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Advance Care Planning and End-of-Life Decision Making for Patients with Cancer

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Abstract

Objective—To highlight the importance, challenges, and evolution of advance care planning for patients with cancer.

Data Sources—Peer-reviewed journal articles and clinical guidelines.

Conclusion—Advance care planning is fundamental to support the personhood of patients with advanced cancer. Patients must be encouraged by physicians and nurses to articulate what matters and provides meaning to them as they live, cope, and receive treatment for their cancer.

Implications for Nursing Practice—Nurses can facilitate advance care planning and primary palliative care, to support patients and families to make informed and value-concordant decisions regarding cancer and end-of-life treatments.

Keywords

advance care planning; advance directives; cancer; value-concordant care

Advance care planning (ACP) is an essential process by which patients with serious illnesses are empowered to articulate their personal values, preferences, and goals to make decisions for their future care. Because ACP is an important domain in providing high-quality palliative care, all physicians and nurses have an obligation to openly discuss prognosis, the uncertainty of treatment outcomes, and provide recommendations for end-of-life care options, at times that are appropriate for each individual relative to his or her disease course. This responsibility is critical for patients to achieve closure, spend meaningful time with their loved ones, and die with dignity. Though widely recognized as an integral component of oncologic care, ACP has not been systematically implemented into everyday practice.

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Further research is needed to facilitate informed and personalized medical decision-making across the treatment trajectory and at the end of life.

The primary aim of this review article is to emphasize the undeniable value, current challenges, and recent improvements in supporting optimal ACP. Based on a PubMed database search for the most relevant and updated literature pertaining to ACP in patients with cancer, we provide a brief description of the origin and impact of ACP for patients with cancer, summarize the common instruments used for documenting advance directives and patient preferences, and highlight the myriad challenges of incorporating high-quality ACP into standard oncologic practice. We then summarize current research that seeks to improve communication techniques, establish models for patient-centered and values-focused care, and define a standardized set of ACP guidelines. The article concludes by specifically addressing the importance of ACP for oncology nursing practice and how nurse-led interventions that utilize primary palliative care skills can enhance end-of-life decision-making for patients with cancer.

ACP: History, Impact, and Documentation

ACP was developed as a result of legal recognition of self-determination and the right of patients or their caregivers to decline life-sustaining treatment or interventions. In the 1970s and 1980s, two landmark cases in the United States involved young women in their twenties who were in persistent vegetative states and whose family members sought removal of life-sustaining interventions, such as ventilatory support and tube feeding. The case of Karen Ann Quinlan in 1976 was the first right-to-die case in the US, and ultimately led to California state legislation of the Natural Death Act of 1976, which allowed individuals to express in advance their wishes for their medical care if terminally ill or if lacking the capacity to make decisions. The case of Nancy Cruzan in 1983 led to the US Supreme Court stipulating that though individuals have the right to die and forgo life-sustaining measures, every state can also govern and set standards to guide these individual rights. As a result, the US Congress passed the Patient Self-Determination Act in 1990. The Patient Self-Determination Act requires that health care institutions provide information to patients upon admission about their rights in decision-making and the state policies for making advance directives.¹ These two cases established a new standard for patient autonomy with advance directives, and provided insight into the importance of ACP and the complex relationship between patients, caregivers, and health care providers in end-of-life decision-making.

ACP discussions for patients with cancer are dynamic, complex, and unique to each individual's medical condition and values. Patients must be prompted and supported as they receive disease-directed therapies to express their care goals and make decisions for their future care that are congruent with their wishes. These conversations may evolve over time, and represent a balance between patient autonomy and the input and guidance from caregivers and health care teams.^{2,3} Decision-making and ACP discussions must also attend to the culture and relationship between patients and their family members. For some patients of minority ethnic groups, cultural values and family dynamics have greater influence on end-of-life decision-making. Oncology providers should ask for preferences on how patients wish to receive information about end-of-life options and prognosis, recognizing that a

family-centered approach for making medical decisions may be more effective for certain cancer patients.⁴⁻⁶ Successful and culturally appropriate ACP therefore concentrates on eliciting patient and family values, reviewing possible clinical scenarios, and discussing appropriate end-of-life care options, in relation to a patient's prognosis.

Though ACP discussions are complex and challenging, the impact for patients with cancer is substantial. Without ACP, there is an increased risk for patients to receive undesired life-sustaining measures and value-discordant care. In a landmark analysis of data from the Health and Retirement Study, Silveira et al⁷ showed that many patients needed to make decisions at a time when they lacked the capacity to do so. Moreover, those patients who had advance directives or who designated a durable power of attorney received care that was consistent with their preferences. This study also demonstrated a positive correlation between those patients who had the opportunity to articulate their wishes and less aggressive care, with 92.7% of patients with advance directives wanting limited care compared with 1.9% desiring all care possible.⁷ ACP may help patients with cancer participate more fully in treatment decision-making, resulting in less chemotherapy and cancer-directed treatment in the last few weeks of life, fewer hospitalizations, and increased hospice utilization.^{8,9}

While the focus of ACP is on having conversations between patients, providers, and families, it should ultimately lead to documentation of patients' wishes, beliefs, and values by way of completing an advance directive while the patient still has decisional capacity.¹⁰ The primary instruments used to document advance directives include a Durable Health Care Power of Attorney to designate a surrogate decision maker and a "Living Will," which typically addresses a person's preferences for life-sustaining treatments such as cardiopulmonary resuscitation, mechanical ventilation, and in some cases, the use of medically administered hydration and nutrition. Other tools for documenting advanced care wishes include Physician Orders for Life-Sustaining Treatment (POLST) forms. Different states have modified and renamed such forms (see Table 1). The basic premise of POLST forms is to specify patients' preferences as actionable medical orders regarding cardiopulmonary resuscitation, medical interventions, antibiotic use, and artificial nutrition, which can be transferred across health care settings. Though POLST programs are largely well-regarded and help to define individualized life-sustaining treatment wishes, there is limited data on their impact, quality, implementation, and generalizability across different patient populations.¹¹ A recent study showed that compared with standard advance directives, POLST completion increased out-of-hospital deaths and was associated with a greater likelihood of hospice admission in patients with advanced cancer.¹² Regardless of whether patients elect to document their preferences via living wills, POLST forms, or through designation of a health care proxy, ACP is a powerful component of oncologic care that honors the humanness of patients living with and dying from cancer.

Challenges of Incorporating ACP in Oncology Care

Multiple patient and provider factors contribute to the difficulty in achieving successful ACP (see Table 2). Prior studies have shown that cancer patients who have expressed their individual values and goals are more likely to receive care that honors and is in alignment with their wishes.¹³ Yet, longitudinal results from the national Health and Retirement Study

indicate that although more cancer patients are assigning durable health care power of attorneys to act as surrogate decision makers, the frequency of terminal hospitalizations and number of end-of-life discussions have not changed.¹⁴ This discrepancy highlights that despite more patients completing advance directives, there is still need for improvement to reduce potentially aggressive and discordant end-of-life care. But, though the need and benefit of ACP is strongly evident, there is no gold standard to guide the quality, content, approach, and timing of care planning discussions. The following sections will address how: 1) poor illness understanding, 2) inappropriate timing, and 3) physician–patient communication barriers can make it difficult for patients to articulate their values and make informed decisions for their end-of-life care.

Illness Understanding and Uncertainty

Clarifying cancer treatment goals and managing expectations are first steps in engaging patients in timely and meaningful ACP. Meaningful ACP requires good illness understanding and realistic expectations about prognosis so that patients can express their values and make decisions in a timely manner.^{15,16} For example, data from the Cancer Care Outcomes Research and Surveillance (CanCORS) study showed that 69% of patients with stage IV lung and 81% of patients with stage IV colorectal cancers expected that chemotherapy would cure their disease.^{16–18} In contrast, patients who understood that the role of chemotherapy was to stabilize disease burden and control symptoms were more likely to utilize appropriate hospice services and less aggressive care at the end of life.¹⁹ Continued efforts to optimize communication are needed to effectively address gaps in illness understanding and temper expectations for benefit, while preserving hope, empathy, and the therapeutic relationship between patients and their oncology team.^{20–23}

Understanding treatment goals and potential outcomes is even more important and difficult in an era of evolving cancer therapeutics.^{24,25} Rapid developments in immune-based and personalized genomic-driven therapeutics have created new dimensions of prognostic uncertainty, adding to the emotional and cognitive complexity of ACP and informed decision-making. Oncologists may be uncertain of treatment durability and response, particularly when used in a clinical trial setting. For example, the promise of immunotherapy to improve survival with fewer drug-related toxicities compared with chemotherapy has raised expectations for therapeutic benefit. Yet, the potential for delayed treatment effect and radiographic pseudoprogression with immunotherapy is one reason why patients may approach their treatment and prognosis with cautious optimism and new levels of anxiety.^{26,27} Therefore, the expansion of cancer therapeutics warrants new paradigms for values-focused communication. Oncology and palliative care specialists must modify their communication approach accordingly and use patients' expressions of uncertainty and treatment expectations as an opportunity to elicit values and introduce ACP.

When is the Right Time for ACP?

The timing of ACP discussions has a significant impact on the comprehension, processing, and choice of care at the end of life. Late end-of-life discussions and completion of advance directives remain problematic for patients with cancer, often occurring during the last 3 months of life or later. Late discussions have been associated with a higher likelihood of

aggressive care preferences.²⁸ In a large prospective cohort of patients with stage IV lung and colorectal cancer, those patients with documented end-of-life care discussions who died during follow-up (n = 959) participated in initial ACP discussions in the hospital at a median of only 33 days before death.²⁹ At such times, when patients and caregivers have less time to think deeply about their values and preferences, they are at risk to have their decisions shaped by unrealistic expectations for recovery and life prolongation.

Discussions in the hospital setting may also feel depersonalized and inadequate, particularly when patients and/or caregivers have such discussions with clinicians or house staff-in-training who are often not intimately familiar with their history or personal values. Inpatient hospital conversations related to ACP can thus be limited in scope because of time constraints and sometimes without the input of a physician or nurse who understands and is aware of the cognitive or emotional challenges pertaining to each patient.^{30–32} Accordingly, inpatient ACP may tend to focus only on patient preferences for cardiopulmonary resuscitation. Simplifying ACP into a single question on code status preferences eliminates the ability for patients to make meaningful and thoughtful decisions. As a result, patients may receive care that is more aggressive and does not reflect their true wishes.

Early end-of-life discussions, however, also present a set of challenges to providing quality ACP. When advance directives are completed too early, patients may not be able to accurately predict or emotionally invest in what they would want at the end of life because they may still be coming to terms with the reality of their cancer diagnosis.^{33,34} Consequently, patients may choose care that is not consistent with their values or true preferences. The impractical challenge of finding an optimal time – one that is neither too early nor too late – to discuss life-sustaining treatment options suggests that ACP can and should not be performed at a single clinical encounter. Instead, ACP should be an iterative process, with conversations conducted at strategic and appropriate times so that patients have an opportunity to be thoughtful and can have a dialog with their team about their preferences and goals over time.

Barriers to Effective Patient–Provider Communication

Lastly, ineffective ACP may be the result of communication barriers between clinicians and patients. Time constraints, poor health literacy, and misunderstandings within the clinical encounter can hinder a patient's ability to make informed decisions and articulate his or her values and preferences.^{35–39} Education about end-of-life care options is necessary for patients with cancer to engage in meaningful discussions.⁴⁰ But, oncology providers may lack formal training in helping patients to understand the nuances of these options and thereby feel unprepared to confidently answer questions about advance directives.⁴¹ Moreover, oncology providers may be concerned that participating in end-of-life discussions may negatively impact the patients' mood, quality of life, and mental health, and consequently interfere with the patients' coping and desire to receive active cancer treatment.^{42–44} For these reasons, it may be difficult to know how to best introduce and appropriately conduct ACP encounters.

Discussing ACP in the context of prognostic disclosure is a complex but essential task that demands communication with honesty and empathy.^{20,45} Accurate estimates of life

expectancy to within a year is associated with greater illness awareness and higher rates of ACP, resulting in less undesired care near death.⁴⁶ However, accurate prognostication can be difficult, particularly when patients participate in clinical trials or are receiving new therapeutic regimens that have limited survival statistics.

Solutions and Future Directions

Innovative communication strategies, values-focused care models, standardization of core ACP principles and documentation, and new ways for integrating primary palliative care can address the above challenges to foster progress in clinical practice and policy (see Table 2).

Strategies to Enhance Communication with Technology

Barriers in communication and patient education can be mitigated by technology, such as with the recent advent of informational video tools. Such videos have been proven to be effective vehicles for improving discourse between patients and physicians about end-of-life care options. First studied in patients with advanced dementia, Volandes et al⁴⁷ demonstrated that a video representation of care options can provide clarity and increase the number of patients who feel secure in their health care decisions. Furthermore, preferences for life-sustaining, basic, and comfort care changed significantly following the video intervention, with more patients electing for comfort care and symptom relief instead of resuscitation efforts.⁴⁷ Similar findings have been shown for patients with advanced cancer, with multiple randomized controlled trials establishing that informational video aids can educate patients about their care options with improved visualization. Patients randomized to watch videos instead of receiving verbal narratives describing the act of resuscitation were less likely to choose aggressive care, including life-sustaining measures, at the end of life.^{48–50} Epstein et al⁵¹ confirmed these results in patients with advanced pancreatic and hepatobiliary cancers; not only did patients randomized to the video arm have less desire for CPR, but also, a trend toward increased rates of ACP documentation. Though patients with cancer may be apprehensive about ACP, they are still cognizant of the early need for learning and communicating about their end-of-life care options.⁵² Examples of these videos can be viewed at www.acpdecisions.org.

In addition to informational video tools, patient-centered ACP Web sites are also effective at increasing ACP documentation rates. In the PREPARE study (prepareforyourcare.org), veterans with at least two chronic and/or serious medical conditions were randomized to either review an interactive, easy-to-read Web site about ACP and end-of-life care options plus read an advance directive document or to read the advance directive document alone. Sudore et al⁵³ tested if ACP knowledge, engagement, and documentation could be improved without clinician or system-level interventions. Of note, patients in the intervention arm who utilized the ACP Web site had statistically higher rates of ACP documentation at 6 months compared with the advance directive only arm (35% vs. 25%), along with higher self-reported measures of behavior change and action measures.⁵³ This study again suggests that innovative and interactive ACP options may be well-received by patients and effective options for introducing or communicating about ACP.

Patient-Centered and Values-Focused Care Models

Patient-centered models that address the myriad factors that contribute to medical decision-making, such as the Respecting Choices or the Patient-Centered Oncologic Care and Choices (P-COCC) evidence-based frameworks, can potentially optimize ACP for patients with advanced cancers.⁵⁴⁻⁵⁶ These models encourage patients to openly discuss their culture and spirituality, family dynamics, values and hopes, and ideally, all that matters to them as they consider their choices for their future health care. An ACP approach that also attends to the needs and concerns of cancer caregivers is of equal importance for shared decision-making because caregivers often assume the primary role of health care proxies to support and fulfill patient wishes.⁵⁷ The examples below support the concept that oncology clinicians who utilize patient-focused models may be able to stimulate value expression by patients and caregivers in the clinical encounter and, in doing so, more effectively introduce topics of advance directives and end-of-life care.

Specifically, the P-COCC model utilizes both an informational video about care goals and an interview about patient values to elicit both external and internal person factors that impact a patient's decision-making for his or her care. This model has been pilot tested in patients with gastrointestinal cancers at Memorial Sloan Kettering Cancer Center (New York, NY) to test for patient acceptability and to assess whether it impacts patient well-being and decisions. Of the 33 patients randomized to the P-COCC arm, 97% rated the intervention acceptable. However, mean distress scores modestly but statistically significantly increased in the P-COCC arm, and did not in the video alone and usual care arms. There was no significant effect of the P-COCC intervention on anxiety, depression, stress, or quality of life.⁵⁸

Another approach, "VOICE," combines interventions for both oncologists and patients with advanced cancer to determine if a dual approach can foster patient-centered communication and reduce aggressive end-of-life care. In this trial, oncologists were randomized to receive communication training with standardized patients or no training; patients were randomized to receive communication coaching and question prompt lists or no coaching. The VOICE study showed that a combined approach improved physician-patient communication that focused on patient concerns and values through audio recordings of clinic visits, but that outcomes did not differ between treatment arms with regards to prognostic understanding, quality of life, or end-of-life health care utilization.⁵⁹

To potentially optimize the timing of conducting ACP conversations, recent data indicates that patient-reported outcomes can inform oncology providers when to intervene and discuss prognosis. The "Living with Cancer" survey is a seven-item assessment that records patients' performance status, financial and family burden, cancer-related pain, personal desires, and depression. Outcome scores correlated with the assessments of oncologists regarding the appropriateness of continuing cancer-directed therapy, suggesting that patient-reported outcomes can be utilized as a stratification tool to identify cohorts of patients with advanced disease who may benefit from discussions of values and care planning.⁶⁰

The Need for Standardization

Without a uniform method for ACP implementation, disparities may still exist in the quality, documentation, and content of end-of-life conversations. Current research endeavors now focus on defining practical and systematic communication guidelines for high-quality care planning, with the goal of achieving personalized value-concordant care plans for each patient that can be systematically documented.^{61,62} For example, communication initiatives like the Serious Illness Care Program can train clinicians to converse with patients about their values and to document these discussions within a structured framework.⁶³ In addition, new ACP codes for Medicare reimbursement add extra incentive for appropriate and methodical documentation.^{64,65}

Given the overall lack of standardization, the European Association for Palliative Care commissioned a taskforce to establish a standard definition and set of recommendations on ACP. These recommendations address the key elements, timing, policy and regulation goals, and evaluation metrics of ACP, as well as characterize the tasks for health care professionals and facilitators to effectively lead end-of-life care discussions.⁶⁶ With two consensus definitions and 41 recommendations for ACP, the European Association for Palliative Care guidelines support that the overlying aim of ACP is to empower patients to identify, reflect, and act in accordance with their values and goals. It encourages patients to discuss openly and regularly with their family members, caregivers, and health care teams to make decisions for their future medical care.

The Role of Primary Palliative Care and Implications for Nursing Practice for ACP

Prior research has established the clear benefit of integrating palliative care principles with cancer-directed treatment to improve patients' physical, mental, and psychosocial wellbeing. Along with alleviating distress and controlling disease-related symptoms, palliative care can enhance prognostic discussions and ACP through a dedicated focus on eliciting patients' values, illness understanding, and expectations for the future.⁶⁷⁻⁷¹ In the last decade, results from multiple randomized controlled trials testing early palliative care interventions support the need for new and sustainable care models that integrate palliative care with standard oncologic care. These data collectively validate that palliative care is a powerful component of oncologic care that can improve patient satisfaction, quality of life, survival outcomes, and end-of-life health care utilization.⁷²⁻⁷⁴ This is of particular importance for ACP and end-of-life decision-making because those patients who receive concurrent and early specialty palliative care are more likely to have less aggressive care near the end of life.⁷⁵ For example, a care model that embedded a palliative care nurse practitioner in oncology clinics resulted in an increase in ACP documentation and hospice referrals before death.⁷⁶ Yet despite strong advocacy and widespread recognition, the workforce shortage of palliative care specialists limit the ability to meet all communication and palliative care needs for patients with cancer.⁷⁷⁻⁸⁰

For this reason, further investment in honing palliative care skills for all members of a patient's primary team, including oncology nurses, is needed to deliver high-quality,

opportune, and comprehensive care.^{81–85} Quill and Abernethy⁸³ have outlined a care paradigm with achievable skillsets for primary and specialty palliative care, enabling primary care team members to have an active role in initiating psychosocial support and ACP alongside providing cancer-directed therapy. Such a model delivers a united and graded network of health care professionals to attend equally to the oncologic and palliative care needs of patients throughout their disease trajectories.

In particular, recent evidence has informed a nurse-led approach to provide primary palliative care and enhanced ACP. Oncology nurses have an invaluable and unique role in all aspects relating to a patient's cancer care. Nurses and nurse practitioners are often the first health care professionals to detect and address each patient's emotional, physical, and cognitive concerns. In fact, patients may feel most comfortable disclosing their symptoms, anxieties, and fears to their nurses as they learn to cope with their diagnosis and treatment. However, in spite of the meaningful relationships that oncology nurses establish with their patients, prior data suggest that they may not have the time nor confidence to adequately assist with completion of advance directives.^{86–88} More recently, Schenker et al⁸⁹ demonstrated in a pilot study of the Care Management of Oncology Nurses intervention, that an oncology nurse-led intervention to address symptoms, provide emotional support, coordinate oncologic care, and enhance ACP was not only feasible, but was perceived by patients, caregivers, and oncologists to be an effective method to strengthen quality care. This has led to an ongoing investigation to assess the impact of care Management of Oncology Nurses compared with standard oncologic care on quality of life, mood, and health care utilization outcomes.⁹⁰

Similarly, the One-Two-Three project at Memorial Sloan Kettering Cancer Center is a structured program in which palliative care is provided by the primary oncology teams, with additional support as needed by palliative care specialists.⁹¹ The intervention addresses palliative care needs, early and frequently, starting in the first three visits after a patient's diagnosis. Initial results show evidence to support feasibility in high-volume solid tumor and hematologic malignancy clinics without disruption of clinic workflow. Moreover, oncology nurses were able to elicit patient core values after receiving communication training from specialists and using a guided framework. The One-Two-Three initiative proves that the skills for primary palliative care and values-focused discussions on ACP can be learned and is in fact endorsed by patients, families, and oncology clinicians to improve comprehensive oncologic care. Further training for nurses to provide primary palliative care is a potentially significant mechanism to facilitate ACP and end-of-life discussions.

Conclusion

Empathic and honest conversations between patients, caregivers, and health care professionals can prevent unwanted, aggressive care at the end of life. Patients with cancer deserve high-quality and timely ACP to make end-of-life care decisions that honor their individual values and preferences. As cancer therapeutics expand and create new levels of prognostic uncertainty for patients and oncologists, continued research on primary palliative care interventions and values-focused communication strategies are needed to overcome the challenges of implementing ACP in clinical practice.

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TABLE 1

Physician Orders for Life-Sustaining Treatment (POLST) Forms in the United States

Names of POLST Programs*	US States
POLST	California, Florida, Georgia, Hawaii, Illinois, Maine, Minnesota, Montana, Nebraska, Nevada, New Hampshire, New Jersey, North Dakota, Oklahoma, Oregon, Utah, Washington, Wisconsin, Wyoming (WyoPOLST)
POST	Idaho, Indiana, Michigan, Mississippi, South Carolina, Tennessee, Virginia, West Virginia
MOLST	Alaska, Connecticut, Maryland, Massachusetts, New York, Ohio, Rhode Island
MOST	Colorado, Delaware, Kentucky, New Mexico, North Carolina, Texas
IPOST	Iowa
LaPOST	Louisiana
TPOPP	Missouri, Kansas
LWDO	Utah
COLST	Vermont
PAPOLST	Pennsylvania
OkPOLST	Oklahoma
AzMOST	Arizona
DMOST	Delaware
Other POLST Programs in Development	Alabama, Arkansas
No POLST programs yet	District of Columbia, South Dakota

* Data from www.polst.org.

Abbreviations: POLST, Physician/Provider Orders for Life Sustaining Treatment; POST, Physician Orders for Scope of Treatment; MOLST, Medical Orders for Life Sustaining Treatment; MOST, Medical Orders for Scope of Treatment; IPOST, Iowa Physician Orders for Scope of Treatment; LaPOST, Louisiana Physician Order for Scope of Treatment; TPOPP, Transportable Physician Orders for Patient Preferences; LWDO, Life with Dignity Order; COLST, Clinician Orders for Life Sustaining Treatment; PAPOLST, Pennsylvania Orders for Life Sustaining Treatment; OkPOLST, Oklahoma Physician Orders for Life Sustaining Treatment; AkMOST, Arizona Medical Orders for Scope of Treatment; DMOST, Delaware Medical Orders for Scope of Treatment.

TABLE 2

Overview of the Challenges and Strategies for Advance Care Planning (ACP)

Challenges for Success	Strategies for Improvement
Patients' treatment expectations and illness understanding	Integration of primary palliative care and nurse-led interventions
Prognostic uncertainty with evolving cancer therapeutics	Patient-centered and values-focused ACP models, including utilization of patient-reported outcomes
Optimal timing of ACP discussions	Engaging in iterative ACP discussions
Barriers in physician-patient communication	Using technology to enhance communication (eg, informational video tools, ACP Web sites)
Heterogeneity of quality, content, approach, and documentation of ACP discussions	Standardization of ACP principles and documentation

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