

Perspective from a non-prescribing
palliative care physician from a state
where PAD is legal

**Panel #2: Potential Approaches for Handling
Requests**

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My main points

- The goal, of course, is to maintain the ability to care for patients whether they are for or against physician aid in dying
- Clinicians should never suggest physician aid in dying as an option
- Many health systems automatically opt out
- The necessity of respecting individual health professionals' right to not be involved means accessibility is highly dependent on health professionals' personal stance

Some challenges for palliative care

- Goal: To be able to care for all patients, regardless of how they feel about physician aid in dying.
 - Shouldn't palliative care be a resource for cases where prognosis or decision making capacity are not clear cut?
 - How to ensure your service can be seen as a resource to patients (and referring clinicians) who are adamantly opposed?
 - How important is it to keep palliative care and physician aid in dying separate in the minds of clinicians and patients & families?

In urban areas access limited

- In Portland, the 3 faith-based health systems, the VA, and many smaller MD groups adopted policies that forbade MDs to prescribe
 - Intentionally or not, this also inhibited open discussion
- Forces patients to abandon their request or seek care from the 2 health systems who had not forbidden prescription

One Oregon health system has changed over time

- 1997: "neither encourage nor discourage" participation under the Death with Dignity Act.
 - System physicians could not prescribe the end-of-life medications for qualified patients, nor could they act as the second-opinion consultant or refer patients
- 2004, policy updated to allow physicians to refer patients to other resources and to act as consulting
- 2018, system physicians allowed to prescribe end-of-life medications
 - "...providers felt forced to abandon patients at their greatest time of need, often after a long and difficult medical journey."

In rural areas, access unclear

- Rate of requests low, no access to specialty palliative care
- Many hospice organizations adopted policies to not participate
- Physicians in rural communities reported unwillingness to get involved because of concerns they would alienate some in their community

An opportunity for palliative care

- Ethics leaders in Oregon used the physician aid in dying statute to leverage institutions to invest in palliative care
 - “What do you want to be known for?”

Handling requests: organizational challenges

- Tension between non-encouragement and non-abandonment
- Health professionals should never suggest physician aid in dying as an alternative
 - One of the state's most vocal opponents claimed his activism was triggered by wife's MD's suggestion that she had the option of pursuing physician aid in dying
 - Health plan wrote a letter (2008) denying patient (1) Barbara Wagner Tarceva for lung cancer "...but that it would cover palliative, or comfort, care, including, if she chose, doctor-assisted suicide". (1)

(1) <http://www.pccef.org/latestnews/index.htm>

Handling requests: organizational challenges

- Many physicians are unwilling to prescribe or to be involved as consultants
- Many physicians are undecided awaiting their first request
- Others are willing or not in 4 areas

	Own patients	Any patient
Willing to consult but not prescribe	Y/N*	Y/N
Willing to consult or prescribe	Y/N	Y/N

Initially managed by Patient Advocate Office

- Handled calls from patients outside system
- Helped patients navigate system, including helping them find a prescribing physician
- Helped ensure reporting requirements were met
- Process should not, but was highly dependent on individuals' personal stance
 - Worked because the patient advocate felt strongly that her office's involvement was in-scope

One large clinic's solution

- Clinicians responded to a semi-anonymous survey to indicate their willingness to consult and prescribe for their own and others' patients
 - Social workers and clinic leadership had access to results
- Requests were triaged to social workers who new individual MD attitudes and could help patients navigate
- SW's instructed to inform patients that it was their (the patients') responsibility to drive the process, we would not 'nag' them.

Handling requests: organizational challenges

- This needs to be, and should be a patient-driven process, but the complexity of navigating a health system to access physician aid in dying creates an major hurdle and an access disparity

My experience with handling refusals

- Prognostic uncertainty puts clinicians in vulnerable position – how certain do you have to be?
- No one ever evinced lack of respect for life.
- Patients uniformly respect clinician's personal moral boundaries about participation
 - For patients trying to find a prescribing or consulting MD, it's important for them to be told up front so they don't waste their time

My experience with handling refusals

- Patients who are not thought to be terminally ill are anxious, but willing to wait
- Patients who don't qualify because they do not, or will not have decision making capacity are angry
 - Rarity of psychiatric referral reflects that the requests are never frivolous, never poorly thought through.
 - Patients seem coached not to endorse depressive or anxiety symptoms

A few points

- Many patients who want physician aid in dying do not want to be taken care of, they don't want to *need* to be taken care of
- Studied neutrality seems impossible with such a polarizing topic.
 - Many people's strong opinions about physician aid in dying are uninformed by experience.
 - Experience leads to a position of involved ambivalence.

Two groups of patients who got prescriptions require very different approach

- Patients who'd made up their minds and just wanted a prescription
 - Most got prescription and took it
- Patients who worry the dying process will be overwhelming and want to cover their bases
 - Many got a prescription, many did not take it, some waited until it was too late

Assessing the quality of conversations is difficult

- Qualitatively it's easy to tell a good conversation from a poor one
- Quantitatively it's impossible
 - Can measure presence or absence of different elements, proportion of talking vs. listening, etc.
 - Do patients feel 'heard and understood'?