

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)

Clinician-Patient Interactions About Requests for Physician-Assisted Suicide

A Patient and Family View

Arch Intern Med, 2002; 162(11):1257-65.

Anthony L. Back, MD; Helene Starks, MPH; Clarissa Hsu, PhD; Judith R. Gordon, PhD; Ashok Bharucha, MD; Robert A. Pearlman, MD, MPH

The Pursuit of Physician-Assisted Suicide: Role of Psychiatric Factors

J Pall Med, 2003; 6(6):873-83.

ASHOK J. BHARUCHA, M.D.,¹ ROBERT A. PEARLMAN, M.D., M.P.H.,²⁻⁶ ANTHONY L. BACK, M.D.,²⁻⁴ JUDITH R. GORDON, Ph.D.,^{7,8} HELENE STARKS, M.P.H.,^{5,9} and CLARISSA HSU, Ph.D.^{7,10}

Motivations for Physician-assisted Suicide

Patient and Family Voices

J Gen Intern Med, 2005; 20(3):234-39.

Robert A. Pearlman, MD, MPH,^{1,2,3,4,5} Clarissa Hsu, PhD,⁶ Helene Starks, MPH,⁴ Anthony L. Back, MD,^{1,2,3} Judith R. Gordon, PhD,⁷ Ashok J. Bharucha, MD,⁸ Barbara A. Koenig, PhD,⁹ Margaret P. Battin, PhD¹⁰

Why Now? Timing and Circumstances of Hastened Deaths

J Pain Symp Man, 2005; 30(3):215-26.

Helene Starks, PhD, MPH, Robert A. Pearlman, MD, MPH, Clarissa Hsu, PhD, Anthony L. Back, MD, Judith R. Gordon, PhD, and Ashok J. Bharucha, MD

FAMILY MEMBER INVOLVEMENT IN HASTENED DEATH

HELENE STARKS, ANTHONY L. BACK, ROBERT A. PEARLMAN, BARBARA A. KOENIG, CLARISSA HSU, JUDITH R. GORDON, ASHOK J. BHARUCHA

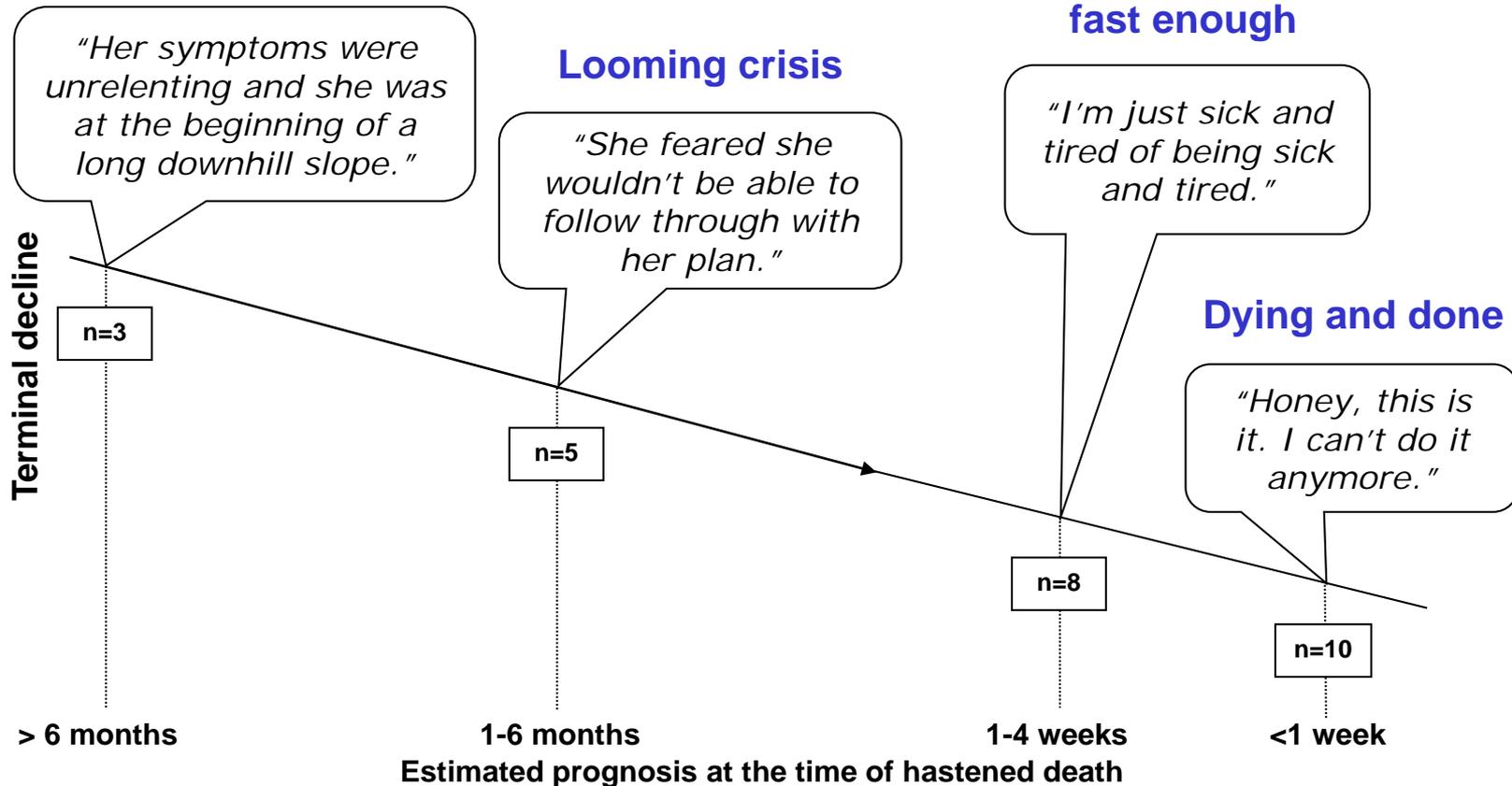
Death Studies, 2007; 31(2):105-130.

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



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

End of Life Option Act at 1 Year 2017-2018, 21 families in CA

Funded by California Health Care
& Stupski Foundations

- Judy Thomas, JD



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

- Neil Wenger, MD
- Cindy Cain, PhD



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

- Barbara Koenig, PhD
- Helene Starks, PhD MPH
- Lindsay Forbes
- Cristina Nigro, MS PhD(c)



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)

Age (yrs, mean [range])	74.0 [37-90]
Female (n, %)	13 (62%)
Patients' Primary Diagnosis (n, %)	
Cancer	15 (71%)
Neurologic	3 (14%)
Organ failure	3 (14%)
AID Medications (n, %)	
Still alive	5 (19%)
Used medications	14 (67%)
Too sick to complete process	1 (5%)
No willing provider	2 (10%)

Prescriptions (n=18)

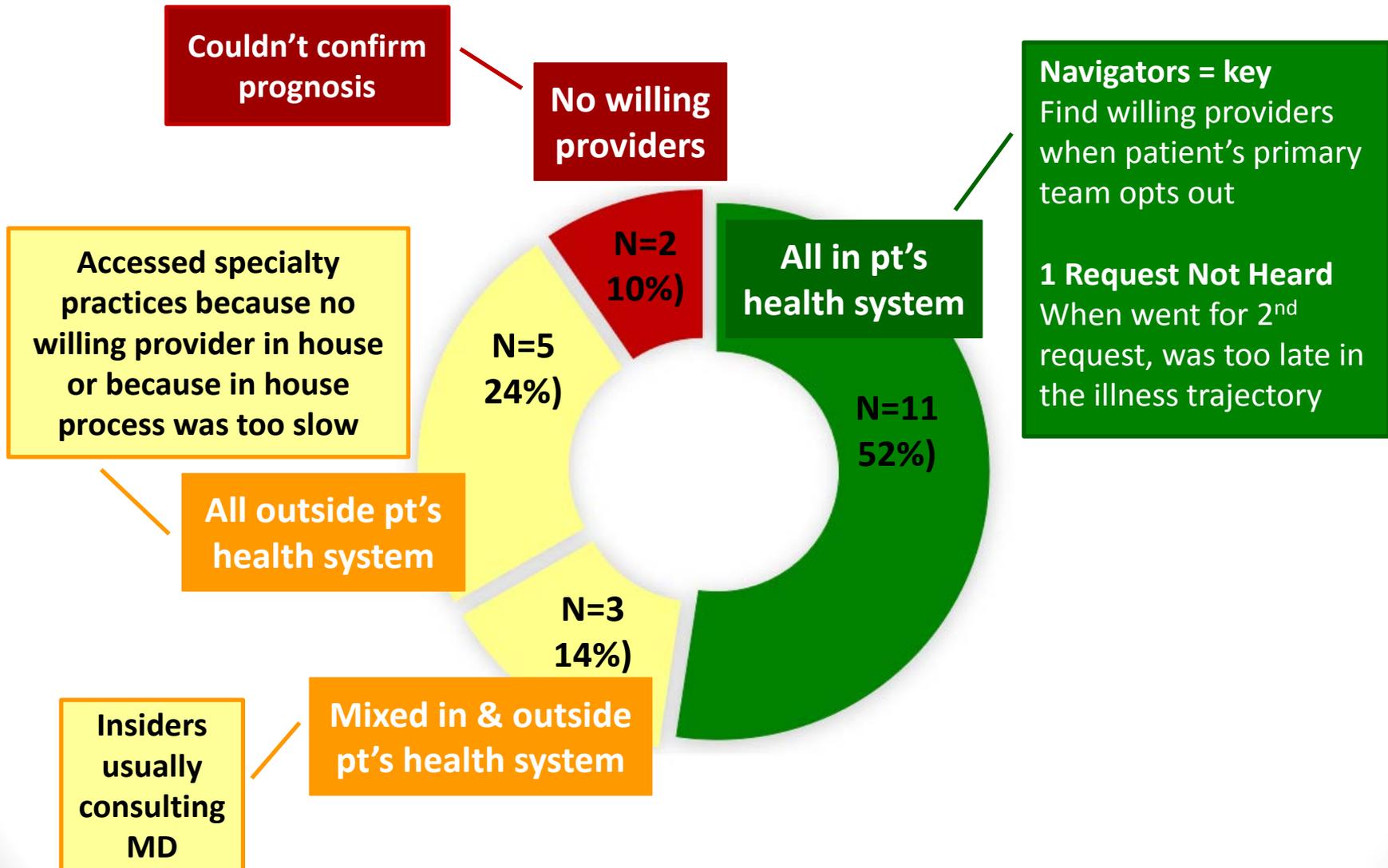
Seconal (n=13, 72%)

- 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



Process takes time

**Few evaluations
completed
in 15 days**

**Exception: when
PAD specialists
are the attending**

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 support

**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.

Family experience

**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.