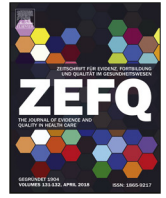




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Schwerpunkt / Special Issue „Advance Care Planning around the World: Evidence and Experiences, Programmes and Perspectives“

## Advance Care Planning conversations: What constitutes best practice and the way forward



## Advance Care Planning-Gespräche: Was Best Practice ausmacht und wie es weitergehen kann

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### ABSTRACT

**Background:** Advance Care Planning (ACP) conversations are a cornerstone of modern health care and need to be supported. However, research indicates that the uptake thereof is limited, regardless of various campaigns. ACP conversations are complex and specific elements thereof should be discussed at various timepoints during the illness trajectory.

**Objective:** This narrative review delineates what ACP conversation should entail, and a way forward.

**Methods:** A PEO (Population, Exposure, Outcome) search was performed using relevant keywords, and 615 articles were identified. Through screening and coding, this number was reduced to 24 articles. All the authors were involved in the final selection of the articles.

**Results:** Various themes developed throughout the review which include timing early on in the disease trajectory; incorporating beliefs and culturally relevant contexts; conversations needing to be iterative and short; involving surrogates and family; applying various media formats.

**Discussion:** ACP conversations are relevant. ACP is not static and needs to be dynamic as patients' illness trajectories and goals change. The care team needs to guard themselves against having ACP conversations to satisfy a metric and should instead be guided by the patient's expressed values and wishes. A system-wide operational plan will help alleviate common barriers in having appropriate ACP conversations.

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### ZUSAMMENFASSUNG

**Hintergrund:** Beratungsgespräche im Rahmen von Advance Care Planning (ACP-Gespräche) sind ein Eckpfeiler der modernen Gesundheitsversorgung und müssen gefördert werden. Die Forschung legt jedoch nahe, dass die Inanspruchnahmerate trotz verschiedener Kampagnen niedrig ist. ACP-Gespräche sind komplex, und bestimmte Gesprächselemente sollten zu unterschiedlichen Zeitpunkten im Krankheitsverlauf thematisiert werden.

**Ziel:** Dieser narrative Review beschreibt, was ein ACP-Gespräch beinhalten sollte und wie die weitere Entwicklung aussehen könnte.

**Methodik:** Es wurde eine Literatursuche nach PEO-Kriterien (Population, Exposition, Outcome) anhand einschlägiger Suchbegriffe durchgeführt; dabei wurden 615 Publikationen identifiziert. Diese Anzahl wurde mittels Screening und Kodierung auf 24 Beiträge verringert. An der endgültigen Auswahl der Beiträge waren alle Autorinnen und Autoren beteiligt.

**Ergebnisse:** Im Rahmen der Reviewerstellung ergaben sich verschiedene Themen, u. a.: Vereinbarung von ACP-Gesprächen zu einem frühen Zeitpunkt im Krankheitsverlauf; Einbeziehung von Glaubens- und kulturell relevanten Überzeugungen; Notwendigkeit wiederholter, kurzer Gespräche; Einbindung von Bevollmächtigten/Betreuern und Angehörigen; Nutzung unterschiedlicher medialer Formate.

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**Diskussion:** ACP-Gespräche sind relevant. ACP ist nicht statisch, sondern muss sich dynamisch dem sich verändernden Krankheitsverlauf der Patientinnen und Patienten und den sich ändernden Zielen anpassen. Das Behandlungsteam muss sich vor ACP-Gesprächen hüten, die nur geführt werden, um Vorgaben zu erfüllen; stattdessen sollten sie sich von der Patientin bzw. vom Patienten geäußerten Wertvorstellungen und Wünschen leiten lassen. Eine für das Gesamtsystem gültige Vorgehensweise kann helfen, die üblichen Hindernisse bei der Durchführung qualifizierter ACP-Gespräche abzubauen.

## Introduction

Advance Care Planning (ACP) is an ongoing process where patients and providers engage and focus on preferences for future care, discuss these goals and preferences with family and health-care providers, especially towards end-of-life, and may include discussions around the usage of ventilators and cardio-pulmonary resuscitation (CPR) [1–3]. ACP may also include who the patient would like to make decisions for them if they are unable to speak for themselves. As a good clinical practice, these conversations should then be documented in the medical record [2].

Advance care planning has been heralded, as a mechanism, to support patient rights, autonomy, and dignity in a patient's health-care trajectory [4,5]. By satisfying the aforementioned ethical principles, through ACP conversations, healthcare professionals not only attempt to minimize potential future harms, they also put the patient at the center of care-planning.

However, regardless of the introduction of legislation in the United States of America (Patient Self Determination Act of 1990), national campaigns (i.e. Respecting Choices), and reimbursement for ACP conversations by Medicare in 2016, the documented encounters remain relatively low with only about 33% of documented wishes and preferences [6–9]. Similar occurrences are reported in Europe [10] with limited reporting of advance directives (AD), and in Asia [11,12] on AD completion and ACP conversations.

In the USA there is currently a healthy dialogue around ACP to allow a re-evaluation of the existing systems and processes with the aim to continue strengthening the total delivery of patient-centered care [13,14]. In a scoping review of ACP interventions and opportunities, McMahan et al. showed that the majority of the process (readiness) and action (communication and documentation) outcomes of ACP interventions were positive, however, outcomes for quality of care, health care utilization, and goal-concordant care were not always positive [3]. The authors highlight the complexity of ACP and the need to set appropriate expectations of ACP outcomes across interventions, disease states, populations, and resources [3]. Morrison et al. argue that there is a gap between the hypothetical scenarios that ACP uses (what WOULD you do IF...) and the real-world experience of patients making decisions when confronted with an uncertainty that they have little insight or understanding of their condition [13]. The authors argue that ACP can only succeed if care providers correctly elicit patients' values and goals [13]. As values (treatment-specific values; life priorities and philosophies; and socio-cultural and personal background) [15] and treatment preferences are influenced by health and recovery [16], health care providers must be constantly aware that values are dynamic and may change during the illness trajectory [17].

Given the fact that values [15] change, the aim of this paper is to do a narrative review of published articles to delineate when is the best time to have ACP conversations, and what these conversations should entail.

## Methods

A research librarian assisted in compiling a list of relevant articles per the authors' request in August 2022. The PEO (Population,

Exposure, Outcome) search included articles of original literature published in 2018 and later, in English, focusing on ACP conversations. The MEDLINE – OVID database was used in the search. The following search terms, in addition to ACP were included: advance directive(s), future care planning, advance preferences. A total of 615 articles were identified. From these, 284 were removed because they were either duplicate, or did not focus on ACP *per se* (see Figure 1).

The authors evaluated all resulting 331 articles' abstracts. Before this review, the authors agreed upon inclusion Criteria, namely: only adult population, advance care planning process; advance care planning conversation; advance care planning interventions. Most of the excluded articles focused on clinical palliative care, DNR-only conversations, hospice interventions, and religion. Once the vetting was completed, the authors compared their selections. If two (or more) authors chose an article, it qualified for final inclusion in the study. From the 331 articles, only 24 met the criteria and were included in the final review (as shown in Table 1).

## Results

ACP conversations hold value as they are a catalyst through which the patients get the opportunity to think about different potential outcomes and then have the "language" to talk to their loved ones about their wishes [33]. ACP conversations help not only the patients but also their loved ones cope with the road ahead and ensure the focus can remain on the patients' wishes [7,20,25,27,29].

Although the American healthcare system is built on the principle of autonomy, where the patient's voice is important and should guide the conversation, it is evident from the articles reviewed that it is crucial to involve the loved ones/surrogate decision-makers/family in the discussion [19,26,34,38]. This will give the patient agency to keep control and express his/her wishes and may also help the patient feel supported in the journey ahead [7,20,25,27,29]. Furthermore, it may also contribute to a better understanding of the patient's wishes and consequently make it easier (reducing the burden of guilt) for the family to make decisions that align with the patient's wishes when needed [3,37,39].

With regards to when it is best to have an ACP conversation, it is evident from the articles reviewed that it should never be left to the end, nor should it be only a one-off conversation [7,18,20,21,23,29,30]. In the USA, the National Quality Forum (NQF) endorsed quality measures supports avoidance of the ICU in the last 30 days of life and the Dartmouth Atlas reports hospital admissions in the last six months of life. To meaningfully impact these measures requires conversations well upstream of those time points. Starting to have short conversations early in the illness trajectory will not only normalize the conversation and content thereof but also allow the patients to analyze what is important in the specific moment and then have the opportunity to change their goals as circumstances change [30]. This will also allow the medical teams to align with the patient's values and goals. Since priorities are not static and ever-changing with new experiences [16,17], these should be incorporated into the conversation and care planning.

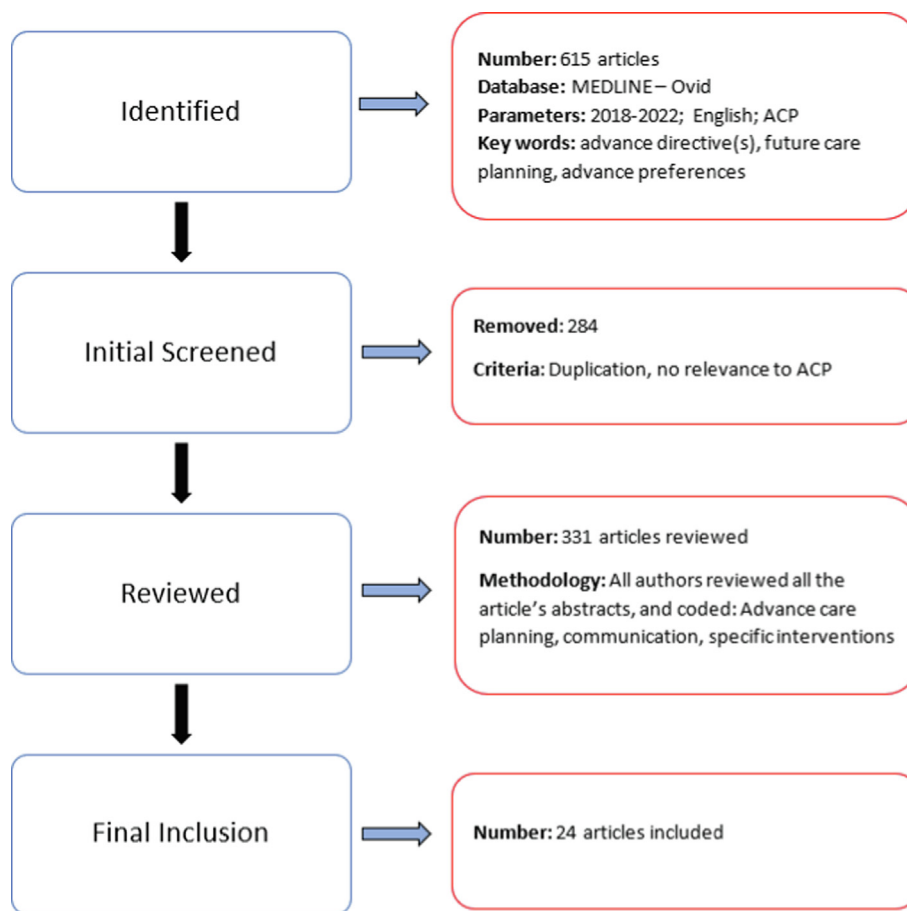


Figure 1. Summary of methodology.

Patients do want to talk about their wishes and goals but in a manner that they feel comfortable. Patients appreciate being educated in a non-threatening manner that is relevant to their current situation and in a way that is understandable and accessible [28,35]. Various forms of media, behavioral approaches, or even community members trained in ACP may be necessary to achieve this [18,30]. There is great value in having timely ACP conversations and documenting the patients' goals in an easily accessible ACP note in the electronic health record (EHR). These conversations may result in fewer aggressive treatments, improved communication, decreased family/caregiver distress, and improved patient well-being and quality of life [7,21,23,25]. Interestingly, one article suggests that the success of having a high-quality ACP conversation depends on the physicians' self-awareness and outlook on the value of life [28].

Many articles [26,32,34,38] indicate that for many patients these conversations cannot take place in isolation of their families/loved-ones. It is therefore important to make sure that those who will "speak" for the patient when they cannot, are also involved in ACP conversations.

## Discussion

We concur that static, ambiguous documentation, filled out in a healthy population long before it is ever applicable and never revisited, or practices that ask just about the presence/absence of an ACP document are insufficient. For best practice, ACP conversations must occur regularly, especially when there is a change in the clinical condition of a patient, or when the treatment plan is being

altered. Respecting patients' choices of who they want to involve in their ACP conversation is important. The healthcare provider has a moral obligation to ask the patient whether they would want to include his/her surrogate decision-maker or other family members in the conversation. Creating this opportunity will indicate to the patient that his/her whole context is important to the healthcare provider, and not merely the clinical conditions. While there are mixed sentiments on approaches and diverse outcomes from studies on the efficacy of ACP and goal-concordant care efforts [13], clear and timely incorporation of patient values in their care plan remains central to healthcare's mission to deliver patient-centric care [40].

Most of the studies reviewed were conducted at individual healthcare settings with limited system support which limits global impact beyond the intervention. Bhatia and colleagues recently published evidence of the positive effects of ACP, in a system-level intervention, demonstrating that high-quality ACP conversations increased the quality of patient value integration, decreased aggressive interventions needed at end-of-life, and lowered overall cost of care [41]. A similar study was published by a large oncology hospital (MD Anderson Cancer Center) in Texas, USA, that a concerted effort at all levels of the institution to encourage and engage with patients in Advance Care Planning conversations, did not only lower deaths in the ICU, it also decreased length of stay [42]. It is evident from the aforementioned two publications that only through a culture change can healthcare professionals get better at ACP conversations as institutional support will help address many of the reported barriers to having effective ACP conversations [28].

**Table 1**  
Summary of literature

Author	Title	Why is ACP important?	Important elements of ACP Conversations.	When is it best to have ACP conversations for a meaningful impact?	Key finding
Aslakson RA, Isenberg SR, Crossnohere NL, et al. [18]	Integrating Advance Care Planning Videos into Surgical Oncologic Care: A Randomized Clinical Trial.	Nothing specific is mentioned.	Nothing specific is mentioned.	Have conversations often to normalize the concepts.	Using alternative technology (i.e., video) to enhance the ACP conversation pre-surgery helps normalize the conversation when it is done by a clinician.
Bar-Sela G, Tur-Sinai A, Givon-Schaham N, Bentur N. [19]	Advance Care Planning and Attainment of Cancer Patients' End-of-Life Preferences: Relatives' Perspective.	ACP conversations help loved ones know what the patient would want and can align the patient's wishes with the surrogate's enactment.	Having a conversation where the patient and family are involved.	Nothing specific is mentioned.	Only 1/3 of patients received EoL care that was correlated to their expressed wishes.
Bond WF, Kim M, Franciskovich CM, et al. [7]	Advance Care Planning in an Accountable Care Organization Is Associated with Increased Advance Directive Documentation and Decreased Costs.	Help facilitate a rich interaction between patients and family to inform caregivers of wishes.	Outpatient setting is better and involving family early on is beneficial.	Outpatient setting.	ACP is associated with reduced overall cost of inpatient admission, and reduces caregivers' anxiety, depression, and stress.
Case AA, Epstein AS, Gustin LG [20]	Advance Care Planning Imperative: High Quality patient-centred goals of care.	ACP-related outcomes were associated with improved patient-clinician communication and a reduction in patient and caregiver health sequelae.	ACP conversations should be more than a check box and should evolve over time with changes in prognosis, taking into account how much patients want to know and what they should expect.	From the start of care, regardless of illness extent or prognosis.	Respecting patients' wishes and values and incorporating these into care planning will not only help patients die peacefully, but it is also imperative for health systems to change their practice.
Cohen MG, Althouse AD, Arnold RM, et al. [21]	Hope and advance care planning in advanced cancer: Is there a relationship?	ACP conversations may lead to stronger coping skills, better quality of life, less pain and anxiety.	Having it with an oncologist. ACP should not focus on end-of-life, when you have no control, but rather on keeping agency of control, and hence, on hope early on in the illness trajectory.	Early on. If ACP discussions occur too late, it may be seen as "giving up hope".	Hope is not decreased after ACP conversations but rather increased, which may lead to stronger coping skills, a better quality of life, and less pain and anxiety.
Epstein A, Riley M, Nelson JE, et al. [22]	Goals of Care Documentation by Medical Oncologists and Oncology Patient End-of-Life Care Outcomes	Having documented encounters facilitates better communication about patients' wishes and values across the healthcare team.	Nothing specific is mentioned.	Earlier and ongoing conversations were associated with better End-of-Life care.	Physicians inclined to engage their patients in discussions about preferences are less likely to recommend aggressive treatments for patients with advanced diseases.
Falzarano F, Prigerson HG, Maciejewski PK. [21]	The Role of Advance Care Planning in Cancer Patient and Caregiver Grief Resolution: Helpful or Harmful?	Patients and their caregivers experience the value of ACP differently. For patients it may be an acknowledgment of a change in his/her health status, whereas for the caregiver, it is a comfort (sense of relief) to know rather than assume what a patient would want for him-/herself.	Having an awareness of the impact ACP documentation can have on a patient's experience of grief. Including family in these discussions.	Throughout the illness trajectory.	Patients had an increase in grief when completing an advance directive (living will) whereas caregivers had a decrease in their grief when a patient completed a DNR.
Gallo JJ, Abshire M, Hwang S, Nolan MT. [23]	Advance Directives, Medical Conditions, and Preferences for End-of-Life Care Among Physicians: 12-year Follow-Up of the Johns Hopkins Precursors Study.	Advance Directives indicate more what people do not want than what they want.	Nothing specific is mentioned.	Periodic reassessment of wishes is important as the clinical picture changes.	Those with ACP documentation would generally request less aggressive treatment than those with nothing.
Kelly EP, Henderson B, Hyer M, Pawlik TM. [24]	Intrapersonal Factors Impact Advance Care Planning Among Cancer Patients.	It helps with a patient-centered approach to care.	Nothing specific is mentioned.	Nothing specific is mentioned.	Self-identified religious patients had a higher likelihood of participating in ACP. Patients with more depressive symptoms had a higher rate of DNR completion and medical power of attorney documentation. Minority groups were less likely to have ACP documentation.

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Table 1 (continued)

Author	Title	Why is ACP important?	Important elements of ACP Conversations.	When is it best to have ACP conversations for a meaningful impact?	Key finding
Kim J, Park J, Lee MO, Park EY, Heo S, Shim JL. [25]	Modifiable Factors Associated with the Completion of Advance Treatment Directives in Hematologic Malignancy: A Patient-Caregiver Dyadic Analysis.	Making sure patients and caregivers discuss and align ACP preferences may circumvent unnecessary and unwanted aggressive treatment toward the end of a patient's life.	Having a dyadic approach (patient and caregiver), where both parties are educated.	Early on.	Patient vs. caregiver consensus around end-of-life treatment was poor. Patients are less inclined to receive aggressive care and more willing to accept hospice than their caregivers are.
Ko E, Keeney AJ, Higgins D, Gonzalez N, Palomino H. [26]	Rural Hispanic/Latino cancer patients' perspectives on facilitators, barriers, and suggestions for advance care planning: A qualitative study.	Family-centered decision making, even if the patient is able him-/herself.	Where family is involved, and all their questions are answered. Death education is important to bridge the taboo. Having early ACP conversations can hopefully change the perception that ACP is only needed with impending death. Lastly, having ACP conversations in the participants' native language. Nothing specific is mentioned.	Nothing specific is mentioned.	Patients want to safeguard their families from suffering or having family conflicts when decisions need to be made. Therefore, clear ACP must be communicated by the patient to his/her family.
Kubi B, Istl AC, Lee KT, Conca-Cheng A, Johnston FM. [27]	Advance Care Planning in Cancer: Patient Preferences for Personnel and Timing.	Reduced hospitalization decreased anxiety and depression, increased satisfaction and quality of life. Having timely ACP conversations enable patients to maintain control and decrease potential family strife related to guessing what the patient would have wanted.	Nothing specific is mentioned.	Early on, before their diagnosis gets worse.	Discussing with their primary care provider because they are familiar with him/her, and there is greater trust. Furthermore, the cohort felt that having it early on before their prognosis gets worse is better. Almost half indicated they wish they had been exposed to ACP conversations before their cancer diagnosis.
McMahan RD, Tellez I, Sudore RL. [3]	Deconstructing the Complexities of Advance Care Planning Outcomes: What Do We Know and Where Do We Go? A Scoping Review.	Nothing specific is mentioned.	Nothing specific is mentioned.	Nothing specific is mentioned.	ACP is complex and needs to be seen as an interplay between patients, surrogates, communities, clinicians, health systems, and policy. Outcomes for the ACP process, action, and interventions were all predominantly positive, especially patient/surrogate satisfaction demonstrated by a decrease in surrogate/clinician distress.
Nortje N, Stepan K. [28]	Advance Care Planning Conversations in the Oncology Setting: Tips from the Experts.	Nothing specific is mentioned.	Talking about patients' fears, and concerns.	Throughout the illness trajectory.	Physicians' self-awareness and outlook on the value of life and the importance of death as part of the care continuum greatly influence how they approach ACP conversations.
Nouri SS, Barnes DE, Shi Y, et al. [29]	The PREPARE for Your Care program increases advance care planning engagement among diverse older adults with cancer.	For patients to have control over their care and alleviate family burden.	Nothing specific is mentioned.	A dynamic and iterative process	The study used a methodology grounded in behavioral change theory called PREPARE. Its aim is to increase ACP engagement and broadly equip adults with medical decision-making skills to engage in ACP. PREPARE helped to reduce disparities in ACP and clinical care for older patients.
Pajka SE, Hasdianda MA, George N, et al. [30]	Feasibility of a Brief Intervention to Facilitate Advance Care Planning Conversations for Patients with Life-Limiting Illnesses in the Emergency Department.	Nothing specific is mentioned.	Using multiple modalities to complete ACP. Interventions should be shorter.	Nothing specific is mentioned.	Using an ACP intervention while in the Emergency Department shows success, as patients were increasingly willing to engage in these discussions if they were short.

**Table 1** (continued)

Author	Title	Why is ACP important?	Important elements of ACP Conversations.	When is it best to have ACP conversations for a meaningful impact?	Key finding
Patel MI, Kapphahn K, Dewland M, et al. [31]	Effect of a Community Health Worker Intervention on Acute Care Use, Advance Care Planning, and Patient-Reported Outcomes Among Adults with Advanced Stages of Cancer: A Randomized Clinical Trial.	Nothing specific is mentioned.	Nothing specific is mentioned.	Early on.	Developed an approach of using Community Health Workers to fill the time and staffing gap in addressing ACP with patients. This led to reduced acute care usage, improved ACP documentation, improved mental and emotional health
Rosa WE, Izumi S, Sullivan DR, et al. [32]	Advance Care Planning in Serious illness: A Narrative Review	It intends to support person-centered medical decision-making.	Since social determinants of health influence ACP perceptions, better ACP needs to be multilingual and culturally inclusive ACP material.	A continuous process throughout the continuum of Serious Illness, however, sensitivity of patient and caregivers' readiness needs to be incorporated.	Patients and their families must be equal partners with their healthcare team in the process.
Schubart JR, Levi BH, Bain MM, Farace E, Green MJ. [33]	Advance Care Planning Among Patients with Advanced Cancer.	Nothing specific is mentioned.	Nothing specific is mentioned.	Early on and throughout.	Patients diagnosed with serious illness are more likely to participate in ACP. This study showed that decision-making aids do not necessarily encourage ACP documentation, although it may stimulate conversations between patients and their families.
Shen MJ, Gonzalez C, Leach B, Maciejewski PK, Kozlov E, Prigerson HG. [34]	An examination of Latino advanced cancer patients' and their informal caregivers' preferences for communication about advance care planning: A qualitative study.	Nothing specific is mentioned.	Being culturally sensitive and family centered. Discussions to happen in the native language, incorporating medical beliefs.	Nothing specific is mentioned.	Latino patients engage with their family members more than with physicians when it comes to ACP. Sensitivity to the family's role is vital in ACP discussions and religious beliefs in decision-making. Therefore, education geared toward families is also essential. Latino patients value their physicians' recommendations at the end of life.
Stepan K, Bashoura L, George M, et al. [35]	Building an Infrastructure and Standard Methodology for Actively Engaging Patients in Advance Care Planning.	Nothing specific is mentioned.	Nothing specific is mentioned.	Early on and throughout the trajectory of their illness.	Changing an organization's culture takes time. Having a multi-disciplinary approach is essential.
Trevino KM, Rutherford SC, Marte C, et al. [36]	Illness Understanding and Advance Care Planning in Patients with Advanced Lymphoma.	Nothing specific is mentioned.	Nothing specific is mentioned.	Nothing specific is mentioned.	Integrating palliative care services early on in the disease trajectory may enhance the patient and family's understanding of treatment options, as well as the severity of the disease.
Wiener L, Bedoya S, Battles H, et al. [37]	Voicing their choices: Advance care planning with adolescents and young adults with cancer and other serious conditions.	Nothing specific is mentioned.	Nothing specific is mentioned.	Nothing specific is mentioned.	Creating an educational platform to expose and guide patients through ACP helps to decrease their anxiety and increase communication with families. However, it does not necessarily do the same with health care providers.
Zhou M, Bressler T, Weinberg A, Snow A. [38]	Lessons learned from a social worker's approach to advance care planning discussions with Chinese-immigrant oncology outpatients.	Nothing specific is mentioned.	Family involvement	Nothing specific is mentioned.	In Chinese culture, there is a fear of talking about death as it may evoke bad luck. This brings about a reluctance of medical teams to discuss ACP with Chinese patients, which is contra to their willingness. Decision-making is a family-centered collective process and involving family members in the discussions is beneficial.



Changing clinical culture successfully is hard and needs a well-developed operational plan. There is currently an initiative underway at 10 Dedicated Cancer Centers (ADCC) in the USA, namely the *Improving Goal Concordant Care Initiative* (IGCC) [43]. These cancer centers collectively embarked on a 3-year project focusing on 4 components to help support a greater implementation of ACP conversations. The components include implementing a formal communication skills training program that focuses on ACP communication; creating a structured ACP document in the electronic health record; establishing expectations regarding goals of care communications among priority populations; and implementing a measurement framework.

As healthcare professionals normalize ACP conversations, patients may feel more at ease to express their perspectives and values and would want to incorporate these into their care preferences. Developing communication skills of care teams to convey the goals of treatment, discuss prognosis, identify changes in patients' priorities, and elicit patients' goals will allow for dynamic alignment of the treatment plan with patient preferences. Early and ongoing communication (through ACP documents and conversations) makes it more likely that healthcare providers will achieve alignment.

### Conflict of Interest

All authors declare that there is no conflict of interest.

### CRediT author statement

Nico Nortje: Conceptualization, Methodology, Validation, Data curation, Writing – original draft, Writing – review & editing. Finly Zachariah: Conceptualization, Methodology, Validation, Data curation, Writing – original draft, Writing – review & editing. Akhila Reddy: Conceptualization, Methodology, Validation, Data curation, Writing – original draft, Writing – review & editing.

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