End of Life Planning for Body & Spirit

Drew A Rosielle MD, FAAHPM, Medical Director of Palliative Care, M Health Fairview
Paul Galchutt MPH, MDiv, BCC, Research Staff Chaplain, M Health Fairview

SPONSORS

PARTNER

FREE WEBINAR
May 18, 2020
12:00 – 1:15 pm

Handouts: mngero.org
Type your questions during the webinar

Tweet: @mngero
Facebook: /mngerosociety

End of Life Planning for Body & Spirit

Paul Galchutt MPH, MDiv, BCC
Drew A Rosielle MD, FAAHPM
Minnesota Gerontological Society webinar May 2020
Disclosures

• We have no relevant disclosures

Objectives

• Describe an approach to end of life preparation that focuses on human connection and love, more than legalistic notions of ‘rights’ and ‘choices’
• Identify the key role health care clinicians play in end of life preparation by discussing prognosis with patients and families
A patient

- 83 year old M with HFpEF, CKD3, DM, mild cog impairment, tobacco use disorder, mild COPD.
- Divorced, lives alone in ALF. Slowly increasing frailty last few years but remains I in ADLs. Hospitalized 6 months ago with influenza and AKI, 4 weeks in TCU, returned to nearly his baseline.
- Has a HCD naming his 60 yo dtr who’s a nurse as his surrogate. Has clicked off the few boxes on MN HCD form: “if I’m permanently unconscious” “If I’m terminally ill” – don’t keep me alive.
- Now has what looks to be CAP, sepsis, resp failure, intubated, hospital day 10, “stable” but not improving. Off pressors. AKI bump but back to baseline of eGFR ~30. Delirious, not decisional.

A patient

- Review HCD:
  - Is he perm unconscious? Probably not.
  - Is he terminally ill? Not exactly.
- He’s in this different category: he is in a severe, life-threatening, high-morbidity situation
  - A “guarded” chance of surviving the hospital
  - If survives hospitalization will have a long and arduous and uncomfortable recovery to something less than current baseline
  - Low likelihood of long-term (several years) survival
A patient

• What has ‘gone wrong’ here? (Has anything ‘gone wrong’?)

• Why has his HCD not prepared us for this decision? (Is it fair to even expect HCDs to prepare anyone for such a decision?)

• What can health care professionals do to “help” prepare patients/families?

Why ACP?

• The Entirety of Human History until ~50 years ago
  – We were mostly powerless to delay death
  – Rich cultures around caring for the sick & dying, mourning
  – Medical “Paternalism”
  – No decisions to be made

• Last ~50 years
  – Massive science-driven transformation of medicine
  – Trach, vents, vents, LTACs, G tubes, dialysis, antibiotics, states of permanent unconsciousness
  – Reign of “patient autonomy”
  – Plenty of decisions!
Should we place a feeding tube in your father’s stomach?

New technology

Should we place a feeding tube in your father’s stomach?

New question
Advance care planning movement...

• Tension at its heart – what is the deep goal of ACP?
  – “Honoring Choices” “Respecting Choices”
  – Legalistic, consumerist notions of patients pre-specifying ‘choices’ about future medical care vs.….something else
  – Citizen X: at time point A, has a discussion/completes a document, and ‘decides in advance’ about medical decisions.
    o “If ABC happens, I want XYZ.”
  – Role of clinicians is passive, we apply the pre-specified “choices”; emphasis is not on clinician-patient-family discussions about their likely future

The consumerist view of ACP
Kirchhoff JAGS 2012

- 313 patients with advanced CHF or ESRD-HD
- All had baseline EOL wishes recorded for various scenarios
- Half were randomized to a ~90 min extensive, disease specific ACP intervention
- 110 died by end of study and had data (survival same in both groups)
- Data about concordance, EOL outcomes came from chart review by blinded reviewers

JAGS 2012

- 110 died (mean 1y post), 74% did not need surrogacy
- 74% intervention vs 62% control had EOL care concordant with initial wishes (P=NS); NS difference between patients who did not get what they wanted
- For CPR, 44 vs 35% had concordant care (p=NS).
- 1/3 of all patients changed minds about CPR at some point before dying
- These investigators did not look at other outcomes (suffering, qol)
Enough
THE FAILURE OF THE LIVING WILL

By Angela Fagerlin and Carl E. Schneider

In pursuit of the dream that patient autonomy of autonomy could extend beyond their span of competence, living wills have passed from controversy to conventional wisdom, to widely promoted policy. But the policy has not produced results, and should be abandoned.

By their fabric it should not bear them.

Enough. The living will has failed, and it is time to let it go.

We should have known it would fail. A notable but unsupported psychological literature always presents non-voluntary consent to expect the policy of living wills to fail. Given their evident potential, prudence would seem to require the right to expect any institution or patient who operates the living will to expect that decisions will not be made in the best interest.

The success of living wills has been minor. We find no evidence supporting their claim of being an effective way to protect the interests of all patients. We find no evidence that they are effective in accomplishing their stated goals.


RESEARCH
The impact of advance care planning on end of life care in elderly patients: randomised controlled trial

Karen M Detering, respiratory physician and clinical leader,1 Andrew D Hancock, project officer,2 Michael C Coates, project leader,3 William Silverstein, intensive care physician and director4

OBJECTIVE To investigate the impact of advance care planning on end of life care in elderly patients.

Setting Single centre study in a university hospital in Melbourne, Australia.

Participants 309 legally competent medical inpatients aged 80 or more and followed for six months or until death.

Interventions Participants were randomised to receive usual care or usual care plus facilitated advance care planning intervention. The randomisation was stratiﬁed by contact and public and private health decision-makers other than the patient

ABSTRACT

Objective To investigate the impact of advance care planning on end of life care in elderly patients.

Setting Single centre study in a university hospital in Melbourne, Australia.

Participants 309 legally competent medical inpatients aged 80 or more and followed for six months or until death.

Interventions Participants were randomised to receive usual care or usual care plus facilitated advance care planning intervention. The randomisation was stratiﬁed by contact and public and private health decision-makers other than the patient

BMJ
A collaboration among the University of Minnesota, University of Minnesota Physicians and Fairview Health Services

BMJ
A collaboration among the University of Minnesota, University of Minnesota Physicians and Fairview Health Services

BMJ
A collaboration among the University of Minnesota, University of Minnesota Physicians and Fairview Health Services

BMJ
A collaboration among the University of Minnesota, University of Minnesota Physicians and Fairview Health Services

BMJ
A collaboration among the University of Minnesota, University of Minnesota Physicians and Fairview Health Services
Melbourne RCT of ACP

- Melbourne, 309 inpatients 80+ yo
- Measured baseline “wishes” for all patients (50% would want CPR attempted; 75% wanted ongoing life-prolonging tx)
- Active patients received a comprehensive facilitated ACP aimed at values assessment, wishes for EOL care, CPR wishes, surrogate naming. Median 60 min, 1-3 visits
- Primary outcome % of patients who died (53) whose wishes were known and followed: concordance
- Outcome determined by chart review and bereaved interview

56 died within 6 months and had data
- Fewer deaths in ICU: 0 vs 4 (P .03)
- Intervention group had more ‘concordance’ but that is only because their ‘wishes’ were documented more extensively; no evidence control group wishes weren’t followed, they just weren’t documented.
- Surrogates however were much better off
  - Less anxiety and depression (HADS)
  - Less trauma symptomatology (IoE scale)
  - Reported greater satisfaction with quality of death and perception of patients’ ‘satisfaction’
The other goal of ACP – to reduce suffering

- Less a legalistic, consumerist notion of respecting ‘rights’
  - More of a clinical-therapeutic model aimed at reducing patient and family stress, suffering

- Less pre-deciding decisions
  - More giving guidance about what to expect, preparing for shared decision-making

- Goals before holes
  - [Video](https://www.youtube.com/watch?v=ezxgeghqhk)

Preparng for EOL, preparing for future decisions

- “Healthy” patients with full range of possible morbidity

- Future need for specific decisions are extremely hypothetical and provisional

- I personally don’t know how to prepare them for EOL, nor do I think there’s any research on that, nor am I sure clinicians have much of a role here

- Large cultural phenomena are important here

- Patients who have seen their iceberg

  - Relatively narrow range of future events – we know what range of medical events/decisions they are very likely to be faced with
    - Advanced cancer
    - Severe HF
    - ESKD+frailty
    - Dementia
    - Severe COPD

  - Centers the clinicians’ role in having discussions with patients about prognosis and goals, and deliberately giving patients/families guidance when they are at a crossroad
“Requires clinicians to have discussions with patients about prognosis and goals”

• This is a massive, complex challenge
• But there has absolutely been a major shift in the last decade to focusing efforts in medicine less on getting otherwise healthy adults to complete paperwork, and more to supporting “clinicians” (docs, advance practice providers, but also others – SW, nurses, chaplains) to have deliberate, ‘early’ (=before the ‘crossroads’) discussions about ‘prognosis’ and ‘goals’

“Prognosis”

• ≠ “You have 2 years to live”
• = “Given [your illness/es], I think you and your loved ones should prepare for the following…”
  – These sorts of events/decisions (hospitalization, resp failure, need for ICU care, inability to live independently, need for help with I/ADLs, cognitive failure, burdensome therapies, etc etc)
  – Preparing for the possibility (or even likelihood) of death within a certain time-frame
“Goals”

* ≠ “Do you want a feeding tube?” “Do you want CPR?”
* ≠ “What gives your life meaning?” “Who gives your life meaning?”
  - Knowing what you now know about what is likely these coming (months, years), what is most important to you? What are you hoping things will look like?
  - What things are less important?
  - What fears do you have? What worries you thinking about the future?
  - Knowing that [your health will worsen in the ways I disclosed], what sort of recovery, if it wasn’t a full one, would be acceptable to you? What would clearly be unacceptable?
  - etc

Serious Illness Care. Ariadne labs.
https://www.ariadnelabs.org/areas-of-work/serious-illness-care/

When they are at the crossroads

Stepping back from handing patients/families a menu of options: What tubes would you like today to be inserted into the dying body of your loved one?

1. Remove why the status quo isn’t working.
   ・ “It’s hard to deal with all this.”
   ・ “I can see you are really concerned about [x].”
   ・ “Tell me more about that—what are you worried about?” Is it ok for us to talk about what this means?

2. Expect emotion & empathize.
   ・ “Does this situation, what’s most important for you?”
   ・ “When you think about the future, are there things you want to do?”
   ・ “As you think towards the future, what concerns you?”

3. Map the future.
   ・ “I’ve heard you say that this is really important to you. Keeping that in mind, and what we know about your illness, I recommend that we [x]. This will help us make sure that your treatment plans reflect what’s important to you.”
   ・ “How does this plan seem to you?”

4. Align with the patient’s values.
   ・ As I listen to you, it sounds the most important things are [x,y,z].

5. Plan medical treatments that match patient values.
   ・ Here’s what I can do now that will help you do those important things. What do you think about it?

Best Case Worst Case by Dr Gretchen Schwarze et al. https://www.hipxchange.org/BCWC
A patient

• 83 year old M with HFrEF, CKD3, DM, mild cog impairment, tobacco use disorder, mild COPD.
• Divorces, lives alone in ALF. Slowly increasing frailty last few years but remains I in ADLs. Hospitalized 6 months ago with influenza and AKI, 4 weeks in TCU, returned to nearly his baseline.
• Has a HCD naming his 60 yo dtr who’s a nurse as his surrogate. Has clicked off the few boxes on MN HCD form: “if I’m permanently unconscious” “If I’m terminally ill” – don’t keep me alive.
• Now has what looks to be CAP, sepsis, resp failure, intubated, hospital day 10, “stable” but not improving. Off pressors. AKI bump but back to baseline of eGFR ~30. Delirious, not decisional.
• Family meeting. “What would he want?” Trach? “Comfort care?” Dtr is not sure what is best.

What has ‘gone wrong’ here? (Has anything ‘gone wrong’?)
• Why has his HCD not prepared us for this decision? (Is it fair to even expect HCDs to prepare anyone for such a decision?)
  – Unfair to expect a HCD to ‘help much’ here: difficult, shared decisions are still needed
  – Trach/PEG are not the most important point of discussion: long-term QOL is far more relevant, what gives this patient’s life meaning, what less-than-full recovery would be ‘acceptable’ or not?

What can health care professionals do to “help” prepare patients/families?
• Arguably this patient could have had a serious illness care discussion, so his dtr would be better prepared
  – It is an act of abandonment for us clinicians to ask patients/family members ‘what they want to do’ in these situations without adequately exploring “goals” such that we can give patient-specific guidance on the best course of action
End of Life Planning for Body and Spirit

Paul Galchutt, MPH, MDiv, BCC
Research Staff Chaplain, M Health Fairview
Convener, Hospice-Palliative Spiritual Care Research Network sponsored by Transforming Chaplaincy

Palliative - Whole Person Care: Clinical Practice Guidelines for Quality Palliative Care, 4th edition

Domain 1: Structure and process for care
Domain 2: Physical aspects of care
Domain 3: Psychological and psychiatric aspects
Domain 4: Social aspects of care
Domain 5: Spiritual, religious, and existential aspects of care
Domain 6: Cultural aspects of care
Domain 7: Care of patient at the end of life
Domain 8: Ethical and legal aspects of care
Spirituality and Religion

“Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred” (Puchalski et al, 2009; Palliative Spirituality White Paper).

Religion as “a search for the significance in ways related to the sacred” (Pargament, 1997).

Heightened Sense of Spirituality

- Stressors Pervading this Time
- The Atlantic – The Coronavirus Prayer
- Increased Attention on Chaplains

The Atlantic

Rex. Katie Rimer, left, with Rev. Johannah Murphy, says the pandemic forces chaplains “to do things differently and creatively and not perfectly.” (Courtesy Katie Rimer)
Faith Has Grown during Pandemic

24% of surveyed U.S. adults (10,139) indicate that their faith has grown during this pandemic.
(Gecewicz 2020; Pew Research)

Serious Illness

- Not only about dying/death, but...
- Death awareness
  - Nine Contemplations by Atisha; Roshi Joan Halifax of Upaya Zen Center
  - 1st Contemplation – “Death is inevitable. No one is exempt. Holding this thought in mind, I abide in the breath.”
- Heightened sense of our mortality, impermanence, transience
- Increases our sense of vulnerability/strength
Planning: Looking to the Future

• Remembering (Past):
  • “People remember by telling stories of times past, but they tell in response to the needs of the reassembly at the time when the story is told” (Frank, 2010).

• Sense-Making (Present):
  • “Making sense of the disruption restores a sense of order and coherence to her life” (Becker, 1997).

• Imagining Possible (Future):
  • “…our possibilities are always possibilities within a particular situation, and our sense of them keeps shifting” (Meretoja, 2017).

Conversation, Story, and Planning

“Conversation is a process of coming to an understanding” (Gadamer, 2004; original 1960).

“The power of stories is the problem with stories: they are far too good at doing what they do, which is being the source of all values” (Frank, 2010).
Advanced Care Planning

- Honoring Choices®
- The Conversation Project
- Angelo Volandes, MD – *The Conversation* (2015)
  - Life-Prolonging Care: Prolong life at any cost.
  - Limited Medical Care: Maintain functioning, but don’t escalate care.
  - Comfort Care: Maximize comfort and relieve pain.

Advanced Care Planning Research Using Go Wish™ Game

Randomized Controlled Trial - 100 advanced cancer patients
MD Anderson Cancer, Delgado-Guay et al (2016)

Results:
To be at peace with God (74 vs. 71 %)
To pray (62 vs. 61 %)
To have family present (57 vs. 61 %)
To be free from pain (54 vs. 60 %)
A Case: Keith Simons

- 59 years old, husband, father
- Director for a local non-profit, entrepreneur, college/professional athlete
- Christian faith
- Fiercely loved life, his family, the people he supported and helped

- Enrolled in a clinical trial: “I’m not ready to die.”
- Completed trial. Brief benefit. Cancer spread: “I don’t think it is in me to do more chemo.”

Galchutt (2020)

Providers and Types of Spiritual Care during Serious Illness

n = 103; identified 237 spiritual care providers

41% family or friends
29% health care providers
17% clergy

(Hanson et al, 2008)
Spiritual Care: Outcomes

Provision of Spiritual Support to Patients With Advanced Cancer by Religious Communities and Associations With Medical Care at the End of Life (Balboni, T et al, 2013)

“Spiritual care and EoL discussions by the medical team may reduce aggressive treatment, highlighting spiritual care as a key component of EoL medical care guidelines.”

Provision of Spiritual Care to Patients With Advanced Cancer: Associations With Medical Care and Quality of Life Near Death (Balboni, T et al, 2010)

“Support of terminally ill patients’ spiritual needs by the medical team is associated with greater hospice utilization and, among high religious copers, less aggressive care at EoL. Spiritual care is associated with better patient QoL near death.”

Spiritual Care: When It Is Most Intense

- Health Care Professionals’ Responses to Religious or Spiritual Statements by Surrogate Decision Makers During Goals-of-Care Discussions (Ernecoff et al, 2015)
- 13 ICUs across the United States
- 249 Goals of Care (GOC) conversations
- 651 surrogate decision makers; 441 healthcare professionals
- Conversations were audio recorded (457 used)
- An Objective: “...how frequently surrogate decision makers and health care professionals discuss religious or spiritual considerations during family meetings in the intensive care unit...”
Poll

What percentage of the surrogate decision makers endorsed religion or spirituality to be fairly important or very important in their lives?

a. 46%
b. 57%
c. 65%
d. 78%

Results

• **R/S Importance**: 457 surrogate decision makers, 355 (77.6%) endorsed religion or spirituality as fairly or very important in their life.

• **Prevalence During Care Conference**: Discussion of religious or spiritual considerations occurred in 40 of 249 (16%) conferences.

• **First to Initiate During Care Conference**: Surrogates were the first to raise religious or spiritual considerations in most cases (26 of 40).
Spiritual Pain & Meaning for the Body

Spirituality, Religiosity, and Spiritual Pain in Advanced Cancer Patients; Delgado-Guay et al (2011)

- n = 100; 98% religious; 98% spiritual
- Spiritual pain: 44% of sample
- Spiritual Pain Def: “A pain deep in my soul (being) that is not physical.”
- “Patients with spiritual pain...contributed adversely to their physical/emotional symptoms.” (next slide)
Whole Person: Body & Spirit Connection

“...narratives are efforts to give meaning to, or find meaning in, bodily dysfunction and thereby to relieve suffering. People who narrate their illness or disability may be said to share their bodies with others in a kind of secular healing ritual” (Couser, 1997).

References


References


Q and A

Drew A Rosielle MD, FAAHPM, Medical Director of Palliative Care, M Health Fairview

Paul Galchutt MPH, MDiv, BCC
Research Staff Chaplain, M Health Fairview
Questions or Comments:

contact info@mngero.org

Next Webinar: June 11, noon - 1:15 pm

Telemedicine for Physical and Mental Health: Lessons Learned from the Pandemic

Roberta Meyers, MD, Hennepin Healthcare;
John Brose, PhD, LP, LADC, LMFT, Founder, CEO,
Associated Clinic of Psychology