

Requests for Physician Hastened Death: A Palliative Approach

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Objectives

- To review the context and some of the issues from a palliative care perspective
- To review the literature re desire to die statements and requests for hastened death
- To propose an approach for responding to requests for hastened death with an integrated palliative approach to care

Current context

In BC: 38% of health care spending is in last year of life.

- Greatest expenditures: Associated with hospital based intensification of care.
 - Also associated with the greatest suffering; least quality; and negative health outcomes for bereaved family
- Palliative Care often introduced too late or not at all
 - Access to specialized Palliative care ~20% of dying
 - Limited support in rural or remote areas;
- Minimal supports “upstream” - limited out-patient options except in cancer; or bereavement supports

Language issues

- Canadian Society of Palliative Care Physicians: Propose Physician Hastened Death (PHD):
 - Physician administered PHD = Euthanasia
 - Patient administered PHD = Physician Assisted Death
 - Most of the public does not understand issue
- Palliative Care community world wide:
 - PHD does NOT belong within Palliative Care (PC):
 - WHO definition: PC is an approach to care which neither hastens or prolongs dying
 - Access to Palliative Care is the main issue
 - Current PC options (including Palliative Sedation) would alleviate most suffering

Palliative Approach to Care

Palliative approach to care : From diagnosis

- Person-centred, evidence informed care
- Support to “live as well as you can for as long as you can” while regarding dying as a normal process
- Excellent communication skills
- Provision of roadmap -> less use of aggressive therapies: Improved outcomes

End of Life Care

End of Life Care:

- Administratively: All care in last year of life
 - In BC - Palliative dataset project: In 2012: 20% of those who died had access to specialized palliative care services; 30% other access; 50% no access
- In Palliative approach to care EOLC often refers to the last weeks of life

Legal Context:

Autonomy & Consent in Canada

- With **informed consent** a patient or a legally appointed substitute decision maker can decide not to start (withhold) or to withdraw treatment(s)
 - In BC this can be documented in an Advance Directive if there is a durable intent to refuse a given treatment
 - Palliative Sedation can control refractory symptoms /suffering in the last days of life & does not hasten death
- Consent is required prior to initiating a palliative course of treatment (Ontario: Rasouli)

Desire to die & Requests for Hastened Death



Death with Dignity Program: Seattle Washington Cancer Centre

- Over 2.5 years: 114 pts enquiries
 - 38.6% did not pursue the program
 - 26.3% initiated but did not continue or died naturally
 - 35% received prescriptions
 - 60% died by lethal doses of secobarbital(**21% of total**)
- Typically white, male, and well educated
 - 9% lived > 6 months after prescription receipt but 82% still ingested lethal prescription
- Most common reasons:
 - Loss of autonomy (97%); inability to enjoy activities (89%); loss of dignity (75%)
 - 22% reported uncontrolled pain or concerns of future pain

Reasons for requesting DWD (Oregon)

	2010	13 Yr
▪ Losing autonomy	94%	91%
▪ Less able enjoy activities of life	94%	88%
▪ Loss of dignity	78%	84%
▪ Loss bodily function	46%	56%
▪ Burden	26%	35%
▪ Pain (Present or future concerns)	15%	21%
▪ Financial	1%	3%

Guirimand. BMC PC 2014 13:53

81 bed PC hospital: All admits during 2010–11 2157 pts

- 9% (195) had some expression of a Wish to die:
 - 6% (119) expressed an interest in dying but did not want any action taken
 - 3% (61) expressed an interest in Euthanasia;
 - In 6 (0.3%) this was persistent. All had poorly controlled symptoms.
 - 1% (15) described suicidal thoughts;
- Conclusion: Low incidence of requests for Euthanasia
- Expression of a wish to die = good communication /trust between the patients and the care teams.
 - Required additional attention to the individual, their suffering & the context of care

Desire for Death in Canada

377 Canadian cancer patients; 8 palliative care programs

- 69.5% no desire for death
 - 20.2 % met criteria for a psychological disorder
- 30.5% desire for death: 18.3% transient thoughts
- **12.2% apparently genuine desire to die**
 - **52% met DSM-IV criteria for depression or anxiety; 47.8% no mental illness**
 - *Only 39% would opt for euthanasia*

Wilson KG et al BMJ Supportive and Palliative Care 2014

- Studies in the Netherlands & Oregon: 8 - 47% of patients who request hastened death have high level of depression (Levine et al. J Med Ethics 2011; 37:205-11)

ALS patients & Desire for Hastened death (DHD)

- 14% had DHD at time of diagnosis and this was stable over the 13 months of the study.
 - 50% could imagine asking for PAD
 - However none had discussed this with a MD although 50% would welcome the discussion
- PAD requests: Higher levels of depression, hopelessness, attachment issues (*dependency as a threat*); lower levels of spirituality (*no meaning in the dying process*)
- In the Netherlands: 20% of ALS patients elect PAD
- In Oregon: 5% of ALS patients request PAD

Stutski, R et al. Attitudes towards hastened death in ALS in Germany and Switzerland. *ALS Journal* 2014; 15:68-76

Ohnsorge: Desire to die statements

Intentions toward dying: On a continuum

- **Wish to live; Acceptance of dying**
- **Wish to die**
 - Not considering hastening death but
 1. Looking forward to dying
 2. Hoping that dying happens more quickly
 3. Desiring to die (but hastening death is not considered)

Ohnsorge: Intentions toward dying

- **Considering hastening death**
 4. Hypothetically considering hastening death (in future, if certain things happen)
 5. Actually considering hastening death but not at the moment (for moral or other reasons)
 6. Actually considering hastening death as an option
- **Will to die**
 7. Explicit request
 8. Refusing life sustaining support (e.g. food or treatments) with the intention of hastening death
 9. Acting toward dying (such as suicide or assisted dying)

Ohnsorge: Motivations

- **Reasons:** Specific factors ->triggers
- **Meaning:** Larger narrative reflecting personal values (self determination; sparing others; life “no value”)
- **Impact:** On themselves or others:
 - Appeal for reassurance; a vehicle to talk about dying; re-establishing agency or manipulation
 - Social interactions huge factor

Ohnsorge et al. Intentions in wishes to die: Analysis and a typology- a report of 30 qualitative case studies of terminally ill cancer patients in palliative care.

Psycho-Oncology 2014;23:1021-1026

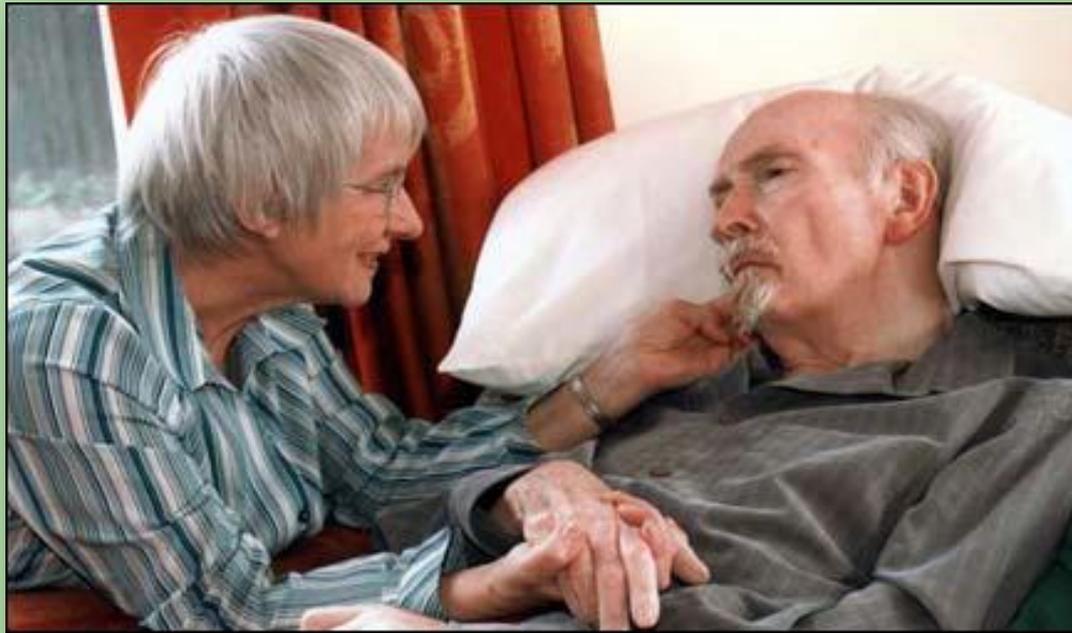
Wish to hasten death

Systematic review and meta-ethnography: Seven studies; 155 patients: Six themes:

1. Physical/psychological/spiritual suffering
 2. Loss of self
 3. Fear of dying
 4. Desire to live but “not like this”
 5. Death as a way of ending suffering
 6. Hastening death as control over one’s own life
- Response to ***overwhelming emotional distress that did not always imply a wish to die***

Monforte-Royo et al: What lies behind the wish to hasten death? A systematic review and meta-ethnography. PLoS ONE 7(5):e37117. doi:10.1371/journal.pone.0037117

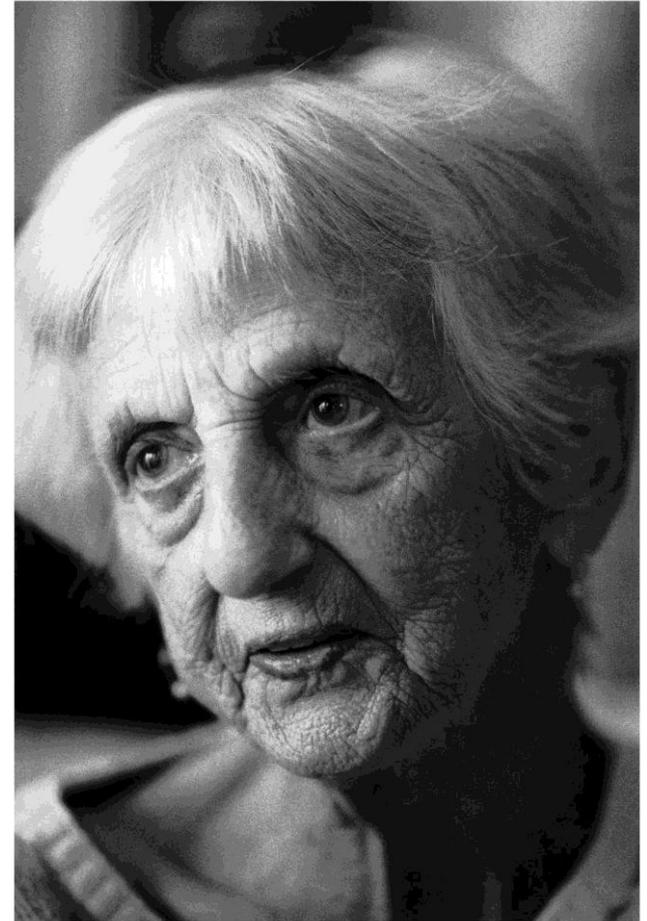
Responding to desire to die statements



Quality Care: Patient perspectives

- Pain & symptom management
- Sense of control
- Clear approach to decisions and roles
- Strengthening of relationships
- Continuity of self before, during & after illness
- Meaning and completion:
 - Life review, purpose and meaning

Steinhauser et al., Factors considered important at the end of life by patients, family, physicians and other health care providers. *JAMA* 2000; 284:2476-2482;
Singer. Quality End of Life Care: patients' perspectives. *JAMA* 1999; 281: 163-168)



Aspect of Care	Curative	Life-Prolonging Palliative	Symptomatic Palliative
Impact on disease	Eradicate	Arrest progression	Avoid complications
Acceptable adverse effects	Major	Moderate	Minor/none
Attitude	WIN	FIGHT	ACCEPT
CPR?	Yes	Probably	Probably not
Symptom management	Secondary	Balanced	Primary
Support for family	YES	YES	YES
Advance Care Planning	YES	YES	YES

Communication Skills: End-of-Life

- Be willing to talk about dying: introduce the topic
- Listen; Ask encouraging questions
- Talk in an honest & straightforward way
- Give bad news sensitively
- Be sensitive to when patients are ready to talk (Readiness)
- Talk about what you can do: “Intensive comfort care”

Empathy: “NURSE”

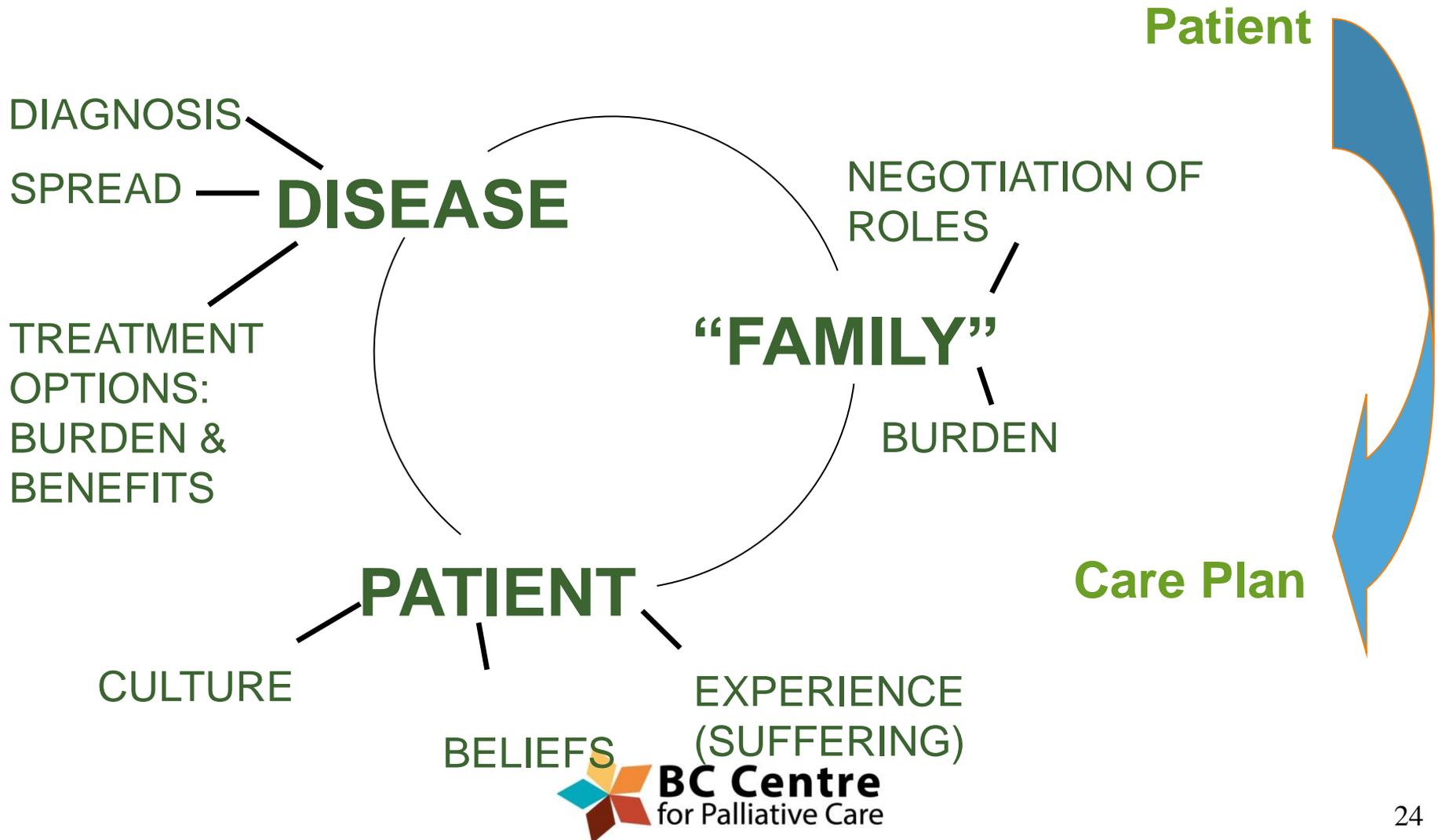
- **N**aming the emotion: “That sounds pretty scary.”
- **U**nderstanding: “that you’d feel that way.”
- **R**especting: “You’re doing the right thing ...”
- **S**upporting: “How can I help you with this?”
- **E**xploring: “Tell me more about how this is affecting you?”;
“Do you have any questions?”

(Smith, 1996; 2002)

Provide a road-map ...

- Help them understand the benefits and burdens of treatment options & make informed decisions
- Appropriate timing of choices to stop or refuse treatments (e.g. IV antibiotics)
- Help with care planning: What supports are available (e.g. Hospice); Engage the family
- Provide support; Non-abandonment key
- Pain and symptom control.

Build shared understanding



Address fears

“It’s not that I’m afraid of dying —
I just don’t want to be there
when it happens”



Educate and inform

- Normalize dying: *Part of the cycle of life*
- Address myths, fears and concerns such as
 - Dying is painful
 - Dying is lonely
 - Dying is the enemy to be beaten (Giving up)
- Be honest and truthful: **Build trust**
- Share prognosis
- Make recommendations

Atul Gawande: “Being Mortal”

- Ask about
 - Previous experience with death and dying?
 - *If time was short... What would you want to do with the time you have left?*
 - Trade-offs they are prepared to make or “*what would be worse than death*”?
 - Revisit goals of care conversations over time as prognosis changes or treatments fail: “*Serious Illness Conversation Guide*”

We can help..



- Assurance of support:
- Involve other supports
- Help “*negotiate the overwhelming anxiety:*
- *Anxiety about death, anxiety about suffering, anxiety about loved ones, anxiety about finances.*
- *There are many worries and real terrors and no one conversation can address them all.*
- *This is a process not an epiphany.”*

(http://www.newyorker.com/reporting/2010/08/02/100802fa_fact_gawande?printable=true)

Person centred care

- *Focus on “best possible day”.*
- Personal wishes (Person-centred care)
- Strengthening relationships
- Preferences for Location of care; location of death
- Life closure/ Dying well



Positive outcomes

- Increased patient & family satisfaction with care
- Diminished fear & anxiety with an enhanced sense of control
- Improved quality of life ratings
- Less decisional conflict; less burden & stress for families
- Opportunity to prepare for *living well* and *dying well*



System Outcomes

- Documentation increases adherence to person's wishes and goals of care.
- Decreased use of intensive care units, life-sustaining technologies (e.g. feeding tubes); increased hospice use (US) .
- Greater satisfaction amongst all care providers; less moral distress regarding the issues surrounding death and dying:
 - Honoring person's values and goals for ***living well & dying well***
- Alleviates conflict

Shifting role for physicians

- Dr Arthur Frank: *The wounded storyteller. Body, illness and ethics*. University of Chicago Press; 2013: 3 common narratives
 - **Chaos narrative:**
Does not matter what you do...
 - **Restitution Narrative**
 - **Quest Narrative**



Restitution Narrative

- Physician as the hero rescuing patients from death; disease; disability; from suffering
- The narrative we have been taught and therefore the restitution narrative may try to impose itself on our subconscious
- Even in the palliative care setting it is often used to bend death to our will—the heroic doctor relieves the patient’s pain and suffering and makes death a dignified experience.

Quest Narrative

- “About being forced to accept life unconditionally; about finding a grateful life in the midst of conditions that the previously healthy self would have found intolerable.”
- How do we embrace the quest narrative:
 - Accompaniment (when we cannot fix)
 - Non-Abandonment in the struggle to find meaning
 - Assurance that life still has meaning; that they are a person of worth and value (not a burden)



Pimlott: CFP Editorial Jan 2015

*Perhaps the lesson is that
we cannot apply the restitution narrative
when confronted with death,
forcing us to have difficult conversations with our patients
and their families, and
to acknowledge our own feelings of sadness and loss at
the death of a patient.*

Navigating the waters

Atul Gawande: *Being Mortal*. Doubleday

- Living well with the 3 Ds: Disability; dependence and death requires informed and shared decision making.
- Takes courage and resilience: Embrace alternative ways to live and to find connection and belonging; meaning, worth and purpose
- Medicine: Focus on disease and repair of health, safety not sustenance of the soul

Death as a negotiated event

- Daniel Callahan: “*Death has been moved out of nature into human responsibility*”
 - Shared individual & professional agency and responsibility:
 - Asks: Is suffering an unavoidable part of human existence or a medical problem to be fixed
- Best practice: “Compassionate therapeutic engagement with our patients and families
- As well as a public health approach which considers the impact of choices about how and when we die on others/society
 - Branigan, M *Desire for hastened death: Exploring the emotions and ethics. Curr Opin Support Palliat Care* 2015,9:64-71

Responding to desire to die statements (DTDSs)

- Respond professionally & compassionately
- Assess to identify treatable problems or concerns especially psychological or spiritual issues
- Assess and explore current feelings and fears
- Respond to specific issues
- Summarize the discussion and ensure shared understanding of next steps
- Document and advise other team members
- Hudson PL et al. Responding to Desire to die statements from patients with advanced disease. *Palliative Medicine* 2006; 20:703-710

Dealing with end of life issues

Requires a societal shift in paradigms:

- Promote healthy living in advanced illness;
- Promote understanding of loss and grief
- Normalize dying role and tasks of dying
- Ensure access to Palliative Care supports from time of diagnosis
- Empower patient voice and celebrate stories
- Accept dying as a social phenomenon (Mobilize Compassionate Communities)
- ***Ethics of caring vs medicalized dying***

Death as a negotiated event

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Summary:

The only way death is not meaningless is to see yourself as part of something greater: a family, a community, a society and to be able to express that in a meaningful way

AND

"You matter because you are you, and you matter to the end of your life.

We will do all we can not only to help you die peacefully, but also to live until you die."

Dame Cicely Saunders, nurse, physician and writer, and founder of hospice movement (1918 - 2005)

