

Aid in Dying and End of Life Options: Chaplaincy Practice in States where Physician Assisted Dying is Legal

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Aims for Presentation

- Present key points from literature review about *spiritual needs* of people interested in physician assisted dying.
- Present practices of chaplains in states where this is legal through clinical vignettes.
- Identify and explore ethical principles, issues and opportunities for spiritual care.
- Learn and practice a model for assessing and addressing spiritual needs with patients who express interest in this option.

Brief Overview of Literature – Spiritual Needs & Chaplain Practice

- Overview of laws in California and Oregon
- Basic cultural and socio economic statistics
- Relationship between PAD and palliative care; opens the discussion; “on the spectrum of interventions”
- Some spiritual considerations:
 - Myths and facts about people having the “option” but not ultimately committing the act
 - Lack of access to adequate palliative care and psychosocial, spiritual support services drives many people to seek this option
 - Spiritual and existential suffering may be disguised; anxiety and fear about pain and dignity/worthiness as spiritual issues to be explored by chaplain
 - Role and concerns of families
 - The fact that many patients choose to raise this with the chaplain suggests the inherent spiritual nature of this decision
 - Moral and theological beliefs (of everyone involved); particularly related to “suicide”

Spirituality as PAD Predictor

- “Results. We found that PAD requesters had higher levels of depression, hopelessness, and dismissive attachment (attachment to others characterized by independence and self-reliance), and lower levels of spirituality. There were moderate correlations among the variables of spirituality, hopelessness, depression, social support, and dismissive attachment. There was a strong correlation between depression and hopelessness. **Low spirituality emerged as the strongest predictor of pursuit of PAD in the regression analysis.**”

Predictors of Pursuit of Physician-Assisted Death, Smith, Kathryn A. et al. Journal of Pain and Symptom Management, Volume 49, Issue 3, 555 - 561

Vignettes Based on Literature & Our Clinical Experiences

Break out into groups of ~3 people to discuss the following vignettes. Here are some questions to guide your conversation:

- 1) What are the spiritual needs that you would screen and assess in this situation?
- 2) As the chaplain, how would you respond to the patient? What, if any, outcomes would you be looking to achieve?
- 3) What are your personal reactions, feelings and concerns? How do you feel about us asking you about your personal reactions?

Vignette #1: Setting - Home Hospice

James is an 89, year-old man living at home with end stage Lymphoma disease. He has declined in his ability to take care of himself and now spends all of his days in bed, without adequate care. He had a fall two weeks prior, while attempting to reach the bedside commode and was traumatized about his physical limitations. After many months of hospice care, he finally admits to the team that he is unhappy and expresses suicidal ideation during a social work visit. He states that he wants to take his life and has no desire to continue living as he has. He wishes to talk with someone about PAD and feels it is his only viable option. The team intervenes.

Vignette #2 - Setting: Outpatient Palliative Care

Mr. P is a 45 year old man with lung cancer. He emigrated to the US from Vietnam about 20 years ago. He attends a Catholic Church but has not told his priest or community about his illness because he wishes to keep the information private. He is married and has two school age children. In his second visit with outpatient palliative care, he tells you and the doctor that he is in severe, uncontrolled pain and experiencing other symptoms related to disease progression and treatment. He worries incessantly that he is burdening his family and hides at home so that his children can concentrate on their studies and, he believes, not see him in pain. He states that he is interested in pursuing the End of Life Options Act.

Working Within Institutional Policies – Providence as Case Study Example

- Providence operates within the parameters of the Catholic Healthcare Directives and is doctrinally against PAD as is the Catholic Church. We are created in the image of God and therefore possess intrinsic dignity. Taking life in any way goes against the sanctity of life.
- We have a moral obligation for self-preservation due to our intrinsic dignity. We do not get to “play God.”
- We have the right to be fully human, this includes living with sickness and death. What does it mean to be fully human? It means that we should be able to live out all aspects and stages of life. The dying process is one of the stages.
- Essential to have clear communication with patient that we are not able to participate. Are able to provide neutral resources for patients to consult with, but that is the extent.
- Concern about ‘material cooperation’-presuming the immorality of PAD, clinicians have concerns about participating in any way in the process that leads to discernment to utilize PAD. This can get blurry for different clinicians and make it stressful to even have a conversation with patients

UC San Diego Health as a Case Example

- Role of Ethics Committee
- Role of psycho social spiritual caregivers
- Policies and protocols

Ethical Issues and Opportunities

- Autonomy, beneficence, non-maleficence, justice
- Moral distress of caregivers
- Discussion about engaging with institutional procedures, obstacles and opportunities
- Reflections about working as chaplains in states where PAD is legal

Ethical Principles and Chaplaincy Standards

- Function in a manner that respects the physical, emotional, cultural, and spiritual boundaries of others.
- Use ones' professional authority as a spiritual care provider appropriately.
- Advocate for the person's in one's care.
- Formulate and utilize spiritual assessments, interventions, outcomes, and care plans in order to contribute effectively to the well-being of the person receiving care.
- Promote, facilitate, and support ethical decision-making in ones' workplace.
- Incorporate a working knowledge of different ethical theories appropriate to one's professional context.
- Articulate an approach to spiritual care, rooted in one's faith tradition that is integrated with a theory of professional practice.
- Be self-reflective, including identifying one's professional strengths and limitations in the provision of care.

Presenters' Reflections

- How do our faith backgrounds and communities play into our chaplaincy practice? Must we get clear about our own theological/ethical position on PAD? How do we hold this?
- Where do our understandings of religious/spiritual context intersect with the needs and wishes of those we serve? How do we handle moral distress if there is a conflict with our own faith background? What is the appropriate response, if any?

REST Model for Assessing & Addressing Spiritual Needs for Patient Interested in PAD

Receive

- Request from patient or referral from team
- Review patient's medical record for pertinent background information

Explore

- Use genuine pastoral curiosity
- Fears and assumptions about unmanaged physical, psychosocial spiritual symptoms and dying process
- Experiences they have had with other people dying

Support patient by

- Screening for religious and spiritual resources, community, clergy; etc. Encourage those to be brought in.
- Exploring patient's family's awareness of their interest in PAD

Team

- Ensure education and advocacy for excellent palliative care
- Facilitate conversation with team – ask “dumb” questions on behalf of patient

Roleplays

- Break up into groups of two and practice using the the REST Model.
- Each person will have two minutes to practice responding to the request for PAD.

Reflections from Roleplays & Open Discussion

- What did you find most difficult about the roleplay?
- What thoughts and feelings were you aware of while doing the roleplay?
- How can you apply this model to your work with patients?
- What limitations do you see in this model?

Resources Consulted

Articles

Carlson B, Simopolous N, Goy ER, Jackson A, Ganzini L. Oregon hospice chaplains' experiences with patients requesting physician-assisted suicide. *J Palliat Med*. 2005;8(6):1160-1166.

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Websites

<https://www.compassionandchoices.org/wp-content/uploads/2016/02/FS-Medical-Aid-in-Dying-Improves-Care-at-the-End-of-Life-FINAL-2.2.16-Approved-for-Public-Distribution.pdf>

<https://www.deathwithdignity.org>