

Empirical Studies about Physician-Assisted Suicide: Methodological Considerations



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Approach

- Opponent of the practice
- Physician and philosopher
- Unlicensed health services researcher
- Contributions:
 - Methodological
 - Relationship between empirical research, policy, and ethics

METHODS in MEDICAL ETHICS

Second Edition



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EDITORS

Empirical research about controversial medical practices

- What does one hope to learn and why?
- Opponents will look for evidence of abuse
- Proponents will look for signs of reassurance
- Do personal/political views suppress certain hypotheses from being explored?
 - e.g. – recent Canadian straightforward, formal cost-benefit analysis:
 - Trachtenberg AJ, Manns B. Cost analysis of medical assistance in dying in Canada. *CMAJ* 2017;23;189(3):E101-E105.
 - Many US proponents find the idea of studying or expressing concerns about specific economic effects or motives inadmissible for discussion

Taking up a question for empirical research

- Dispassionate, disinterested desire to know as a scientific ideal
- Why has the NAM undertaken this topic?
- “Critical issues in health, medicine, and related policy”
 - What makes this critical?
 - Not a public health crisis if so few act upon the laws
 - Good arguments can be made that it is a distraction from improving care for our aging population
- A “health services research” approach:
 - Presumes (without argument) that the goal is good
 - “Bad” is assessed in terms of efficacy, safety, cost, and access
- The composition of the panels in this workshop
- Potential upshots, whether intended or not:
 - Normalization
 - Medicalization as a worthy subject of medical research, even of NAM
 - Preparatory for a major NAM study?
 - Political, not metaphysical

Language

- Shapes one's attitudes and approaches
- No scientific basis for deciding terminology
 - Except marketing science
- Can obscure distinctions of ethical or even empirical importance
 - e.g, sideroblastic anemia is more precise and useful than "blood disorder"
 - similarly: PAS, euthanasia, vigorous symptom control, forgoing life-sustaining treatment are better than "assisted death"
- Political use of terms

Community engagement

- A new standard in human subjects research
- Helps to:
 - Shape the approach
 - Set the agenda
- Which community?
- Who represents that community?
- Avoid advocacy groups
- At least balance
 - e.g., PCSBI study of incidental findings:
 - One iatrogenic disaster
 - One life-saving finding

Study design I

- Unscientific online polls
 - Medscape
 - NEJM
- Scientific study: national, weighted probability-based random sampling, 1144 docs: 69% opposed
 - Curlin et al. *Am J Hosp Palliat Care* 2008;25:112-20.
- Complex, ambiguous, and leading questions
 - Gallup
 - "When a person has a disease that cannot be cured and is living in severe pain, do you think doctors should or should not be allowed by law to assist the patient to commit suicide if the patient requests it?"*
 - C&C
 - "Should terminally ill, mentally capable patients have the option to receive aid-in-dying medication in cases of intractable pain or suffering?" (Handbook for Engaging State Medical Associations)*

Study design II

- One can only find what one looks for in “the landscape”
- Biases in recruiting subjects through a political advocacy group
 - Their own agendas
 - Not representative of all dying persons who might think about PAS
- Biases in retrospective surveys of surviving family members
 - Cognitive dissonance
- Legal reporting mechanisms
 - “Thin” to protect privacy
 - Bureaucratic appearance of monitoring
 - Self-reported and not validated
 - No good data on unreported cases

Data interpretation

- The appearance of a landscape depends upon where one sits
- Abuse
 - Inevitable
 - How much is too much?
- Slippery slopes
 - Studies: disabled and minorities are not overrepresented
 - Does not answer the question
 - The fact that dependence on others is a socially sanctioned reason for death
- Small numbers participate
 - If this is good care what would be wrong with larger numbers?
- Year on increases in numbers
 - Increasing social comfort in prescribing and receiving
 - What does the pitch of the slope mean?
- The unstudied psychological slippery slope
 - Practitioners: self-justification
 - Patients and practitioners: pressure to conform
- Logical and legal slippery slopes
 - Not amenable to empirical study

Above all: scientific facts are not ethical arguments

- The naturalistic fallacy or fact/value distinction
- No “ought” from “is”
- Today’s meeting “not to discuss at length the moral or ethical arguments”
 - Yet the topic is primarily of interest *because* it is ethically controversial
 - Speakers were given the latest arguments for and against 4 days ago
- Good policy is based on both facts and ethics:
 - Scientific facts are not a policy argument
 - The data are not the primary issue here

Invalid causal inferences

- *Post-hoc, ergo propter hoc*
- “Palliative care has improved in Oregon since the legalization of PAS.”

Invalid ethical/policy inferences

- *Argumentum ad populum*
 - Ethical issues are not decided by polls
- Pragmatic biases:
 - “This is legal, we just have to deal with it.”
 - “This is inevitable, we just have to deal with it.”
 - Political effect is to promote the controversial practice
 - Law can be ethically wrong
 - Laws can be changed
 - “Ethics is about what to do, when what to do is up to us”
 - It is up to us

Publication bias

- Bias towards what is “new”
 - Defense of the status quo is not new
- Bias towards the empirical
 - Easiest empirical studies simply report on what has transpired
 - What transpires is PAS
- Gives the appearance that “science and medicine” are marching towards accepting PAS

What *can* we know?

- At present, the number of reported cases, following the law, is small
- But increasing steadily
- Those who make use of the law tend to:
 - be white, wealthy, and educated
 - have a distinct personality style: “dismissive,” focused on control
- A small (but growing) number of physicians write the prescriptions
- A substantial portion are depressed
- Very few are ever sent for psychiatric referrals
- Reasons: not symptoms but lost autonomy, independence, control
- About 1/3 die without taking the drugs
 - Died too soon
 - Decided not use them
 - Cannot assume this means they “only wanted the security of having a way out”

Major gaps

- Serious deliberative polling
- Validity of legal reporting
- Prevalence of unreported cases
- Incidence of abuses
- Psychology of participation by physicians
- Psychiatric impact on families
- Impact on the vast majority of patients who do not participate
- Incomplete suicides & whether/how/when they are completed
- More data regarding effects on general psychiatrically ill population
 - Copy cat suicides
 - Marzuk, P.M., K. Tardiff, C.S. Hirsch, A.C. Leon, M. Stajic, N. Hartwell and L. Portera. Increase in suicide by asphyxiation in New York City after the publication of Final Exit. *N Engl J Med* 1993;329: 1508-10.
 - Suicide contagion
 - Jones, DA, Paton D. How does legalization of physician-assisted suicide affect rates of suicide? *South Med J* 2015;108: 599-604.
 - Boer TA. Does euthanasia have a dampening effect on suicide rates? Recent experiences from the Netherlands. *Journal of Ethics Mental Health* 2017. <http://www.jemh.ca/issues/v9/documents/JEMH%20article%20Boer%20final%20proof.pdf>
- If this is just normal medicine, then need an RCT:
 - Drugs, doses, side effects
 - If investigators and/or the public hesitate, why?