Patient, Family & Clinician Experiences with PAD

Helene Starks, PhD MPH
University of Washington School of Medicine
Associate Professor, Bioethics & Humanities
Director, Metrics, Quality & Evaluation Core,
Cambia Palliative Care Center of Excellence
tigiba@uw.edu
Insights into Hastened Deaths Study

- Funded by Greenwall and Walter & Elise Haas Foundations
- 1996-2001
- 35 families in WA & OR
- First longitudinal narrative study to gather patient & family experiences where it was (OR) /was not legal (WA)
Motivating factors for requests

- Illness-related experiences
  - Feeling weak, tired and uncomfortable
  - Pain and/or side-effects of pain medications
  - Loss of function

- Sense of self
  - Loss of sense of self
  - Desire for control

- Fears about the future
  - Fears about future quality of life and dying
  - Negative past experiences with dying

Timing & Circumstances of Death

Not recognized by others as dying but suffering just the same

“What her symptoms were unrelenting and she was at the beginning of a long downhill slope.”

Looming crisis

“She feared she wouldn’t be able to follow through with her plan.”

Dying but not fast enough

“I’m just sick and tired of being sick and tired.”

Dying and done

“What, this is it. I can’t do it anymore.”

Terminal decline

> 6 months

1-6 months

Estimated prognosis at the time of hastened death

1-4 weeks

<1 week

Family Involvement

- Accepted different levels of responsibility
  - Planning & logistics with acquiring information & medications
  - Being present at the death
  - Mixing and administering medications
  - Implementing back-up plans

- Felt isolated & ill-prepared

- Illegality did not prevent involvement
  - Barriers to obtaining quality information, care, and support
  - Families on uncertain legal and moral ground

Death Studies, 2007; 31(2)105-130
End of Life Option Act at 1 Year
2017-2018, 21 families in CA

Funded by California Health Care
& Stupski Foundations

- Judy Thomas, JD
- Neil Wenger, MD
- Cindy Cain, PhD
- Barbara Koenig, PhD
- Helene Starks, PhD MPH
- Lindsay Forbes
- Cristina Nigro, MS PhD(c)

Aim 1: Host a main convening
of 120 California stakeholders
(Sept 25-26, 2017)

Aim 2: Develop and administer
a survey of health care systems,
institutions and providers

Aim 3: Conduct an interview
study with ~20 participant triads (patient, family member, providers)
Progress to Date

Enrolled Participants
Total Families: 21

12 Retrospective (family only, recruited after the patient’s death)
9 Prospective (includes patient)

Participating Physicians: 25
11 Attending (1 involved w 7 pts)
14 Consulting (1 also was attending)
1 Psychiatrist

- 7 Health Systems & 4 Community/Specialty Practices
# Patient Characteristics (n=21)

<table>
<thead>
<tr>
<th>Age (yrs, mean [range])</th>
<th>74.0 [37-90]</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female (n, %)</td>
<td>13 (62%)</td>
</tr>
<tr>
<td>Patients’ Primary Diagnosis (n, %)</td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>15 (71%)</td>
</tr>
<tr>
<td>Neurologic</td>
<td>3 (14%)</td>
</tr>
<tr>
<td>Organ failure</td>
<td>3 (14%)</td>
</tr>
<tr>
<td>AID Medications (n, %)</td>
<td></td>
</tr>
<tr>
<td>Still alive</td>
<td>5 (19%)</td>
</tr>
<tr>
<td>Used medications</td>
<td>14 (67%)</td>
</tr>
<tr>
<td>Too sick to complete process</td>
<td>1 (5%)</td>
</tr>
<tr>
<td>No willing provider</td>
<td>2 (10%)</td>
</tr>
</tbody>
</table>
Prescriptions (n=18)

**Seconal** (n=13, 72%)
- Average cost = $3,045 (Range $650 - $4,700)
- Time from ingestion to death = 26 minutes (Range 3 – 150)

**Other Drugs** (n=5, 28%)
- Average cost = $350 (Range $150 - $550)
- Time from ingestion to death = 28 minutes (Range 10 – 45)
Accessing Willing Providers

- **Navigators = key**
  - Find willing providers when patient’s primary team opts out
- **1 Request Not Heard**
  - When went for 2nd request, was too late in the illness trajectory

- **Accessed specialty practices because no willing provider in house or because in house process was too slow**
- **All outside pt’s health system**
- **No willing providers**
  - N=2 (10%)
  - N=5 (24%)
  - N=3 (14%)
- **All in pt’s health system**
  - N=11 (52%)

- **Insiders usually consulting MD**
- **Mixed in & outside pt’s health system**
- **Couldn’t confirm prognosis**
  - N=2 (10%)

- **Accessed Willing Providers**
  - N=5 (24%)
  - N=2 (10%)
  - N=3 (14%)
  - N=5 (24%)
  - N=3 (14%)
  - N=11 (52%)
I’d put in all this time with these doctors, thinking that they were going to be making the decision and I find out that they were not able to at all. And then I talked to {social worker} a day or two later and she tells me that she thought that the doctor who told me originally that he would be attending me could not sign the papers and she thought probably my case would go along, but that there might be some delays and she wasn't sure. Sometimes people had to wait a while.

At this point I was very confused.
Honesty about participation

Patients want providers to be honest about participation

Some providers took weeks to months to decide if they would participate

Wait time was very stressful and anxiety provoking for patients

Let your patients know that you’re either on board or not on board and then they would know, instead of being frustrated and trying to jump through hoops. Instead of putting it off.

[It took 2 months.] We had problems with her primary doctor going back and forth saying she was going to do it, not going to do it. ...she says, “okay, we’re going to get this for you and then we’re going to get this figured out” and then another two weeks would go by, and then we would call and they wouldn’t return our calls.
Family members did most logistics = “project manager”

More information needed about preparing medications

I wish somebody had said, it’s not easy to empty 100 Seconal capsules, that it’s like emptying baking soda, and there’s 100. ... It takes longer than 15 minutes.

We had all four of us doing it. ... And I’m glad we [did] because it took nearly 27 minutes to get those 90 pills opened and, you know, get all the powder off and shake it off. Again, we didn’t know like if we left too little powder or if we left, you know -- so you’re kind of going for -- we don’t know what to do.
On the day of death being “project manager” making sure everything went according to plan

- Meant that family missed out on some of the precious last moments

I wish I could say it was a special time because I almost feel like I got cheated out of that special time.

The other people in the room, they all felt it was a special time for them. But for me, because I was so worried about helping him administer the medicine, it was more stressful for me.

I feel like I got cheated out of his last couple minutes because I was helping him with the medicine.