat Support Care*. 2019;17(6):707-19.
07. Jimenez G, Tan WS, Virk AK, Low CK, Car J, Ho AHY. Overview of Systematic Reviews of Advance Care Planning: Summary of Evidence and Global Lessons. *J Pain Symptom Manage*. 2018;56(3):436-59.e25.

08. Rietjens JAC, Sudore RL, Connolly M, van Delden JJ, Drickamer MA, Droger M, et al.
Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncol.* 2017;18(9):e543-e51.
09. Houben CHM, Spruit MA, Groenen MTJ, Wouters EFM, Janssen DJA. Efficacy of advance care planning: a systematic review and meta-analysis. *J Am Med Dir Assoc.* 2014;15(7):477-89.
10. Higuel T, Alaoui A, Bouton C, Fournier JP. Effect of Living Wills on End-of-Life Care: A Systematic Review. *J Am Geriatr Soc.* 2019;67(1):164-71.
11. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ.* 2010;340:c1345.
12. Lewis E, Cardona-Morrell M, Ong KY, Trankle SA, Hillman K. Evidence still insufficient that advance care documentation leads to engagement of healthcare professionals in end-of-life discussions: A systematic review. *Palliat Med.* 2016;30(9):807-24.
13. Wen FH, Chen JS, Chou WC, Chang WC, Hsieh CH, Tang ST. Extent and Determinants of Terminally Ill Cancer Patients' Concordance Between Preferred and Received Life-Sustaining Treatment States: An Advance Care Planning Randomized Trial in Taiwan. *J Pain Symptom Manage.* 2019;58(1):1-10.e.
14. Nair R, Kohen SA. Can a patient-directed video improve inpatient advance care planning? A prospective pre-post cohort study. *BMJ Qual Saf.* 2019;28(11):887-93.
15. Konttila T, Finne-Soveri UH, Leskinen R, Niemelä K, Antikainen R. Progress in advance care planning among nursing home residents dying with advanced dementia-Does it make any difference in end-of-life care? *Arch Gerontol Geriatr.* 2020;86:103955.

16. Tang VL, Dillon EC, Yang Y, Tai-Seale M, Boscardin J, Kata A, et al. Advance Care Planning in Older Adults With Multiple Chronic Conditions Undergoing High-Risk Surgery. *JAMA Surg.* 2019;154(3):261-4.
17. Turley M, Wang S, Meng D, Kanter M, Garrido T. Impact of a Care Directives Activity Tab in the Electronic Health Record on Documentation of Advance Care Planning. *Perm J.* 2016;20(2):43-8.
18. Silvester W, Fullam RS, Parslow RA, Lewis VJ, Sjanta R, Jackson L, et al. Quality of advance care planning policy and practice in residential aged care facilities in Australia. *BMJ Support Palliat Care.* 2013;3(3):349-57.
19. Gardner DS, Kramer BJ. End-of-life concerns and care preferences: congruence among terminally ill elders and their family caregivers. *Omega (Westport).* 2009;60(3):273-97.
20. Haines L, Rahman OK, Sanders JJ, Johnson K, Kelley A. Factors That Impact Family Perception of Goal-Concordant Care at the End of Life. *J Palliat Med.* 2019;22(8):927-32.
21. Waller A, Sanson-Fisher R, Brown SD, Wall L, Walsh J. Quality versus quantity in end-of-life choices of cancer patients and support persons: a discrete choice experiment. *Support Care Cancer.* 2018;26(10):3593-9.
22. Levi BH, Heverley SR, Green MJ. Accuracy of a decision aid for advance care planning: simulated end-of-life decision making. *J Clin Ethics.* 2011;22(3):223-38.
23. Song MK, Ward SE, Hepburn K, Paul S, Kim H, Shah RC, et al. Can Persons with Dementia Meaningfully Participate in Advance Care Planning Discussions? A Mixed-Methods Study of SPIRIT. *J Palliat Med.* 2019;22(11):1410-6.

24. Geerse OP, Lamas DJ, Bernacki RE, Sanders JJ, Paladino J, Berendsen AJ, et al. Adherence and Concordance between Serious Illness Care Planning Conversations and Oncology Clinician Documentation among Patients with Advanced Cancer. *J Palliat Med.* 2021;24(1):53-62.
25. Rietjens JA, Sudore RL, Connolly M, van Delden JJ, Drickamer MA, Droger M, van der Heide A, Heyland DK, Houttekier D, Janssen DJ, Orsi L. Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care. *Lancet Oncol.* 2017 Sep 1;18(9):e543-51.
26. Biller-Andorno N, Biller A. Algorithm-Aided Prediction of Patient Preferences — An Ethics Sneak Peek. *New Eng. J. Med.* 2019 Oct 10;381 (15): 1480-5.
27. Biller-Andorno N, Ferrario A, Joebgies S, Krones T, Massini F, Barth P, Arampatzis G, Krauthammer M. AI support for ethical decision-making around resuscitation: proceed with care. *J. Med. Ethics.* 2021 Mar 9.