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Advance Care Planning: A Window to Palliative Care

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**Advance Care Planning:
A Window to Palliative Care**
Suleyki Medina, MD



Miami Cancer Institute

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Disclosures

- There are no financial relationships or conflicts of interest to disclose



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Objectives

- Define Advance Care Planning (ACP)
- Identify benefits to ACP
- Discuss why ACP is a priority in the seriously ill population
- Review strategies to initiate this process and implement ACP practices
- Identify barriers to ACP and how to overcome them



Background

- Advocacy for ACP began 25 years ago, with the focus on completing an **Advance Directive** only
- Many have advocated a more comprehensive approach stressing communication
- This is known as the **Advance Care Plan**--a broader construct that **focuses on conversations about eliciting goals rather than the creation of a document**



Background

- Patients believe ACP is important but only a **minority** of them have had discussions with a doctor before or during a hospitalization
- Most patients expect physicians to initiate the conversation
- This topic is frequently avoided due to a number of barriers



Advance care planning

- Ongoing communication whereby patients, their families, caregivers, and healthcare providers reflect on and explore:
 - Goals
 - Values
 - Beliefs
 - Medical Care/Treatment options
 - Fears, hopes, needs, and illness understanding



Advance Care Planning

- Ongoing
- Proactive
- Appropriately timed
- Integrated into routine care
- Revisited



ACP Planning Resources

- www.healthcareproxy.org
- www.betterending.org
- www.agingwithdignity.org
- www.abcd-caring.org



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ACP Planning Resources

- www.abanet.org/aging
- www.caringinfo.org
- www.respectingchoices.org
- www.polst.org



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Why is ACP important?

- Patients want to learn more about what they can expect and the options for life sustaining treatment and palliative care.
 - want a sense of control over their medical care and their future
 - want to be cared for in a manner that is consistent with their preferences
 - Want to reflect
 - Want to settle business



Why prioritize ACP in the seriously ill population

- Misalignment between the medical care people *want* and the medical care they actually *receive*
- Discussions often occur ***too late***
 - after a health crisis
 - loss of decision-making capacity
- When ACP does happen
 - treatment checkbox forms
 - no emphasis on patient's values, goals and priorities



Benefits to patients, families, and, caregivers

- Lowers risk of stress, anxiety, and depression of surviving relatives
- Higher satisfaction with quality of care
- Better family preparation on expectations and decisions process
- ACP Reduces family decisional burden by planning in the early stages



Benefits to providers

- Ability to create a care plan consistent with patient wishes
- Enhanced trust between patient and provider
- Patients reassured that their wishes will be respected
- Lessens conflict among family members and between family members and the healthcare team



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Benefits to providers

- Facilitates seamless communication among providers and across different care settings
- Supports providers in making difficult recommendations when the patient has lost decision making capacity.
- Reduction of moral distress among healthcare providers



Patient strategies

- See your current health status as it is
- Assess your level of Illness Understanding
- Be familiar with disease trajectory/course
- Identify what is important to you
- Know your thoughts on life prolongation



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Strategies to initiate conversation

- Step 1: Prepare for the conversation
- Step 2: Determine what the patient knows
- Step 3: Determine what the patient wants to know
- Step 4: Deliver any new information

Goldstein, N. M., Sean (2013). Evidence-Based Practice of Palliative Medicine, Saunders



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Strategies to initiate conversation

- Step 5: Notice and respond to emotions
- Step 6: Determine goals of care and treatment priorities
- Step 7: Agree on a plan
- Step 8: Recap

Goldstein, N. M., Sean (2013). Evidence-Based Practice of Palliative Medicine, Saunders.



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Implementing ACP Practices

- Putting ACP in context for health professionals
- Making ACP a team enterprise
- Making it routine
- Education
- Tools



Barriers and solutions

- Accountability
- Poor Communication
- Avoidance
- Fear
- Time
- Poor structure and routine



Barriers and solutions

- Provider
 - lack of training and fear of doing harm by discussing dying
- Patient
 - lack of knowledge about ACP as a whole
 - worry about burdening family
 - perceived lack of physician time
 - uncertain of which physician to talk to
 - perceived unwillingness of doctor to talk about the topic.



Barriers and solutions

- System
 - lack of time
 - lack of reimbursement for time spent
 - lack of systematic reminder
 - lack of a transfer of wishes across care settings
- Media
 - Charged and inaccurate descriptions of ACP



Resources for providers

- American Academy of Hospice and Palliative Medicine
- American Geriatric Society
- Vital Talk
- Serious Illness Conversation Guide from Ariadne Labs.
- American College of Physicians High Value Care Task Force.



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Serious Illness Conversation Guide

Serious Illness Conversation Guide

CLINICIAN STEPS

Set up

- Thinking in advance
- Is this okay?
- Hope for best, prepare for worst
- Benefit for patient/family
- No decisions necessary today

Guide (right column)

Act

- Affirm commitment
- Make recommendations about next steps
- Acknowledge medical realities
- Summarize key goals/priorities
- Describe treatment options that reflect both
- Document conversation
- Provide patient with Family Communication Guide

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CONVERSATION GUIDE

Understanding What is your understanding now of where you are with your illness?

Information preferences How much information about what is likely to be ahead with your illness would you like from me?

FOR EXAMPLE:
Some patients like to know about time, others like to know what to expect, others like to know both.

Prognosis *Share prognosis as a range, tailored to information preferences*

Goals If your health situation worsens, what are your most important goals?

Fears / Worries What are your biggest fears and worries about the future with your health?

Function What abilities are so critical to your life that you can't imagine living without them?

Trade-offs If you become sicker, how much are you willing to go through for the possibility of gaining more time?

Family How much does your family know about your priorities and wishes?

(Suggest bringing family and/or health care agent to next visit to discuss together)



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Resources for patients, families, and caregivers

- www.acpdecisions.org
- www.getpalliativecare.org
- <http://theconversationproject.org/>
- <http://www.honoringchoices.org/>
- <https://www.prepareforyourcare.org/#/>



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Resources for patients, families, and caregivers

- <http://upnorthlive.com/features/your-health-matters/putting-yourself-family-at-ease-with-advance-care-planning>
- <https://www.acpdecisions.org/pr/story/>



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