

Observations and Suggestions for Research: Session 2

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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
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- 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