handout

Suicide at Life's End … Request for Hastened Death
Gerard S Brungardt MD BeL
http://www.brungardtmd.com/wp-content/uploads/2010/06/Hastened-Death-OneNote-handout.pdf

outline
*there is an escalating request for and use of suicide at end-of-life in a variety of guises
*the underlying reasons for this are the same as for all suicide - relationship needs (ourselves - others - God)
*our response then is our presence - we are provoked by and follow the other

key terms - "desire for hastened death"
Suicide - the act of intentionally killing oneself
Euthanasia- the intentional killing of a person who is suffering in order to eliminate that suffering
Physician Assisted Suicide (PAS) - patient requests lethal dose of medication, physician prescribes, patient takes
Palliative Sedation - the lowering of patient consciousness using medications for the express purpose of limiting patient awareness of suffering that is intractable and intolerable - distinguish proportionate palliative sedation (PPS) and palliative sedation to unconsciousness (PSU)

key dates…
1973 Dutch decriminalize euthanasia
1998 Oregon legalizes PAS
1999 Kevorkian convicted
2000 Netherlands legalizes euthanasia (Belgium & Luxembourg soon follow)
2007 AAHPM (hospice md's) adopts position of "studied neutrality" re PAS ("physician assisted death")*
2008 Washington State legalizes PAS
(assisting suicide in Switzerland never criminalized … assisting suicide a felony in Kansas)
[* Supportive Care Coalition letter in response to AAHPM position of 'studied neutrality']

'neither hasten nor prolong'
traditional main stream hospice philosophy = neither hasten nor prolong normal dying process
AAHPM 'studied neutrality' - a step away from this core tenet
physician assisted 'death' - a disfiguring of language
palliative sedation for existential symptoms - "…just as one could not intend to kill the physical body to remove physical pain, one cannot kill the social/existential self to remove existential/social suffering … The 'medicalizing' of existential suffering is problematic …" Mellar Davis, MD
mainstream journals with neutral articles re hastened death
blog/conversation – hastened death is just the individual's choice/opinion

Suicide - risk factors in advanced disease
Depression
Hopelessness
Loss of Control – helplessness
Lack of social support – social isolation
Fatigue - exhaustion
Preexisting psychopathology
Substance/Alcohol abuse
Suicide history – family history
Pain – suffering
Advanced Illness – poor prognosis
Delirium – disinhibition

(we will see these are the same reasons for euthanasia and PAS in those at end-of-life)

Euthanasia
Ancient Greeks "good death"
18th century "help to die well"
Today euthanasia = the intentional killing of a person who is suffering in order to eliminate that suffering
Meaning - language - definitions change …

Dutch Euthanasia
35 yo female ALS … single, high school music teacher … ALS progressed slowly for 2 years … then she declined rapidly - now unable to perform ADL's … parents are caregivers … admitted for pneumonia … patient asked not to live 'on a machine' and asked 'not to suffer' … stated she preferred euthanasia to life on a ventilator … her main fear was 'no air' … 'not having enough air' … admitted for declining lung function … patient assented to euthanasia … case taken to 'terminal care committee' and request approved … condition continued to decline … patient and family decided that 'waiting … was unbearable' … family said good-bye's and left the room … MD gave 1 gm pentobarbital IV then 4 mg curare derivative … breathing stopped a few seconds later … death certificate = "sudden respiratory arrest".

Dutch Euthanasia
unbearable suffering
voluntary and persistent request
competent decision maker
consultation with one other doctor
at least 12 years old (16-18 requires parental notification; 12-16 requires parental consent)
Groningen Protocol (2004) < 12 yo

1991 Remmelink Report
Euthanasia 2300 deaths (1.8%)
Assisted Suicide 400 deaths (0.3%)
Involuntary Euthanasia 1000 deaths (0.8%)
other interpretations of the data count as many as 25,306 instances of euthanasia (19.4% of all deaths) with over half of these being involuntary
[3% of deaths (1.8 + 0.3 + 0.8) … if 2000 pts/year (local hospice) … 2000 * .03 = 60 pts/year … or more than 1 a week]

continuous deep sedation in the Netherlands has increased from 5.6% of all deaths in 2001 to 8.2% in 2005 to 12.3% in 2010

Patient Concerns: Netherlands
Loss of dignity 57%
unworthy dying 46%
dependence on others 33%
tired of life 23%
pain 10%

Oregon PAS
Helen 81 yo lady with breast cancer … requested assisted suicide … primary md and consulting md refused both stating she was clinically depressed … husband called Compassion in Dying whose medical director spoke with Helen … "frustrated and crying because she felt powerless" … daily aerobic exercise until 2 weeks ago … still doing housework … no pain … had experienced the lingering death of her husband … primary concern was anticipated suffering … Compassion in Dying recommended MD … lethal prescription supplied and Helen died soon after.

Oregon PAS
1994 legalized in referendum
1994-1997 legal challenges
1997 Oregon Death with Dignity Act implemented
"Physician Assisted Death"
2007 AAHPM adopts "position of studied neutrality"
adult (18 yo) resident of Oregon
capable of decision making
terminal illness (< 6mo)
two oral requests (15 days apart)
written request signed by 2 witnesses
prescribing MD and consulting MD confirm dx and prognosis and decision making ability

Oregon PAS
psych referral not mandatory
1998 Oregon 19% psych refer
2009 Oregon 0/59 deaths had psych referral
2009 Washington 3/36 deaths had psych referral
no requirement re pain & suffering
very limited data collection and disclosure
no mechanism to ascertain non-reporting

Oregon PAS
steady increase from 1998 to 2007 in requests (24 -> 85) and suicides (16 -> 49)
> 50% do not receive palliative rx of any kind (pain control, social work assess, hospice referral, trial of anti-depressant)
1/2 of the patients for whom any interventions were made changed their minds
MD's completely immune to any/all potential criminal, civil or professional liability
divorced 2X married to commit pas

Patient Concerns: Oregon
Loss of autonomy 89%
Less able to engage in activities making life enjoyable 87%
Loss of dignity 82%
Losing control of bodily functions 58%
Burden on family, friends/caregivers 39%
Inadequate/concern pain control 27%
Financial implications 3%

Patient Concerns – Family Point of View: Oregon
wanting to control circumstances of death
worry about loss of dignity
worry about loss of independence
quality of life
self-care ability
(physical symptoms rated very low)

Voluntary Stopping of Eating and Drinking (VSED)
a type of Physician Assisted Suicide
we suggest it … normalize … give them the option
we have given the means to hasten death

Palliative Sedation

Palliative Sedation - the lowering of patient consciousness using medications for the express purpose of limiting patient awareness of suffering that is intractable and intolerable (NHPCO Kirk)

Palliative Care: Proportionate Palliative Sedation (PPS)

(Sedation of the Imminently Dying)
-patient is close to death (hours-days)
-while treating intractable pain or other burdensome symptoms
-side effect of treatment
-aggressive treatment of symptoms … has a foreseen/unintended side effect of sedation
-other burdensome therapy may be withdrawn/withheld
-dose titration trials

Palliative Sedation: Palliative Sedation to Unconsciousness (PSU)

(Sedation toward death)
-patient is not imminently dying
-'existential' symptoms – autonomy, control, indignity
-patient is sedated to unconsciousness as a means of treating these symptoms
-other life sustaining treatments (including nutrition/hydration) are withdrawn
-no dose titration trials

Palliative Sedation

clarify distinctions …
PPS - proportionate palliative sedation (sedation of the imminently dying) allows the foreseen but unintended side effect of sedation in the face of refractory symptoms in the imminently dying
PSU - palliative sedation to unconsciousness (sedation toward death) hastens the death of someone suffering existential/spiritual distress and abrogates the hope of healing
Continuum - treating pain/other symptoms … PPS … PSU … Euthanasia/PAS

Suffering ….

To suffer is to undergo an experience that makes explicit the essential tension between the Intrinsic Dignity and the finitude that characterize an individual as a member of a Dignified and finite natural kind.

Neuro-cognitive suffering
- occasioned by physiological disturbances or disruptions in physical integrity
- e.g. – pain, depression, delirium, nausea, seizures, etc.
- physicians receive some training in addressing these

Agent-narrative suffering
- occasioned by disturbances in one's sense of agency, narrative history, or relationships with other persons
- e.g. – sadness, loneliness, alienation, rejection, guilt, despair, doubt, self-hatred.
- physicians not trained in addressing these
- these are what underlie most requests for hastened death

Jansen & Sulmasy, Theor Med Bioeth 2002; 23:321-337

our response - provoked … receptive … follow …

Clinical Response

Clinical Issues – risk factors

depression (psych)
hopelessness (spiritual)
-the capacity to •nd purpose in living
-hope – certainty in the future based on the strength of a present reality
social support (social)
-feeling like a burden to others
-loss of autonomy
pain/symptoms – and how they affect activity (bio)

Clinical presentation … suicide – hastened death
passive wish – fleeting – no active plans (up to 40%)
request for assistance (up to 20%)
active desire – with plan (up to 5%)
completed - < 1%

Clinical Issues – assessment
-validate – normalize these thoughts – feelings
-risk factors?
-ideation?
'many have passing thoughts of suicide … have you?'
have you found yourself thinking you'd be better off dead?
-plan?
-intent?
'do you think you would carry out?'
-assessment & exploration of feelings, fears and suffering
Asking patients to describe what they think would happen if they killed themselves may elicit wishes for revenge, power, control, punishment, atonement, sacrifice, restitution, escape, sleep, rescue, rebirth, reunion with the dead, or a new life.
-evaluate & address risk factors
-empathy – active listening – mgmt of realistic expectations – normalize distress

Assessment - interventions …
in those desiring hastened death …
thorough assessment – and talk about it
control physical symptoms
provide supportive presence
encourage life review … recognize … purpose - value - meaning
explore … guilt, remorse, forgiveness, reconciliation
facilitate religious expression
reframe goals
encourage meditative practices
focus on healing (rather than cure)
… in short - an attentive - receptive presence to an other person as person ourselves

Clinical Issues – intervention (state of the art)
-enhance meaning Breitbart,W., Rosenfeld, B., Gibson, C., et al. (2009). Meaning- centered group psychotherapy for patients with advanced cancer. Psycho-oncology, 19, 21–28.
-conserve dignity Chochinov, H.M., Hack, T., Hassard, T., et al. (2005). Dignity conserving therapy. Journal of Clinical Oncology, 23, 5520–5525.
-life completion tasks Steinhauser, K.E., Alexander, S.C., Byock, I.R., et al. (2009). Seriously ill patients' discussions of preparation and life completion. Palliative and Supportive Care, 7, 393–404.

****

interludes … transference/countertransference … ambivalence … hope

Clinical Issues – (counter)transference

-how do doctors and patients behave toward each other in times of stress & tension?
-patient – sick & dying
-doctor – being confronted with 'failure' to cure/fix … being confronted with death
-countertransference = unconscious responses of clinician to patient…
-transference = patient to clinician …
… based upon previous patterns of significant relationships in his/her own life

Clinical Issues – (counter)transference

projective identification - whose emotion is it?
countertransference enactment - whose (emotional) need is it?
-challenges of dying patient …
    confrontation with the limits of medicine
    persistent suffering – despite MD efforts
    stark confrontation with death
-run up against MD attributes …
    heightened sense of responsibility
    tendency to experience guilt
    high self-criticism & perfectionism
    need for control
- … can lead to MD failure to explore and assess risk factors – depression – hopelessness … MD falls back on the cultural rhetoric of 'autonomy' and 'right to die' … "the failure to explore the meaning and basis of the patient's request for hastened death is the real violation of the rights of a dying patient." (Muskin. JAMA. 279, 323-8)
[Kelly FJ, Varghese FT and Pelusi D. Countertransference and ethics: A perspective on clinical dilemmas in end-of-life decisions. Palliative and Supportive Care. 2003 (1), 367-375]

Clinical Issues – ambivalence

-do we ignore the ambivalence death provokes … and operate under an illusion of control?
-Burt argues (Death is That Man Taking Names) that in our hearts we perceive death as inherently wrong – a logical and moral error
-we have designed systems-laws to suppress-silence this perception … PAS in Oregon is one example
-suffering patient - MD needs to eval …
-'in control' patient - MD can prescribe PAS
-re 'streamlined' approach of Oregon … "this compressed format also serves to abet the denial of ambivalence, both by the requesting patient and by any evaluating physician." (Burt)

Hope

The present, even if it is arduous, can be lived and accepted if it leads towards a goal, if we can be sure of this goal, and if this goal is great enough to justify the effort of the journey (Benedict XVI Spe Salvi)
1. … leads toward a goal …
    help those we serve see the goal
    we are relational beings (not autonomous)
    relationships
        ourselves
        others
        our God
2. … we can be sure of this goal …
    hope is certainty in the future based on something present now
    we must be that something present now

we walk with those we serve on the journey and attend to their needs

3. ... if this goal is great enough to justify the effort of the journey.

do we really believe in the power of our presence? ... in the greatness of the goal?

our job is to so image/mirror the destiny ... in ourselves ... that they will want to follow us ...

our own personal work is very important

can't give what you don't have

gsb ... hope is certainty in the future based on the strength of a present reality ... The person requesting hastened death does not have a certainty in the future - most often because they do not have the strength of a present reality - a person to accompany them - their Gerassim ... this is supported by the evidence viz. the reasons for suicide/request for hastened death are relational issues.

****

their journey ... relationships

<u>Relationships ... & Suicide</u>

- autonomy?
- relational?
- are we independent-autonomous beings?
    - our current ethical 'mantra' would tell us so
    - autonomy - beneficence - non-maleficence - justice
- or are we dependent-relational beings?
    - my experience would tell me so
    - those times in my life when I was least 'myself' were also those times in my life when I was most far away from my family - friends - God

<u>Relationships ... Suicide</u>

autonomy - dignity - control - burden on others - dependence

these are all relational issues

Ilyich - Gerassim ...

the real question is ... What is their need? ... in relationships ...

a hastened death allows their relationship need to remain unresolved

*Mathematics, the sciences, and philosophy are necessary for the evolution of man as history. They are fundamental conditions for civilization. But one could live very well without philosophy or without knowing that the earth revolves around the sun. Man cannot live, however, without moral certainties, without being able to form sure judgments about the behaviour of others toward him. This is so true that uncertainty in relationships is one of the most terrible afflictions of our generation. It is difficult to become certain about relationships, even within the family. We live as if we were seasick, with such insecurity in the fabric of our relations that we no longer build what is human. We might construct skyscrapers, atomic bombs, the most subtle systems of philosophy, but we no longer build the human because it consists of relationships. Luigi Giussani Religious Sense

<u>Conclusions ...</u>

* there is an escalating request for and use of suicide at end-of-life in a variety of guises
    * sloppy language blurs reality - palliative sedation, physician assisted suicide
    * mainstream hospice is abandoning 'neither hasten nor prolong'
    * palliative sedation to unconsciousness (PSU) is veiled euthanasia
* the underlying reasons for this are the same as for all suicide -
    * reflect agent-narrative suffering (contra neuro-cognitive suffering)
    * relationship needs (ourselves - others - God)

* suicide at life's end is a loss of opportunity for growth and closure
* our response then is our presence - we are provoked by and follow the other
* are we willing to walk this journey with our patients and families?
* physicians must attend to countertransference and ambivalence issues

Conclusions ... Breitbart

What must be made very clear here, is that patients who are suffering during the dying process, and contemplate PAS because they feel they have lost all meaning, dignity and purpose in life, are asking physicians, "Do you agree that my life is worthless because I am dying? They are searching in our responses for a way to resolve the ambivalence. A response affirming the value of one's life even during the dying process is as powerful and influential as our agreeing that "yes, your life no longer has value and I agree with your decision to die". Our participation in PAS as physicians chooses a side of the patients' ambivalence and moves them towards death, when in fact there are very valid reasons to take the other side of the ambivalence towards death and support the meaning, value and dignity of the patient even during the dying process. To assuage concerns of burden, loss of meaning, hopelessness, worthlessness, and loss of dignity. We need to understand this intense complexity of the request for PAS and not feel content to have it go relatively unexplored and feel satisfied that we have a nice set of guidelines for its performance (guidelines that do not require psychiatric assessment or expert palliative care assessment, but rather suggest them). We are a culture that sees things in black and white rather than shades of grey complexity, and we are pacified by guidelines and algorithms. This is a terrible mistake and an injustice to the very vulnerable population of the dying terminally ill. (Breitbart doi:10.1017/S1478951509990642)

similarly ... "Most suicidally depressed patients are not rational individuals who have weighed the balance sheet of their lives and discovered more red than black ink. They are victims of altered attitudes about themselves and their situation, which cause powerful feelings of hopelessness to abound." Paul McHugh p. 75 Mind has Mountains

bibliography

Death of Ivan Ilyich ... Leo Tolstoy
Ikiru ... Akira Kurosawa
Red Beard ... Akira Kurosawa

Sulmasy ... Sedation, Alimentation ... http://www.ncbi.nlm.nih.gov/pubmed/12044133 ... draws key distinction between sedation toward death (PSU) and sedation of the imminently dying (PPS - proportionate palliative sedation)

Breitbart ... PAS ... http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=7340264

Handbook of Psychiatry in Palliative Medicine. Chochinov and Breitbart. Oxford. 2009.
The Case Against Assisted Suicide. Kathleen Foley and Herbert Hendin. Johns Hopkins. 2002.
The Physician Assisted Suicide Debacle in The Mind Has Mountains. Paul McHugh. Johns Hopkins. 2006.
The Future of Assisted Suicide and Euthanasia. Neil M. Gorsuch. Princeton. 2006.
Physician Assisted Suicide Ruling in Montana. Wm Breitbart. Pall Supp Care. 2010. p. 1-6.
Countertransference and Ethics. Kelly BJ etal. Pall Supp Care. 2003. 1:367-375.
Sedation, Alimentation, Hydration and Equivocation. Sulmasy. Annals Int Med. 2002. 136:845-849.
Palliative Sedation. Claessens. J Pain Symptom Mgmt. 2008. 36: 310-333.
Death is That Man Taking Names. Robert A. Burt. U California. 2002.
Death Talk. Margaret Somerville. McGill Queens. 2001.

Jansen & Sulmasy, Theor Med Bioeth 2002; 23:321-337 (on agent-narrative vzvz neuro-cognitive suffering)

UpToDate

Euthanasia and physician assisted suicide
Palliative sedation
End of life care: Stopping nutrition and hydration
Suicidal ideation and behavior in adults