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

Sophie Gloeckler 1,2, Tanja Krones 1,3, Nikola Biller-Andorno 1

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.

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 hospitalise 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. 3–4 Consensus on 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. 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. 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 centred.

Other ACP evaluation efforts have, though, focused on patient and family-centred 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. These outcomes are relevant to quality end-of-life (EOL) 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 standardised 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 recognised in the field, is that ‘care consistent with goals’ is the primary outcome of ACP. The challenge remains, though, how to effectively measure this outcome. As those undertaking the Delphi study note, ‘there is still no standardised, valid, or reliable method to measure this outcome (goal concordant care, GCC), especially across serious illness populations when preferences may vary over time’.

The aim of this literature review is to capture how GCC, the recognised 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 GCC 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 online supplemental appendix. A review protocol was not registered.

The returned search results were screened for duplicates. Titles and abstracts were then screened for relevance. 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 ACP, defined broadly to consider components such as advance directives, use of proxies, living wills, discussions, POLSTs, etc., led to GCC. GCC 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 GCC, no study was excluded based on population or study design.

**Data extraction**

Each article was assessed to determine if tracking GCC 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 synthesised and summarised 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).

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 GCC was the objective. For example, as one study describes, the aim was ‘to examine the effectiveness of an ACP 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 elements 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%.

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),

| Type of ACP evaluated | %  | n |
|-----------------------|----|---|
| Surrogate decision-makers | 29 | 39 |
| Specific ACP Templates* | 23 | 31 |
| Advanced Directives | 22 | 30 |
| ACP Conversations | 17 | 23 |
| Life Sustaining Treatment Preferences | 16 | 22 |
| Multiple Elements of ACP | 15 | 21 |
| Do Not Hospitalise Orders | 2 | 3 |
| Psychiatric Advance Directives | 1 | 2 |

*Respecting Choices (n=8), Family-Centred (FACE) ACP (n=4), What Matters Most (n=2), Making Your Wishes Known (n=2), Serious Illness Care Programme (n=2), Life Priorities Scale (n=2), Community-Based Palliative Network Care Plan (n=1), Kidney Supportive Care Programme (n=1), Five Wishes (n=1), Proactive Elderly Advance Care (n=1), My Preferences (n=1), Deciding Together (n=1), Personal Values Report (n=1), Vague (n=7).
records of deceased patients’. Using more than one researches (KMD, WS), who reviewed the medical of, ‘compliance with wishes was determined by two were vague, simply stating something along the lines of detail was uncommon. More often, the methods be explicitly requested along with CPR,’ but this example: ‘Data on the receipt of the aforementioned six LSTs (cardiopulmonary resuscitation (CPR), ICU, 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’. 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 [Do Not Resuscitate] 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,’ 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’. 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 it was most common 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=13), and some targeted only 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 EOL preferences, and the extent to which they had discussed these issues with family members’. 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 6 months of study enrollment, the family member was interviewed at about 3 months after the date of death about the quality of death and compliance with known EOL wishes’. 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 at the EOL’. 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. Support persons answered the same questions but from patient’s perspective’ to see how well the two aligned’. 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’. There were other less commonly used methods as well that served as indicators for ACP’s influence on GCC. 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 GCC. 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 GCC 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 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 with the family’s interpretation of those wishes.

DISCUSSION

The present scoping review highlights both that various methods for measuring GCC do exist and also that increased rigour is needed. The Delphi study identifying GCC 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 GCC is that concepts are poorly defined. Fundamentally, the term GCC 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 GCC 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, GCC may or may not indicate that ACP was useful. For example, if there is a conflict between the two, is GCC the care that heeds evolving preferences in the moment of a person who may not exhibit full decisional capacity or care that is loyal to the goals stated in advance when the person had full decisional capacity? If the former, GCC 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 EOL care, for example, are researchers considering the person’s last hours, weeks, month, or some other time frame? In such studies, what EOL 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 predefine 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 GCC in order to concretise 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 generalisability 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 individualised 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 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 may be 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 recognised by earlier researchers and thinkers as, for example, explored by Wolf et al. in an early article from 1991. 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. 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 GCC. As such, some recommendations to further the field’s efforts to track GCC 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 GCC. Drawing on more rigorous guidelines for assessing GCC, it would be meaningful to conduct studies that allow for comparison between the differential impact of various forms of ACP, including innovative approaches such as artificial intelligence based tools, in various settings to determine if certain approaches are more effective.

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

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ORCID iDs
Sophie Gloeckler http://orcid.org/0000-0002-7658-823X
Tanja Krones http://orcid.org/0000-0001-9880-0564

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