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

Panel #2: Potential Approaches for Handling Requests

Erik K. Fromme, MD
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

https://www.compassionandchoices.org/find-care/#find-care-tool
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

<table>
<thead>
<tr>
<th>Own patients</th>
<th>Any patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Willing to consult but not prescribe</td>
<td>Y/N*</td>
</tr>
<tr>
<td>Willing to consult or prescribe</td>
<td>Y/N</td>
</tr>
</tbody>
</table>
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’?

Gramling R. J Pain Symptom Manage. 2016 Feb;51(2):150-4