Observations and Suggestions for Research: Session 2

David Magnus, PhD and Neil Wenger, MD
Observations

• Natural experiment with nearly identical interventions variably implemented in divergent populations
• How to evaluate a paradigm shift that is an anathema to some and essential to others?
• PAD raises questions that can create skepticism about current practices
  • Certainty about capacity and undue influence in withholding and withdrawing decisions
  • Evenhandedness and conflicts of interest in treatment decisions
  • General approach toward persons with disabilities
  • Focusing on the medical model rather than social determinates
Observations (*cont.*)

- The PAD request is powerful
  - Stimulates a cascade of communication and intervention that appears missing in routine care
- Existence of PAD has broad reaching effects
  - Much attention and resources despite few patients
  - Might enable other discussions about advance care planning and palliative care
- Scary slippery slope
Areas for Future Research: Impact of expansion

• What impact would expansion of PAD in different dimensions have?

• Expansion to minors
• Expand or eliminate “terminal” requirement
• Eliminate self administration requirement
• Allow AHCD process
Future Research: Understanding the benefits and burdens of the lawful process

• What harms occur because of the fracturing of continuity as a result of physicians or institutions opting out?
• Impact of medication challenges, especially as medications for PAD are changing (issues of cost, logistics and side effects)
• Impact of 15 day time delay and other logistical barriers to access
• Impact of not allowing family to be present for the private conversation
Future Research: Ancillary Impact

- Qualitative data suggests positive impact on communication in the Netherlands and individual narratives of clinicians
  - Is this finding applicable in the U.S.?
  - Can the impact on clinical care beyond those who receive PAD be measured?
  - Does PAD improve or decrease EOL care generally?

- If there is something about PAD and other similar practices that leads to increase in resources, time, communication, etc., what is it about PAD that causes this result?
Future Research: More/better data on alternatives

• Proportional palliative sedation
• Palliative sedation to unconsciousness
• VSED

• How are these being used? What are the policies and practices governing their use? What are the implications?
Future Research: Impact on Disabled

• Need for better data about views of disabled community
• Need for better data about PAD among patients with disabilities
  • Are patients not getting access to PAD who otherwise would?
  • Are patients getting access to PAD who otherwise would not?
  • Is there evidence that PAD is having ancillary negative impacts on care for disabled patients?
Future Research: Culture Change

- To what extent has long term legalization in Oregon changed the nature of perceptions about the moral dimensions of PAD?
- What are the effects on clinicians who participate and those who do not?
- What are the effects on institutions that opt in or opt out?
Future Research: Developing Best Practices

• What mechanisms exist to support providers in carrying out PAD? Which practices and policies in this area work best?

• What other differences in policy and implementation exist? What works best?
  • Mandatory psych screening
  • Mandatory role for palliative care
  • Mandatory role for ethics
  • Mandatory navigation

• To what extent do participating institutions believe they have an obligation to identify a provider if a patient’s physician chooses not to participate? How is this obligation carried out?
Proposal: Case controlled trial

• Natural experiment: some states permit Aid-in-Dying, some do not

• Identify patients with terminal conditions wanting Aid-in-Dying across three states permitting and not permitting Aid-in-Dying
  • Stratify by healthcare organizations opting in/opting out

• Evaluate the end of life care received by patients and effect on family and clinicians
  • Patient symptoms, hope, depression, anxiety,
  • Bereaved family survey,
  • Course of treatment, mortality, goal concordant care
  • Physician outcomes