The Pains of Dying:

Psychodynamic and other Considerations Regarding Issues at the End of Life

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Disclosure

- With respect to the following presentation, there has been no relevant (direct or indirect) financial relationship between the party listed above (and/or spouse/partner) and any for-profit company in the past 24 months which could be considered a conflict of interest.

- *"Strikingly, the overwhelming majority of those who are terminally ill fight for life to the end."*

- Herbert Hendin

"Lieber Schur, Sie erinnern sich wohl an unser erstes Gespräch. Sie haben mir damals versprochen mich nicht im Stiche zu lassen wenn es so weit ist. Das ist jetzt nur noch Quälerei und hat keinen Sinn mehr."

September 21, 1939

"My dear Schur, you certainly remember our first talk. You promised me then not to forsake me when my time comes. Now it is nothing but torture and makes no sense anymore."

Was anyone asking for this?

Ward (1994) 60% of NHS MD's in England have been asked

Back (1996) 26% of MD's in Washington have been asked

Lee (1996) 21% of MD's in Oregon have been asked

Haghbin (1998) 34% of psychiatrists have been asked and report "at least taking an indirect role in ending a suffering patient's life"

Emanuel (2000) 62.9% of oncologists have been asked for PAS or euthanasia. 10.8% had performed PAS; 3.7% performed euthanasia

Asch (1996) 17% of *nurses* have been asked, 16% aided in a death, 4% hastened death by ***pretending*** to provide life-sustaining treatment ordered by MD

Did I mention the nurses in the study above PRETENDED to provide treatment?

The 69 PEOPLE WHO DIED WITH JACK KEVORKIAN'S ASSISTANCE

	NUMBER (%)
Mean Age (years)	58.4 ± 15.4
Range	21 – 89 years
Female	49 (71%)
Marital status	
Married	23 (33%)
Divorced, Widowed, or Never Married	46 (67%)
Physical health problems	66 (96%)
Cancer	20 (29%)
Neurologic disease	26 (38%)
Terminal illness	17 (25%)
Recent decline in health status	50 (72%)
Depressive symptoms	9 (13%)
Pain	24 (35%)

COMPARISON BETWEEN KEVORKIAN'S AND "TYPICAL" ASSISTED SUICIDE/EUTHANASIA DEATHS

KEVORKIAN *	"TYPICAL" **
58 YEARS OLD	65 YEARS OLD
MOSTLY WOMEN	MOSTLY MEN
25% TERMINALLY ILL	100% (WE HOPE)
MANY NOT OR NEVER MARRIED	SAME
7% - NO FINDINGS ON AUTOPSY	UNKNOWN

Meier et al: NEJ MED 1998

3,102 MD's surveyed in 10 specialties

61% (1902/3102) responded to the survey

16% of these MD's have written an Rx for a lethal dose of medication (3.3% of the total sample)

18% received at least one request for a lethal prescription

11.1% received >1 requests for lethal injection

4.7% of the total sample had administered at least one lethal injection since entering practice

What If PAS Was Legal?

•In 1998	•If Legal
•10.6% **might** Rx medication	•35.7% **would** Rx medication
•7% **might** give a lethal injection	•24.4% **would** give a lethal injection

What Oregon psychiatrists thought about this issue in the last millennium

Ganzini: Am J Psychiatry, 1996

- 66% of Oregon psychiatrists (321/418 responded) endorsed the view that MD's should be permitted to write a RX to end a patient's life
- Only **6%** felt that a **single** evaluation would be sufficient to assess whether a psychiatric disorder impaired the patient's judgment

- *"The very lives of terminally ill persons depend on their own rational assessment of the value of their existence, and yet there is no requirement that they be evaluated by a mental health specialist."*
- 891 F Suppl. 1429, 1995 WL 471792 (D Or)

We are being consulted today, aren't we?

- Oregon, Washington, California, District of Columbia and Colorado: attending or consulting physicians **must** refer patients for mental health assessment under specified circumstances.
- Oregon, Washington and District of Columbia statutes **require** the attending or consulting physician to refer a patient for mental health assessment if either believes that the patient may be suffering from a psychiatric or psychological disorder or depression causing impaired judgment.
- Colorado statute specifies that if an attending or consulting physician does not believe an individual to be mentally capable of making an informed decision, then s/he **must** be evaluated by a mental health professional.
- California requires physicians to refer patients "if there are indications of a mental disorder", and is not restricted to only patients with evidence of impairment.
- All five jurisdictions emphasize that no medication to end life shall be prescribed until a professional determines that the patient is not suffering from a disorder causing impaired judgment.

What about Oregon???

Between 1998-2016, a total of 57 patients (5.1%) out of 1127 who completed PAD were referred for psychiatric evaluation

2016: 5 patients (3.8%) out of 133 were referred for evaluation.

What happened to **must?**

Oregon – Deaths by year

YEAR	SCRIPTS	DEATHS
1998	24	16
1999	33	27
2000	39	27
2001	44	21
2002	58	38
2003	68	42
2004	60	37
2005	65	38
2006	65	46
2007	85	49
2008	88	60
2009	95	59
2010	97	59
2011	114	71

Where is Oregon going?

- **1998-2011: 935 prescriptions written**
- **2011-2017: 804 prescriptions written**
- **Of the 1749 prescriptions written, 1127 (64.4%) have died using the drugs**

OREGON MD's vs. Dutch MD's Willems Arch Int Med 2000;160:63-68

OREGON N=147	NETHERLANDS N=67
Pain	Pain
Increase Morphine 97%	Increase Morphine 96%
PAS 53%	PAS 56%
Euthanasia 24%	Euthanasia 59%*
Debility	Debility
Increase Morphine 36%	Increase Morphine 43%
PAS 37%	PAS 52%
Euthanasia 14%	Euthanasia 49%
Burden	Burden
Increase Morphine 24%*	Increase Morphine 6%
PAS 24%	PAS 9%
Euthanasia 8%	Euthanasia 4%
Meaninglessness	Meaninglessness
Increase Morphine 20%	Increase Morphine 15%
PAS 22%	PAS 18%
Euthanasia 7%	Euthanasia 14%

Washington – deaths by year

YEAR	SCRIPTS	DEATHS
2009	65	36
2010	87	51
2011	103	70

As reported in 2015: 938 Rx's written and 917 deaths in Washington.
4% of patients requesting PAD were referred for psychiatric evaluation.
Did you notice that we now call it PAD (physician assisted death)?

What do C-L psychiatrists think about PAS?

In each vignette rate your willingness for each of the choices on a scale of 1 - 5. 1 =absolutely no and 5 = absolutely yes

1) Would you directly assist the person to die?

2) Would you refer the person to someone who would assist him/her to die?

3) Is it acceptable for other physicians to assist similar patients to die?

4) Is it acceptable for non-physicians (family members, nurses, others) to help similar people die?

1. A 30-year old man suffers from rapidly progressing neuromuscular disease (ALS). After 6 months he can speak only a few simple words, cannot walk, and cannot use his hands to hold objects. He wants to die.

2. A 50-year old woman has suffered from severe pelvic pain for 12 years. The symptoms are thought to be due to depressive and somatoform pain disorders. Eight years of psychotherapy have not helped. The woman refuses antidepressant treatment or ECT. She wants to die.

3. The same 50-year old woman agrees to a complete trial of antidepressants with augmentation, and then agrees to ECT. Both methods of therapy fail to help her, and she still wants to die.

4. A 37-year old man was in prison for raping and killing 3 women. After 4 years of intensive psychotherapy and treatment with intramuscular medroxyprogesterone acetate to diminish his sexual drive he was released from prison. He then raped and killed 2 more women. He claims that he can never change, and he wants to die by lethal injection, although the court sentenced him to life imprisonment.

5. A 27-year old woman with AIDS has severe pneumonia, is unresponsive to antibiotic treatment, and has been in a coma for 2 months. She receives IV morphine and is on a ventilator. Her loving family cannot bear her state, believing her EEG deems her to be "brain dead," and hope that her death will occur soon. They want the ventilator turned off.

6. Same patient in Vignette 5, but her ventilator was turned off, and after 3 weeks, she has not died.

What do ***YOU*** think about PAS?

In each vignette rate your willingness for each of the choices on a scale of 1 - 5. 1 = absolutely no and 5 = absolutely yes

1) Would you directly assist the person to die?

2) Would you refer the person to someone who would assist him/her to die?

3) Is it acceptable for other physicians to assist similar patients to die?

4) Is it acceptable for non-physicians (family members, nurses, others) to help similar people die?

What did C-L psychiatrists think?

Roberts LW, Muskin PR, Warner TD, McCarty TA, Roberts BB, Fidler DC: Attitudes of Consultation-Liaison psychiatrists toward physician assisted death practices. Psychosomatics 1997; 38:459-471

Vignette	Respondent Assist to die?	Refer to someone?	OK for MD to assist?	OK: non-MD assist?	Patient means
Man with ALS	2.07	2.57	2.83	2.17	2.41
Woman in pain	1.06	1.13	1.18	1.16	1.13
After Rx failed	1.36	1.63	1.70	1.46	1.54
37-yo rapist	1.55	1.82	1.86	1.82	1.76
Woman brain dead?	4.25	4.30	3.48	3.39	4.11
Still breathing	2.08	3.12	3.27	2.16	2.66
Agent Means	2.06	2.43	2.55	2.03	2.27

Q: How good are we at prognosticating?

Sample of 2607 patients identified for hospice care: expected not to survive > 6 months

923 who met broad criteria for hospice care: 70% lived longer than 6 months

300 who met intermediate criteria for hospice care: 65% lived longer than 6 months

19 who met narrow criteria for hospice care: 53% lived longer than 6 months

A: Not very good at all

Fox E et al: JAMA 1999;282:1638

Oncology Patients' Beliefs About DNR

75% believe they understand the meaning of "DNR"

32% are able to accurately to define this term

17% believe that DNR is morally wrong

23% believe that DNR is equivalent to suicide

Men are significantly more likely than women to believe that DNR is a form of suicide (p=.012)

Patients who lack an accurate understanding of DNR are more likely to perceive DNR as morally wrong (p=.003)

Sullivan, Muskin, Feldman, Haase: Effects of Religiosity on Patients' Perceptions of Do-Not-Resuscitate (DNR) Status. Psychosomatics 2004; 45:119-128.

How good are patients at prognosticating?

73.5% of terminally ill patients are completely aware of their prognosis and of their foreshortened life expectancy

9.5% of patients deny awareness of their prognosis and life expectancy

Depression is 3 times greater in patients who ***deny*** their prognosis

"Denial, it ain't just a river in Egypt"

Words or lack of them matter

- Notice how we use acronyms such as PAS, PAD, WTHD, and so on?
- Similar to the concept of de-humanizing patients by referring to them as disease states ("the pneumonia" rather than the "man with pneumonia") are we de-humanizing ending life by using acronyms rather that saying what it is we mean to do?

Algorithmic v Heuristic Solutions

•Yes or No answers

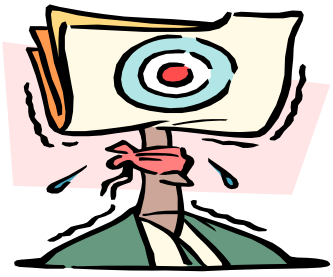
•Not legal – you're on your own here

•We will work together

•You will not be abandoned

Split in the experience of the self

The Living Dead



Control

- *"It is always consoling to think of suicide: in that way one gets through many a bad night."*

- Friedrich Nietzsche

Some "Signs and Symptoms" of Physician Problems

Feelings of anger, contempt, or "feeling trapped," toward the patient or the family

"Not enough time" to see the patient (or family) OR

Spending too much time with the patient

Inability to communicate with other physicians involved in the patient's case

Feelings of guilt or feeling like a failure

Feelings of having to save the patient

Experiencing the patient's complaints as "manipulative"

"Discovering" mistakes, or inattention to the details of the case

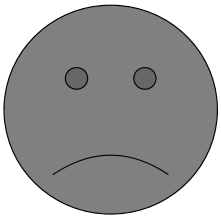
Physician factors that may impact on the care of a terminally ill patient

- Identification with the patient
- Similarities to significant others (alive or not)
- Relationship to patient or family outside of the professional relationship
- Disagreements with patient and/or family regarding case management
- Disagreements with other physicians regarding case management
- Elements in the physician's life
  - recent or unresolved grief
  - feelings of inadequacy
  - experience of conflict regarding professional obligations

Patient factors that may impact on the care the terminally ill patient receives

- Patient is a physician, nurse, medical student
- Patient is "special" – famous, VIP, or related to same
- Multiple hospitalizations over a short period of time
- Prolonged hospitalization
- Prognosis is unclear
- Goals of treatment are not clear
- Patient is doing poorly
- Physician responsible for the case has changed frequently
- Conflict within the family regarding the care
- Pathological family dynamics

Depression



Desire for Hastened Death

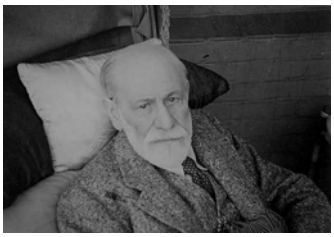
- 44% of terminally ill patients report occasional wishes that death would come soon [1]
  - 8.5% report a "serious and pervasive wish to die"
  - 27-59% of patients who wish to die have depression [1,2]
- Hopelessness, severity of depression, and spiritual well-being are strongly correlated with the desire for death [2]

[1] Chochinov et al: Am J Psych, 1995; [2] Rosenfield et al: Psychosomatics 2006

rage

- *"Ira furor brevis est"*
- (Anger is short madness)

- Horace



How long must I continue to suffer such intolerable pain? When will I be permitted to accept "sweet peace" or even to ask for it?

McCue & Cohen Arch Intern Med 2000;159:1521

- *"Pain is a more terrible lord of mankind than even death itself"*
- Albert Schweitzer

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