

# Assuring Safe Passage: Moving Conversation about End-of-Life Upstream

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# Objectives

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- Review rationale for early values and goals discussions with oncology patients with poor prognoses
- Identify opportunities for and benefits of early conversations about end-of-life (EOL) issues in oncology practice
- Describe barriers to discussion of EOL issues in oncology
- Propose an “Advanced Illness Checklist” for discussing values and goals about end-of-life care
- Demonstrate and reflect on Advanced Illness Checklist

# The end-of-life experience of cancer patients

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- Aggressive care (e.g., use of life-sustaining therapies, ICU admission) is NOT associated with improved survival
- Patients who receive hospice care report better quality of life at the end of life
- Aggressive care associated with reduced quality of life, more physical and emotional distress at the end of life
- In last month of life, cancer patients experience
  - Chemotherapy (40%)
  - Emergency department visits (48%)
  - Hospital admissions (50%)
  - Death in ICU (8%)
    - 55-75% have serious pain, anxiety, discomfort
  - No hospice referral (35%)
  - Late hospice referral (median 16 days)

# Impact on family/caregivers

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- Death in an ICU was associated with 11 times higher rates of post-traumatic stress disorder and 9 times higher rate of generalized anxiety disorder among bereaved caregivers
- Hospital deaths were associated with 10 times higher rates of prolonged grief disorder in bereaved caregivers
- Family members of patients who die report higher satisfaction levels with care in hospice than in hospital

# Quality of end-of-life care

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<b>Families Reporting:</b>	<b>Hospital</b>
Inadequate contact/communication with MD	78%
Inadequate help with emotions	51%
Not enough information about what to expect in the dying process	50%
Poor family support	38%
Lack of respect	20%
Inadequate symptom control	19%

# What is Advance Care Planning (ACP)?

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- A core element of quality care for all patients with cancer
  - ASCO, National Quality Forum identify ACP as quality indicators
- The process through which patients have the opportunity to explore and express their values and choices about future health care, especially for care at the end of life, with the health care team and with family
  - The goal is to assure that patients' values and choices are respected and honored if the patient is unable to speak for him or herself

# Elements of Advance Care Planning

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- Completion of a Health Care Proxy or Durable Power of Attorney for Health Care to identify a decision-maker if the patient is unable to speak for him or herself
- Communication with family members and clinicians about values, preferences and wishes that should guide treatment if the patient is unable to speak for him/herself
- Advance directive/living will (Many questions about impact)
- Ongoing conversations with clinicians and family members as medical situation evolves
- Engagement of family member/health care agent is key
- Documentation of discussion/HCP information in medical record
  - Many states also using MOLST/POLST to document patient values and wishes as medical orders that are valid across settings

# Impact of race, ethnicity, religion on ACP

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## ACP

- Blacks, Hispanics much less likely to engage in ACP than whites and more likely to want aggressive care [Blacks 3x more likely, Hispanics 2x more likely] (Smith AK et al JCO 2008)
- Highly religious patients more likely to prefer aggressive care, express concern about efforts to limit life-sustaining treatments

# Benefits of Advance Care Planning: The Evidence

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- Patients welcome ACP and expect physicians to initiate these discussions
- 80-90% of cancer patients want information about prognosis
- Even when the information is upsetting, caregivers want to know prognosis
  - Helps with decision-making, planning
  - Prognostic information does not compromise hope and appears to support hope in setting of poor prognosis (Mack JCO 2006, 2007)
  - With sicker patients, caregivers tend to prefer more information
- Prognostic information changes patients' choices
  - Patients who expect prognosis of <6 months are more likely to prefer less aggressive care (Weeks et al JAMA 1998)

# Evidence (2)

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- Early discussion of end-of-life care issues among cancer patients is associated with improved outcomes:
  - Patients are more likely to have wishes followed
  - Increases quality of life
  - Reduces rate of hospitalization and ICU admission
  - Increases use of hospice
  - Reduces stress, anxiety, depression, PTSD and bereavement morbidity in survivors
  - Improves family satisfaction
  - Strengthens clinician-patient relationship
  - Reduces costs

# Evidence (3)

- There is no evidence that ACP “takes away hope”
  - Patients are not more depressed or anxious following EOL discussions
- Clinicians (especially house staff) are stressed by EOL discussions and decision-making with unprepared patients who are often in a crisis in the hospital

# ACP prepares patients and family members for end-of-life decisions

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- Helps patient feel confident that EOL wishes will be honored
- Prepares family emotionally
- Provides information about decision-making process (health care proxy) and goals and values
- Relieves burden on family
- Supports oncology staff in doing the right thing

# The desired outcome for patients who die: Peace at the end of life

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- Understanding of prognostic realities
- Preparation
- Absence of struggle
- A sense of appropriateness, meaningfulness
- A feeling of wholeness
- Comfort, absence of fear
- Concordance between goals/values and care received
- Family members at peace re: decisions (Mack et al. Cancer 2008)

# Additional desired outcomes

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- Staff at peace with process and outcome
- Absence of moral distress
- Pride in teamwork
- Less burnout?

# Barriers to ACP in Oncology

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- Time ???
  - Average ACP conversation in oncology is 5.6 minutes
    - MDs do most of talking
    - Little exploration of patient values
    - Conversations do not meet quality standards proposed in literature (Tulsky Ann Intern Med 1996)
  - Expert spend average of 14.7 minutes
    - Less verbally dominant
    - Focused more on psychosocial, lifestyle issues
    - More partnership building (Roter DA et al. Arch Intern Med 2000)

# Barriers (2)

- Perception that patients don't want to talk about this
- Uncertainty re: prognosis, outcomes
- Balancing realistic information with hope
- Perception that palliative care and aggressive care are mutually exclusive
- Lack of MD confidence, competence
- Unrealistic expectations (MD, patient)
- Death = "giving up" = failure

# Problems with EOL conversations

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- Happen late, without patient preparation, and at times patient is at their worst
- Happen without context – prognosis not discussed explicitly and do not provide patient with information about the “big picture” that is needed to make informed decisions
- Focus on procedures inappropriate. Patients are experts on personal values not on procedures.
- “Chinese menu” approach overwhelming; lack of guidance about what makes medical sense
- 30% of patients over 60 require surrogate decision-making, yet families are often not prepared, leading to stress and traumatization related to decision-making (Silveira et al NEJM, 2010; Wendler Annals Intern Med 2011)

# EOL Communication: General Principles

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- Discussions about end-of-life issues are about:
  - Managing anxiety
  - Decision-making
- Decisions require re-negotiation over time
- Patients need time to cope with anxiety– EOL planning/decision-making is a PROCESS
- EOL discussions are procedures, like an appendectomy
  - Skills in performing this procedure can be learned
  - Roadmaps and checklists can be resources
- Focus on what is important to the patient (quality of life, suffering, survival) rather than on what is relevant to the MD (procedures)

# General Principles (2)

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- Hope is important to nearly all patients, but there is great variability in what is hoped for; MDs focus on biomedical hopes (e.g., cure, prolongation of survival) rather than helping patients transition to other types of hopes (Greisinger et al. Cancer Practice 1997; Delvecchio Good, M, Culture Medicine, Psychiatry 1990)
- Key elements of effective, compassionate discussions:
  - Empathy
  - Understanding
  - Commitment to providing support, non-abandonment
  - Attention to symptom control
  - Emphasis on what can be done
  - Focus on non-biomedical hopes (Clayton J et al. Psychooncology 2008)

# What would a system look like?

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All patients would have the right  
conversation at the right time  
with the right clinician

# An accountable system to assure that patients designate health care proxies

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- Patient education campaign
- Health care organizations would be responsible for developing a systematic process that is integrated into overall system of care
  - Patients would designate HCP as part of registration process
  - ACP would be addressed routinely in outpatient setting
- Metrics

# A system to identify high risk populations

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- A system would be developed (e.g., triggers) to assure that patients with complex, chronic, and life-threatening illnesses initiate ACP discussions early
- Structured conversation guides would be developed, evaluated, and used by clinicians to assure that these discussions meet evidence-based standards.

Physicians (and other clinicians) would be trained to conduct appropriate ACP discussions

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- Physicians (and other clinicians) who care for patients with complex, chronic and life-threatening illness would be required to undergo training in conducting effective, patient-centered ACP discussions.
  - Clinicians would be evaluated and expected to meet minimum competency standards.

# Quality standards would be promulgated

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- Electronic medical record systems would support documentation
- Key patient populations would be identified
- Metrics would be developed and incorporated into reported quality measures.

<http://blogs.hbr.org/innovations-in-health-care/2011/03/-the-stuff-i-do.html>

# What should a cancer center do?

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- Cancer is a life-threatening illness in which unexpected medical issues arise regularly
  - All patients should designate Health Care Proxy as part of process of initiating treatment
  - Patients should be encouraged to discuss wishes with proxy
  - DFCI Policy: All patients required to document HCP by third visit
- Patients with advanced cancer and poor-prognosis cancer should:
  - Have early discussions (6 months – 1 year) about values and goals of care as illness progresses
  - At appropriate time, readdress issues such as code status, POLST/MOLST
  - DFCI policy: If oncologist answers “NO” to:  
*Would you be surprised if this patient died within one year?* Is expected to have Values and Goals conversation documented in electronic medical record
- Physicians and other clinicians should be trained.

# Advanced Illness Checklist

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- *Would you be surprised if this patient died in the next year?*
- If “NO”, oncology clinician prepares patient for subsequent discussion:
  - Normalizes discussion, explains goals
    - Assure patient wishes are honored
    - Reduce burden on family members
  - Structured questions provided in advance to help patient prepare for ACP discussion at next visit
    - Prognosis, key values and goals

# Advanced Illness Checklist

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- **Prognosis:** What is your understanding of where you are and what the future may hold with your illness?
- **Information:** How much information do you want from me about what is likely to be ahead with your illness?
- **Fears/worries:** What are your biggest fears and worries about the future with your illness?
- **Goals:** If your health situation continues to get worse, what are your most important goals?
- **Tradeoffs:** If you become sicker, how much are you willing to go through, in terms of procedures, machines, and being in the hospital, in order to have the possibility of gaining more time?
- **Function:** Are there specific health states that you would find unacceptable? For example, being on machines, in a coma, or unable to care for yourself?
- **Family:** How much have you discussed your goals and wishes with your family?

# The ACP module and checklist

Advance Care Planning v1.01.62 (11/22/2010) - Microsoft Internet Explorer provided by Partners HealthCare System

Address: http://docman.partners.org/acp/ACP2.aspx

Gallo, Joanne L AF966  
4600494 (MGH) 11/17/1931 (79 yrs.) F

Select ACP Results LMR Resource

ACP PROD

**Advance Care Planning**

- ▼ ACP Summary
  - ▶ Health Care Proxy
  - ▼ Code Status/Discussion
    - ▶ Code Status Orders
    - ▶ Code Discussions
    - ▶ Comfort Care Form/MOLST
  - ▶ Goals and Values
  - ▶ Other ACP Documents
  - ▶ Resource Links
- ▶ Admin

**ACP Summary**

Document	Status	Date	Site	Visit	Notes
Health Care Proxy	Gallo, Kevin	08/24/2010	CHR	OUTPT	she has dropped copies off to me and to NSMC
Comfort Care Form	N	08/24/2010	CHR	OUTPT	
Living Will	Dr Marianne Moore	08/24/2010	CHR	OUTPT	
Treatment Goals		08/24/2010	CHR	OUTPT	Given copy of 5 wishes to so she can review specific scenarios and give more direction to living will, MKM MD 8/24/10

History

# The ACP module and checklist (continued)

ACP Admin Page (testing) - Microsoft Internet Explorer provided by Partners HealthCare System

File Edit View Favorites Tools Help

Back Forward Stop Refresh Home Search Favorites

Address <http://wlapp.partners.org/ACP/acpTest.aspx>

## ACP

[Test Page](#)

## Values and Goals

[Expand All](#) 2:01:36 PM

- [+](#) **Prognostic** 02/24/11 Serious but not terminal, More that a year. Some understanding of prognosis. Understands metastatic breast cancer to liver and lung. Is experiencing more pain and worries that this means the cancer is growing more actively.
- [+](#) **Information** 02/24/11 Wants to be fully informed.
- [+](#) **Fears** 02/24/11 Pain. Lives alone and worried about her son being burdened. Wants to pursue treatment if there is a reasonable chance that it will help.
- [+](#) **Goals** 02/24/11 Treatment if likely to be successful. Concerned about needing to move to NYC to be near her son if she gets sicker.
- [+](#) **Tradeoffs** 02/24/11 Wants aggressive care including machines if disease process is reversible and she can function, but, if the cancer is progressing and she is feeling miserable, she does not want life sustaining treatments.
- [+](#) **Function** 02/24/11 Unacceptable, Being in a coma.
- [+](#) **Family** 02/24/11 No discussion but plans to address issues. Afraid to upset her son by talking about her wishes, but knows she should and will try.

©Partners [Set Top](#) Local intranet

# Demonstration and Debriefing

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- 57 year old investment banker
- Pancreatic cancer, unresponsive to gemcitabine, informed last week
- Married, 2 children, wife judge
- Patient wants family to live “normal lives”
- NOW: weight loss, poor appetite, bloating discomfort
- GOAL TODAY: begin to discuss values and goals if he becomes sicker

# ACP Improves Quality of End-of-Life Care

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- Early and more frequent patient-centered ACP discussions help assure patients that their wishes will be known and honored
- Early ACP discussions reduce burden of decision-making on relatives
- Early discussion of ACP issues allows patients/families time to process and adapt to challenging illness-related realities and helps them make better decisions about care

# ACP Contributes to Culture Change

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- ACP increases and normalizes discussion about prognosis, quality of life, and end-of-life care for patients, families, and clinicians
  - 90+% of target patients have documentation in pilot disease centers
- More frequent ACP discussions with appropriate training will enhance clinician competency in discussing these issues
  - Opportunities to improve quality of documented discussions => more training

# ACP contributes to more appropriate utilization of health care resources at the end of life

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- Early ACP discussions associated with earlier referral to hospice
- Early ACP discussions associated with reduced use of ICU care
- Early ACP discussions associated with reduced costs of EOL care

# References

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- Patients welcome ACP (Perkins Annals Int Med 2007, Emanuel LL et al. NEJM 1991)
- Patients expect physicians to initiate ACP (Grimaldo et al. Anesthesiology 2001)
- No evidence of increased depression, anxiety, or hopelessness (Wright et al JAMA 2008, Detering BMJ 2010)
- Assessment of patient understanding of illness and possible treatments essential to helping patients make informed decisions (Detering et al BMJ 2010)
- ACP can strengthen clinician-patient relationship (Wright et al JAMA 2008)
- ACP associated with GREATER patient and family satisfaction, and with reduced stress, anxiety, depression and PTSD in family members (Detering et al BMJ 2010)
- ACP associated with patients receiving desired care (Detering)
- Reduced bereavement morbidity in survivors (Wright et al. JAMA 2008)
- Reduced costs (Zhang, Arch Int Med 2009)