

Advance Care Planning Conversations: Laying the Foundation for Goal-Concordant Care at End of Life

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6.1 Overview

Advance care planning conversations lay the foundation for the delivery of personcentered, family-focused, culturally congruent quality care. Exploring the values, wishes and preferences of patients and their care partners enhances the probability of goal-concordant care and minimizes regret at the end of life for all involved. Advance care planning has been demonstrated to improve patient satisfaction and ease complications in bereavement. Yet few health professionals have received formal education regarding these nuanced conversations, nor have many had these conversations with their own families. This chapter will review the key components of quality advance care planning conversations and invite the reader to consider how to better integrate these important communication skills into their practice.

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6.2 Advance Care Planning Conversations

Advance care planning conversations are intended to guide decisions regarding a person's medical care if they are not in a position to speak for themselves. A primary component of palliative care is the promotion of interprofessional, personcentered, family-focused care from diagnosis through bereavement; advance care planning often forms the basis for a palliative care treatment plan [12]. Without specific information to guide care planning, the default standard of care presumes that intensive interventions would be desired. This often results in aggressive and costly medical interventions that may or may not be reflective of an individual's actual preferences, particularly as "end of life" for many has become an increasingly long and developmentally independent phase of life [3]. Families may be left questioning if the care received reflected the actual wishes of the patient and staff may feel moral distress when providing invasive services that seem unlikely to ultimately be "beneficial."

To address these challenges, legislation began being developed in the 1970s, marking a broader cultural shift from the physician as the primary decision-maker to a more patient-centered model. From living wills to durable powers of attorney for healthcare, conversations were being had around how best to ethically empower individuals and their medical teams to personalize care that was tailored to the preferences of those served. It was based on the idea that all treatment should be actively consented to, and formed the basis for ongoing legislative efforts at the local and international levels to clarify the relationship between patient wishes and treatment rendered [14].

Advance care planning conversations have evolved to include a discussion about a person's values, beliefs and preferences and the determination of a surrogate, or healthcare agent who would be able to relay these preferences to the medical team if the person was not able to speak for themselves. These conversations may then be formalized into a document called an Advance Directive. Advance Directives document a person's preferences and when properly completed and shared with one's healthcare team, can be used to inform medical decision-making, resulting in shared care planning.

Shared care planning is a formal attempt to regulate the relationship between medical care and one's own body. The importance of maintaining autonomy regarding what happens to one's body is a theme that plays out in many complex arenas such as sexual consent or abortion. In some of these areas, governments impact one's options, in other situations, individuals may exert more autonomy. The idea of putting legal paperwork in place in anticipation of future tragedy plays out along similar lines—a prenuptial agreement, for instance, gives individuals the right to dictate the outcome of a marital dissolution to override what governments would otherwise decide for them. Advance care planning has elements of these concerns in that there already exists ethical guidance regarding what care should be provided, and, there is an opportunity for an individual to exert some degree of autonomy over their bodies. A decision not to complete an Advance Directive becomes its own decision for a certain level of intensity in care. In the absence

of a specific advance care plan, a person is likely to receive aggressive treatment as the default care plan, even in situations where the outcome is unlikely to be a return to an acceptable state of health.

Ideally, advance care planning conversations would organically occur throughout a person's life starting in early adulthood [3]. A shift in advance care planning culture means normalizing having this conversation as best practice, and not solely in response to urgent or disturbing developments in times of medical crisis. We can empower providers to address this cultural shift, by acknowledging both the reality of the human condition (normalizing our inherent mortality) and the messages patients may receive about these conversations.

For example, when a young person applies for a driver's license, in many states there is a question regarding organ donation. This might naturally invite a conversation about end-of-life wishes and an exploration regarding who they might want to be their medical decision-maker, if they were unable to speak for themselves. Ideally, when the person leaves home, gets married, or has a change in their health condition, decisions previously made would naturally be revisited and revised as circumstances change. As a person ages and relationships change, these conversations would continue to recur, with documents being updated as needs and decisions evolve. Once living with a serious illness, it is particularly important to review and update the Advance Directive to ensure its accuracy.

As health professionals, it is critical that we explain patients' medical conditions and prognosis as well as explore what types of future health states would be unacceptable. These preferences can guide care planning conversations with seriously ill patients and their surrogate decision makers. Informed decisions and the development of shared care planning with seriously ill patients require that the patient fully understands each option. This can be conveyed by exploring the best case/worst case/most likely case scenarios for each available choice. This conversation may lead to the decision to not attempt resuscitation (DNAR) of a hospitalized patient, and for patients for whom future hospitalizations and aggressive interventions are unwanted, the completion of a document indicating physician/medical orders for life sustaining treatment (POLST/MOLST—different states have different terms for these forms) may be warranted.

Engaging in a conversation to limit a particular treatment requires sophisticated and nuanced communication skills and is often best completed in the context of an interprofessional family meeting. Kindness and compassion are essential in explaining why a particular intervention is unlikely to be of benefit for this particular patient under this particular set of circumstances. Developing an ability to cultivate a patient's prognostic awareness takes time and expertise to do well. Seeking additional education to develop these skills and receiving mentorship from palliative care colleagues can be invaluable.

Summarizing your understanding of their thoughts and preferences for care at the end of life and their wishes for their body post-death will aid the surrogate decision maker during what will likely be an especially stressful period. Encouraging patients to consider proactively addressing non-medical issues that may arise (such as providing trusted agents with the information needed to manage finances, access social media accounts, or distribute possessions) can also be helpful. Yet, even for patients without a serious illness, having systems in place to normalize these conversations is beneficial, as approximately 25% of people who die in the United States each year are under the age of 65 [3].

The **Box** below offers a summary of the key steps for successful advance care planning.

Box: Key Steps in the Advance Care Planning Process

- 1. Reflect on your values, beliefs, preferences, focusing on *what gives your life meaning*. Some people find that their faith traditions offer guidance in this regard and benefit from speaking with others about these issues. As you reflect upon how your health may change over time, consider where you would want your care to be delivered and what trade-offs you might (and what you may consider to be a condition or fate "worse than death"), or might not, be willing to make in an attempt to extend life.
- 2. Determine who you would trust to speak for you if you were not able to make your own health decisions. Note: this person is ideally someone who is readily accessible and able to advocate on your behalf. You may also consider making a will and thinking about who you would trust to make financial decisions for you if you were incapacitated. Consider issues of guardianship and support for those who are dependent upon you (children, elders, pets, etc.).
- 3. Talk with this spokesperson (and others who would be impacted by your decisions) about your values and preferences and determine their comfort level in advocating for your wishes with the medical team.
- 4. Record a summary of your decisions and share that with all of those who may be impacted by your decisions. Clarifying your decisions and wishes minimizes family misunderstandings and regrets.
- Complete an Advance Directive (see Resources) in accordance with your state's laws and regulations (and distribute copies to all who may be impacted by your decisions). Ensure that contact information is accurately recorded (and frequently updated).
- 6. Periodically discuss your preferences with your healthcare team. This may result in the completion of additional documents (such as a "Do Not Attempt Resuscitation" order or a "Physician/Medical Orders for Life Sustaining Treatments" form).
- 7. Regularly review and update your Advance Directive. This is especially important to do when your health condition changes (such as following a new diagnosis or a change in prognosis), or if there is a change in who will be your surrogate decision maker (such as due to a death or divorce), or if there is simply a change in contact information.

Health professionals reviewing the information above will note that it is focused on a holistic and non-medical perspective, as these decisions are fundamentally intensely personal and contextual, and may begin outside of a medical setting. Wishes and preferences naturally evolve over time, and ideally, so do these conversations. Yet there is a medical component to these decisions and thus, there is an important role for clinicians to routinely engage with their patients regarding these topics.

An advance care planning conversation might explore the following questions:

- What do you feel would make you more comfortable as you approach the end of your life? Such as physical pain management prioritized over alertness, do you have privacy concerns if care is rendered by family or professionals?
- How important to you is maintaining your independence and being self-sufficient? What would it mean to you to lose these things? Is it to be expected, that at the close of life one is likely to require personal care, or is it seen as an unbearable loss of autonomy?
- What are your priorities when making decisions about your future medical care (for example, symptom management, length of life, quality of life)?
- What are the most important activities of daily living that will contribute to your quality of life (for example, being able to complete daily tasks, speak with family and friends or enjoy food)?
- How important is it to be in a home-like environment as your condition worsens, versus one where medical professionals are likely more readily accessible?
- What religious or spiritual considerations matter to you (for example, are there specific ceremonies or rituals that would be important to you if you were very ill)?

To aid health professionals in these conversations, it might be useful to consider adapting the PLISSIT model as a communication guide. PLISSIT was originally developed by Jack Annon in response to another area that medical professionals had been reluctant to embrace—discussions about the impact of an illness or injury on a patient's sexuality [15]. Because of the sensitive nature of sexual concerns and the limited education that many providers had received regarding how best to address these concerns, many assumed that if the patient wanted to discuss these issues, they would bring them up themselves—not surprisingly, this left many patients with unaddressed sexual concerns.

PLISSIT as an acronym stands for Permission (giving permission/normalizing the concern), Limited Information (giving brief education or resources), Specific Suggestions (determining a specific concern amenable to specific strategies that might be helpful), and Intensive Therapy (identifying a concern best addressed by referring to those with specialized expertise). Annon postulated that all patients benefited from the normalization of these concerns ("P") and therefore, that all providers should be competent in permission-giving, while fewer patients would need the subsequent steps of the intervention, and fewer providers would need to have the expertise to address these.

 Table 6.1
 Adapted Ex-PLISSIT model to guide advance care planning conversations

| Stage/Urgency | Possible interventions |
|--|---|
| Permission (Periodically for all patients) | Comprehensive biopsychosocial-spiritual assessment; Explore what advance care planning conversations have already occurred; If an Advance Directive has been completed—assess for applicability (is it current? Actionable? Contact information up to date?); Invite exploration of wishes, preferences and values to guide care planning; May occur organically in the community without medical guidance GOAL: Plant the seed for future conversations |
| Limited information (When there is a new diagnosis, or a change in setting) | Invite an advance care planning conversation: Provide education and anticipatory guidance regarding care planning; Introduce concept of an Advance Directive; Identify a surrogate; Facilitation of prognostic awareness; Normalize, clarify, explore, and address goals of care; Likely to occur in a medical setting prior to an urgent need GOAL: Understand the concerns of this particular patient at this particular time while educating them about the importance of an Advance Directive to guide future care planning |
| Specific suggestions (When there is a new diagnosis, a change in setting or a change in prognosis) | Complete (or review) advance directive (in accordance with your state's regulations and guidelines); Likely to occur in a medical setting—often when there is an anticipated need (such as a hospitalization) GOAL: Understand the concerns of this particular patient at this particular time while educating them about the importance of an Advance Directive to guide care planning |
| Intensive therapy (When there is a new diagnosis, a change in setting, a change in prognosis) | Complete (or review) a POLST/MOLST form (note that different states may have different names for these documents—ensure compliance with your state's regulations and guidelines); Likely to occur in a medical setting—often when there is the possibility of an urgent need GOAL: Understand the concerns of this particular patient at this particular time while educating them about the importance of an Advance Directive to guide immediate care planning |

PLISSIT has since been modified to become Ex-PLISSIT, to emphasize the importance of *explicitly* normalizing concerns and giving permission to address the concern at *each* subsequent step of the intervention, to ensure that the intervention is as tailored as possible to the individual patient's specific needs [15].

Adapting this communication strategy for those who are providing care to patients with serious illness allows us to consider the following adaptation of Ex-PLISSIT to advance care planning conversations. In Table 6.1, we suggest how this framework might guide advance care planning conversations in a health setting. Note that we are recommending that the provider normalizes each step of the process. And just as PLISSIT recognizes that not all providers have the time or skills to complete each step, the steps below might be delegated to different providers who have different levels of time or expertise.

6.3 Challenges and Controversies

Despite the benefits of advance care planning, there have been those who have questioned the attention and resources that it has drawn. Morrison cites research showing that many of the well-intentioned efforts in patient self-determination (POLST/MOLST forms, e-MOLST forms, advance care planning billing codes) have not measurably increased goal-concordant care. While he notes that the complexities of the decisions on emotional, cultural and situational levels intersect with a profit-driven healthcare system to leave little planned-ahead impact on actual care rendered, he poses an intriguing question about what can be done within the existing system to further the goals of patient self-determination [11]. Commentary was generated on the challenge of quantifying a quality advance care planning conversation as so few professionals have been formally prepared to engage in these complex conversations, and so few institutions have supported the time and educational requirements needed to conduct them well [8]. Additionally, there are difficulties inherent in actually determining if the care provided was goal concordant, as there is no "gold standard" for how that elusive goal is best determined or how it might be widely measured.

Clearly, better measures are needed to evaluate the outcomes and effectiveness of many palliative care and ACP activities. Yet there seems little doubt in the inherent value of engaging in culturally nuanced conversations that explore patient's values, wishes and preferences. There are numerous anecdotal reports of ways in which ACP conversations "...support resilience, understanding, feelings of peace, and recovery from grief even in circumstances where this advance care planning doesn't change the care received..." [4]. A growing number of researchers are creating tools and exploring barriers to ACP from the perspective of the patient [1, 6] to improve the effectiveness of ACP conversations.

Yet, despite these efforts, there continue to be disparities in the completion of Advance Directives in racially and ethnically underrepresented groups [9], and many have worked to make them more amenable to a wider potential audience. As a field we have not routinely addressed the social determinants of health nor

has healthcare always been trustworthy. We have an obligation to be as nuanced and compassionate as possible when engaging with patients to ensure that we understand the historic distrust that many have regarding our recommendations for what might be perceived as a limitation in care. Discussions about "discontinuing" a treatment can easily be interpreted as a cost saving strategy or be perceived as an indication that a particular patient's life is more "disposable" than others. Unintended biases continue to result in unequal care. More education is needed to ensure that health professionals recognize their role as advocates for social justice and the equitable delivery of quality care.

And even when Advance Directives are completed, there can be challenges in reliably (and quickly) retrieving the needed information. The various electronic medical record systems have not yet devised mechanisms to ensure ready accessibility of updated information needed to guide urgent conversations. This can result in delayed access to Advance Directives with some patients receiving unwanted interventions as a result.

While many healthcare professionals intellectually acknowledge the benefits of ACP, in practice, only 44% of hospice providers actually have them themselves

Table 6.2 Addressing barriers to implementation

| Barrier to implementation | Possible responses |
|--|---|
| Provider: It will open a can of worms and take too much time | Uses less resources over time (provider time, inappropriate care); consider how social workers or chaplains might be enlisted to initiate advance care planning conversations |
| System: Forms not available, no witness, notary | Identify accountable person/position to meet legal demands for advance care planning availability |
| Provider: I am not confident I can have this conversation well | See resource list! There are many trainings available, and use the resources of your interprofessional team |
| System: EMR does not support | EMRs were originally developed to assist with billing, not as a care delivery system; identify IT people who can be authorized to create a work-around, most hospitals have created systems |
| Provider: If patients were ready they would bring it up | Unrealistic, people don't know what they don't know; patients rely upon providers to identify important topics for medical discussion |
| System: It won't impact the actual care implementation | Data shows that it does (see Resources: Respecting Choices); higher probability of people having care consistent with their goals when we know their goals |
| Provider: They will think there's something dire going on | Normalize that you have these conversations with all your patients |
| Provider: I will take away their hope | Hope evolves and changes over time |

[10], just about 10% more than the general population [16]. What might account for this disconnect? People in healthcare understand how little control many of us may actually have when we are critically ill and how many of us will change our minds when faced with the reality of a situation. Yet, we have seen the relief of families and providers when care can be rendered according to previously stated wishes, and the sense of empowerment that comes from patients making choices for themselves, as well as the cost benefits of goal-concordant care. A cultural shift is needed, whereby health professionals recognize the value of engaging in these conversations in their own lives, so that they might more authentically have these nuanced conversations with others [2].

Table 6.2 lists common concerns and possible responses regarding the routine implementation of advance care planning conversations. Note the recommendation to utilize the interprofessional team in creating systems in place to support the occurrence of advance care planning. Palliative social workers are particularly well positioned to offer leadership in systemizing these services [13].

6.4 Summary

The likelihood of goal concordant care is enhanced when these nuanced conversations occur outside of the medical setting in a non-emergent situation [8]. To encourage these discussions, we have adapted the PLISSIT communication model that focuses upon normalizing these conversations. Providers may use the suggested interventions and ways to address implementation barriers, as well as the resources listed below, to improve their skills and comfort with this important work. The COVID-19 pandemic has highlighted the urgency for all of us to identify surrogate decision-makers who will be able to translate our wishes, values and preferences into an actionable guide for our medical care, should we find ourselves unexpectedly unable to speak for ourselves [7]. Health professionals have a responsibility to address social determinants of health and advocate for equitable access to care and to minimize disparities in the benefits of ACP.

Recommended Resources for Additional Information

Websites:

- ACP Decisions: https://acpdecisions.org/
- American Bar Association: https://www.americanbar.org/groups/law_aging/ resources/health_care_decision_making/consumer_s_toolkit_for_health_care_a dvance_planning/
- American Society of Clinical Oncology (ASCO Answers: Advanced Cancer Care Planning): http://www.cancer.net/sites/cancer.net/files/advanced_cancer care planning.pdf
- Ariadne Labs (Serious Illness Conversation Guide): https://ariadnelabs.org/ areas-of-work/serious-illness-care)
- Caring Connections: http://www.caringinfo.org/

- Center to Advance Palliative Care: https://capc.org/
- Coalition for Compassionate Care of California: https://coalitionccc.org/tools-resources/advance-care-planning-resources/
- The Conversation Project: http://theconversationproject.org/
- Leukemia & Lymphoma Society (*Advance Care Planning Making decisions for your future*): https://www.lls.org/sites/default/files/National/USA/Pdf/Public ations/PS94 Advance Care Planning2019 FINAL.pdf
- National Hospice and Palliative Care Organization (Caring Connections): http://caringinfo.org
- National POLST: https://polst.org/
- Patient Dignity Inventory: https://www.dignityincare.ca/wp-content/uploads/2010/05/The_Patient_Dignity_Inventory.pdf
- Palliative Care Network of Wisconsin (Fast Facts): https://mypcnow.org/fast-facts/
- Prepare For Your Care: https://www.prepareforyourcare.org/
- Respecting Choices: https://gundersenhealth.org/respecting-choices/
- Shiley Haynes Institute for Palliative Care: https://csupalliativecare.org/programs/advance-care-planning/
- Stanford Letter Project (What Matters Most and Who Matters Most): http://med.stanford.edu/letter
- Vital Talk: https://vitaltalk.org/

Books

- Altilio T, Otis-Green S, Cagle JG (eds) (in Press) Oxford textbook of palliative social work, 2nd ed. Oxford University Press
- Back A, Arnold R, Tulsky J (2009) Mastering communication with seriously Ill patients: balancing honesty with empathy and hope. Cambridge University Press.
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Conversation Aids

- The "Go Wish GameTM" (www.gowish.org) is a card game that helps you to prioritize what will matter most to you during end-of-life care and then share those feelings with your family. You can purchase physical cards to play the game, or you can play for free online.
- The Institute for Healthcare Improvement Conversation Project's "Conversation Starter Kit" is free and can be downloaded at https://theconversationproject.org/ starter-kits/
- "Five Wishes®" is a legal document (available for purchase at Aging with Dignity: www.fivewishes.org) that guides you through advance care planning before you are faced with a health crisis. This Web site provides a free guide on how to talk about healthcare choices and a conversation guide for individuals or families.
- "Voicing My Choices" is a discussion guide (available for purchase at https://fiv ewishes.org/shop/order/product/voicing-my-choices) that empowers young people who are struggling with a serious illness to communicate with family members, friends and caregivers about the type of care that they want now and in the future.
- "Heart to Heart" is a bilingual (Chinese/English) communication activity from the Chinese American Coalition for Compassionate Care (https://caccc-usa.org)
- "Hello/Hi!" Two interactive games that provide discussion prompts to help people discuss what matters most: https://commonpractice.com/pages/land-acp-foreveryone and https://commonpractice.com/pages/hi.

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