

Beyond the Check Box Advance Care Planning

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Hope Hospice & Palliative Care Rhode Island is The Major Teaching Affiliate
of The Warren Alpert Medical School of Brown University



Daunting Realities

- 1 in 3 adults nationally (36.7%) have completed any type of advance directives ¹
- 38% of people with chronic illness have one ¹
- 56% of adults have discussed preferences with their family ²
- 46% providers report they do not know what to say in discussing advance directives with patients³
- Less than 1 in 4 adults have discussed ACP with their provider⁴

¹ Health Affairs Vol 36 No.7 July 2017

² Survey CDC

³ Survey John A Hartford Foundation, Cambia Foundation

⁴ Kaiser Poll

Patients are not Hearing Us

- Guidelines suggest best done when pt stable but majority (55%) initial discussion with advanced cancer patients took place in inpatient setting¹
- Recent study patients with metastatic cancer did not understand chemo was very unlikely to cure their cancer²
 - 69% lung cancer patients did not realize chemo would not be curative
 - 81 % colon cancer patients did not realize chemo would not be curative
- Also known that patients are waiting for us to bring it up

¹ Ann Int. Med 2012; 156 (3) 204-210.

² NEJM 2012; 367 (17)1616-1625.

Key Component of High Quality Health Care: Early Discussions in Serious Illness¹

- Associated with better QOL
- Reduced non-beneficial medical care at EOL
- Enhanced goal-consistent care
- Reduced costs

¹Jama Vol 174 No 12, 1994-2003



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More interventions and life sustaining treatment associated with poorer pt QOL and higher family distress

- 8.8/10 adults report wanting to die in their homes, free from pain
- 52% die in institutions-hospitals and nursing homes
- 29% die after ICU stay in last 3 months of life
- Cancer patients receive chemo late in life -12% got chemo in last 14 days of life
 - Assoc with 30% less chance of hospice use
 - Higher rates of CPR
 - Higher risk of being/dying in ICU

¹ JAMA 2004 291 (1)88-93

² JAMA 2013;309 (5) 470-477.

Barriers- Patient

- Patient Emotion (anxiety and denial) –clinicians “titrate” discussions so as not to overwhelm
 - Denial healthy if facilities adaption
 - Denial harmful when interferes with perceiving reality and engaging in an informed way with key decisions
- Patients are waiting for MD to bring this up so MD reluctance even more challenging
- Uninformed autonomy

Barriers-Physician (more common)

- Physician reluctance for well patients so delayed until no options left
 - Study showed first conv. with cancer patients happened 30 days before death¹
- Lack of training²
 - 72% nephrologists do not feel prepared to manage a pt who stops dialysis
 - 76% nephrologists were not taught how to communicate a patient is dying
- Fear of bring up emotions³
- Uncertainty- fear of harm if wrong
 - Conversations are overly optimistic and shade prognosis more favorably
- Time constraints

¹ JClin Onc 2012;30 (35) 4387-4395

² Am J Kidney Disease 2003;42(4) 813-820

³ Palliat Support Care, 2011 9(1)3-13

Barriers- System

- Opt out, not Opt-in – system oriented to life sustaining by default even though 70% patients would want less quantity over quality at EOL¹
- Few health care systems with processes and structure to assure that seriously ill patients get this important info
- Whose job is it? Ambiguity
- EHRs- where do we put it, how do we find it?

¹Med Care 2007 45 (5) 386-393

Nevertheless...we MUST press on

- Although potentially time consuming, absent, delayed or inadequate communication about EOL preferences is associated with
 - Poor QOL and anxiety
 - Family distress
 - Prolongation of the dying process
 - Undesired hospitalizations
 - Patient mistrust of health care system
 - Physician burnout
 - High costs

Improved Outcomes

- 37% cancer patients had discussed EOL issues with MD an average of 4 months before death¹
 - Better QOL
 - Received less aggressive care near death
 - Were more likely to receive hospice care
 - Families with better bereavement adjustment
- Patients who reported having an EOL conversation²
 - Were more likely to know they were terminally ill
 - Report more peacefulness
 - Desired and received less invasive care
- RCT of intervention for ACP showed pts who got intervention and died were more likely to have their wishes known and followed (86% vs 30%)³

¹JAMA 2008; 300(14)1665-1673

²J Palliat Med 2006; 9 (6)1359-1368.

³BMJ 2010; 340:e1345

No Increase in Patient Distress

- Evidence does not support commonly held belief that communication about ACP and EOL does not increase depression, anxiety or hopelessness
- Patients and families agree that false hope is not an acceptable way to maintain hope¹
- Surrogates believe having a realistic view allows them to support patient and each other better¹

¹Ann Int Med 2008;149(12)861-868

Reduction in Distress for Surrogates

- Family thrust into decisions when no documentation, sometimes without knowing preferences
- Study older adults who required decisions to be made, 70% did not have capacity to make them near EOL¹
- 1/3 of surrogates has long lasting negative consequences²
 - Stress
 - Guilt about decision made
 - Doubt about if decision was right
- When surrogates knew that decisions were what pt wanted, reduced this negative impact

¹ NEJM 2010;362 (13) 1211-1218.

² Ann In t Med 2011; 154 (5)336-346.

Reduced Costs

- Study looking at expense and EOL discussions, costs 35.7% lower in patients who reported having an EOL discussion
- Pall Care (who often has these discussions) has been shown in multiple studies to decrease costs
- Increasing practice of early EOL conversations has been proposed by experts as 1 of 5 key changes to “bend the cost curve” for oncology care

In RI

- Not a hierarchy State
- Only legally protected surrogate decision maker is a DPOA
- RI Durable Power of Attorney very important for anyone over age 18
- Revisit periodically as people's life changes
- Free and easy to use

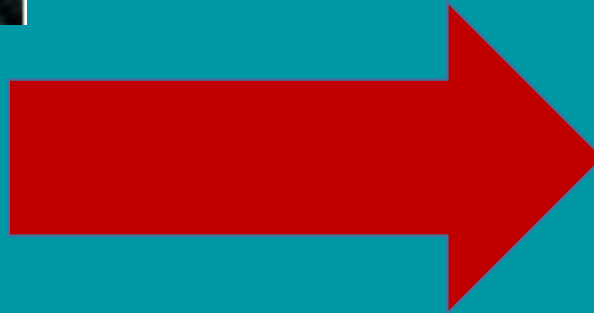
RI- MOLST State

- “Would you be surprised if this patient died in the next year?”
- Medical Order
- Must be signed by patient or their H-POA and MD/DO/RNP/PA

More than just a checkbox

- A conversation between patient and provider
- Free exchange of info
 - Patients values, priorities, understanding of illness
 - Providers sharing what is ahead with illness, likely scenarios
- Only then can we be sure we are aligning care to preferences and giving patients a real voice in this process

Communication is a Procedure



Complex Care Conversations



Complex Care Conversations

- 8hour CME/CEU Accredited
- Uses “conflict resolution” format
- Road map for a GOC conversation
- Formally elicits patient and family priorities
- Balance these with medical reality
- Small group, interactive, role playing
- Surrogate decision making, substituted judgement
- Prognostication

SIM and DOH Collaborations

- CCC funded under State Medicare Innovations Grant- goal to train 480 clinicians/year over 2 years- started 9/17
- DOH awarded CDC Grant and CCC-Cancer funded for 5 years to train 150 providers/year-starts 3/18
- Outcomes:
 - Clinicians more comfortable with conversations
 - Increased number and quality of conversations
 - Increased use of specialty palliative and hospice care

Pre-SIM Pilot-HH and Coastal

Outcome	How Measured	Result
Increased # Conversations	3 month post survey	72%
Improved Conversations	3 month post survey	61%
increased overall satisfactions caring for seriously ill	3 month post survey	81%
Pall Care Referrals Increased	By attributed Provider	23%
Hospice Referrals Increased	By attributed Provider	18%
Increased Hospice LOS	Coastal Medical Group Average at Hope Hospice	35%