ASSISTED DYING FOR INDIVIDUALS WITH MENTAL DISORDERS: A RISKY CONCEPT?

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Story of Ah Bun

- Hospitalised since
- 2003-2004, typed letter appealing to CH Tung (then Chief Executive)
- Triggered widespread attention and debate
- Money poured in, more advanced equipment provided, his living environment improved
- Published the book 2007 ‘I Want Euthanasia’
- Home after 19 yrs in hospital in 2010.
- Passed away 2012. Acute infection.
Current status in Hong Kong

- Euthanasia
- Assisted suicide
- Refusal of/ Withholding and Withdrawing Futile Life-sustaining Treatment

ILLEGAL

LEGAL
Assisted Death Allowed Based on Right to Self-Determination

- A competent individual has the right to determine when he/she dies, the manner in which he/she dies
- As long as there is no harm to others
- This right to autonomy overrides other concerns and values
- Entitled to assistance: denying it is cruelty and allowing it is kindness
- Initially restricted to terminal cases, where treatment is futile and death is imminent
- Now there is a movement towards allowing assisted death in individuals with chronic, incurable but non-terminal conditions
Arguments for assisted death in psychiatric disorders

• Despite advances, there are still some conditions that are ‘incurable’ (e.g. treatment-resistant depression, dementia) but they may not be terminal
• Suffering can be irremediable and unbearable from these non-terminal illnesses
• Non-terminal: worse because suffering is of uncertain duration, likely to be longer
• Fairness: excluding non-terminally ill people would be discriminatory

Schuklenk & van de Vathorst, 2017
Vandenberghe, 2018
Due care criteria in the Netherlands

Termination of Life on Request and Assisted Suicide Act

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  - Be satisfied that the patient’s request is voluntary and well-considered
  - Be satisfied that the patient’s suffering is unbearable, with no prospect of improvement
  - Have informed the patient about his situation and his prognosis
  - Have come to the conclusion, together with the patient, that there is no reasonable alternative in the patient’s situation
  - Have consulted at least one other, independent physician, who must see the patient and give a written opinion on whether the due care criteria set out above have been fulfilled
  - Exercise due medical care and attention in terminating the patient’s life or assisting in his suicide
Treatment Resistant Depression (TRD)

- Prevalence: 20-33% of all treated for depression
- Defined as ‘failure to achieve remission despite adequate treatment’
- Standard therapeutic treatments fail a substantial proportion of patients who have been trying these treatments for an extended period
- Chronic unrelenting depression: suffering comparable to terminal illness
- Non-terminal therefore ‘no natural way out’
- Competence to choose
- Suicidal ideas part of the psychopathology
- Advances in treatment
- Inadequate treatment
Dementia

- Progressive, irreversible
- Life expectancy 3-12 years after diagnosis
- Increasing numbers in the Netherlands: from 12 in 2009 to 81 in 2014
- Voluntariness: dementia infiltrates core of autonomy
- Earlier decision: it’s now or never?
- Advance directive
- Suffering: current or future? Loss of dignity
- Same person as before onset?
- Can adjust to a new kind of happiness?
• The American Psychiatric Association, in concert with the American Medical Association’s position on Medical Euthanasia holds that a psychiatrist should not prescribe or administer any intervention to a non-terminally ill person for the purpose of causing death.
A physician’s duty, first and foremost, is the promotion of health, the reduction of suffering, and the protection of life. The psychiatrist, among whose patients are some who are severely incapacitated and incompetent to reach an informed decision, should be particularly careful of actions that could lead to the death of those who cannot protect themselves because of their disability. The psychiatrist should be aware that the views of a patient may be distorted by mental illness such as depression. In such situations, the psychiatrist’s role is to treat the illness.
Main Areas of Concern

- Concept of suffering
  - What is intolerable suffering in psychiatry? What is irreparable disease?
  - Nature of suffering: physical/non-physical
- Mental competency
  - Change in thinking patterns, cognition, view of the world and of oneself
- Risk of abuse
  - Risk of coercion (overt or covert)
- Adequate treatment
- What is ‘authentic self’? Rational Suicide?
- Role of doctor
- The Slippery Slope
Suffering

• Dees et al (2010) reviewed definition of ‘unbearable suffering’ in the literature in patients who request euthanasia/physician assisted suicide (EAS)
• Dees (2011): qualitative study of 31 patients who have requested EAS (including those granted and those who were not)

• Distress brought about by actual or impending threat to the integrity or life of the person
• Factors undermining quality of life
• Perceived loss of meaning and purpose in life
• Profoundly personal perceptions
• 4 themes
  • Medical
  • Psycho-emotional
  • Existential
  • Socio-environmental
Suffering

- **Medical**
  - Physical: fatigue, pain
  - Decline
  - Cognitive symptoms
  - Side effects of treatment
  - Psychiatric symptoms
- **Psycho-emotional**
  - Loss of self
  - Negative feelings
  - Fears of future dependency
  - Loss of autonomy
  - Mental exhaustion
Suffering

- **Existential**
  - Loss of important and pleasurable activities
  - Hopelessness *****
  - Pointlessness
  - Being tired of life

- **Socio-environmental**
  - Loss of social significance
  - Communicative problems
  - Discontent with current residence and quality of care
  - Being a burden
  - Loneliness
Suffering

• Wealth of motivations for EAS in those who requested it
• Illustrates that unbearable suffering is the result of the complex interaction of symptoms of the disease, personality and personal experiences, the existential background and the social situation
• Profoundly personal and subjective experience
• Professionals should explore the four themes for early diagnosis and treatment, also for assessment when EAS requested
• Most patients did not experience continuous unbearable suffering: those who did were more likely to be depressed
• Depressed mood associated with 4 times higher risk of request for EAS (in cancer patients): illustrates importance of ruling out depression
Competence

- Understanding relevant information
- Appreciating current situation and its consequences
- Manipulating information rationally
- Communicating a choice

- Needs detailed assessment of each individual patient
- Time and Decision-specific
Risk of abuse

- Coercion can be overt or covert
- By family members, health care team, public figures
- Eg Baroness Warnock in the UK in 2008 said dementia sufferers may have a moral duty to die when their continued living ‘wastes’ the lives of others and the resources of the National Health Service.
- Duty to die = License to kill?
- Made to feel a burden to others: Dependency = Burden?
- Not following procedures (‘Due Care Not Met’ cases)
- More malicious intent: BBC 2 Sept 2018
An Australian man has been convicted of aiding his wife’s suicide, after a court heard he had coveted payouts from her life insurance.

Jennifer Morant, 56, had suffered from chronic pain but was not terminally ill when she died in 2014, a court heard.
Adequate treatment

- Adequate treatment for adequate duration of time
- Advances in treatment
- People are allowed to refuse unwanted treatment: problematic for mental health patients
- Will EAS be a replacement for providing adequate services for individuals with mental health problems?
Authentic Self

- Is there continuity between a demented person and his/her premorbid self?
- Can the demented person have another kind of happiness?
- How long does one have to be depressed for the ‘depressed self’ to become the ‘authentic self’?
- Is it a matter of time? Is it a matter of severity? Is it a matter of incurability?
- Experience of illness is always influenced by a person’s social conditions and personality
Rational Suicide

• WHO estimated 800000 people died of suicide per year worldwide, that is one person every 40 seconds
• Is suicide always the result of a disturbance of mind?
• Rational suicide is a logical prerequisite for assisted dying to be morally defensible
• postal survey of 1000 senior doctors 72% (sample size 372) of respondents agreed with possibility of rational suicide, psychiatrists not different from other specialists
• Those who approved of physical assisted suicide legislation were more likely to agree with possibility of rational suicide (86%) than those who disagreed with PAS (66%)

Ginn et al, 2011
Role of Doctor

- Doctor’s role (WPA)
  - promotion of health
  - the reduction of suffering
  - the protection of life
- Suicide prevention
- Does the reduction of suffering include offering assisted death?
Why need assistance?

- Richards, 2017: in depth interviews with people who were suicide tourists
- What is a ‘good death’?
- Certainty in timing and outcome
- Painless
- Social legitimacy because it involved a medical professional
- ‘Shared’ responsibility: less like a suicide
- Aesthetic preference: appearance of going to sleep
- Concern about effects on others (e.g. witnesses, the person to find the body)
The Slippery Slope

- **Practical slippery slope**: more instances of non-compliance with the law

- **Logical slippery slope**: expansion of situations where EAS is allowed. In the Netherlands, euthanasia can be offered to children, new born babies with severe disabilities, and people with depression, dementia without physical illness.
Experience in Belgium

- Retrospective case notes review of 100 consecutive requests for euthanasia in patients suffering from psychiatric disorders (from Oct 2007-Dec 2011)
- 23 men, 77 women. Age range 21-80.
- 90/100 had more than one diagnosis
- Most had TRD (58), 48 with MDD, 10 with bipolar disorder and/or a personality disorder (50). 29 had both.
- Others: PTSD (13), schizophrenia (14), anxiety disorders (11), eating disorders (10), substance use disorders (10), somatoform disorders (9), ASD (7), ADHD (1), OCD (7), dissociative disorders (7), complicated grief (6)
- Somatic illness: chronic fatigue/ fibromyalgia (8) or other chronic somatic suffering (15)
- All had chronic, constant, unbearable suffering, without prospect for improvement, due to treatment resistance (??)
Experience in Belgium

• In total 48/100 requests for euthanasia accepted
  • Euthanasia performed in 35
  • 2 committed suicide before the procedure
  • 11 decided to postpone or cancel explained knowing they had to option gave them sufficient peace of mind
  • 2 withdrew due to strong family resistance
  • 1 was imprisoned

• Among 52 whose requests were not accepted
  • 38 withdrew their requests before a decision was reached
  • 8 continued to pursue euthanasia
  • 4 committed suicide
  • 2 died spontaneously
Experience in Belgium

• More women than men compared to other studies (77 women: 23 men) on euthanasia cases due to epidemiology of mental health issues
• Younger (median 47 yrs) compared to overall group of people requesting euthanasia for any reason due to early onset and chronic nature of mental disorders
• 35 euthanasia deaths: 28 domestic, 7 clinical
• Patients and relatives report a more humane death than suicide, aiding grieving process

Thienpont et al, 2015
Experience in the Netherlands

- Online summaries reviewed. 85/110 cases of psychiatric EAS for 2011-2014
- 70% were women
- Wide age range
- Most had more than 1 condition
- Commonest Depression, including depression with psychotic features (35%), followed by anxiety other than PTSD (13%)
- PTSD (11%)
- Psychotic disorders (8%), somatoform disorders (7%) (pain dis, somatisation dis, hypochondriasis), bipolar depression (6%), substance misuse (5%), eating disorder (3%), neurocognitive impairment (3%), prolonged grief (2%), ASD (2%)
- Others (5%) (including alexithymia, Cotard syndrome, dissociative disorder, factitious disorder, reactive attachment disorder, kleptomania)

Kim et al, 2016
Experience in the Netherlands

- Many comorbid medical conditions
- 26 received ECT, 7 had tried all medications
- 37 also refused some treatment (no motivation, side effects, no use)
- 21 had been refused EAS at some point. In 3, doctors changed their minds, in 18, they got EAS from doctors new to them. In 14, new doctors associated with End-Of-Life Clinic.
- Only in 27 cases were physicians performing EAS psychiatrists, others by GP
- 7 cases: no independent psychiatric consultation at all
- Disagreement in 16 cases but EAS proceeded with disagreements unresolved for most cases
Reasons for Concern

• Many cases do not have TRD
• Autistic Spectrum Disorder
• Personality disorders: strong reactivity to environmental and interpersonal stresses, raising questions about the stability of the expressed desire to die
• 20% in Dutch sample never had a psychiatric hospitalisation
• 56% in Dutch sample: social isolation or loneliness mentioned: substitute for adequate psychosocial intervention and support
• 24% of cases, 3 independent physicians disagreed amongst themselves
• 56% patients refused some treatment
• 12% of cases, EAS went ahead although psychiatrist believed the criteria were not met
• 27%: EAS assistance requested from a doctor new to patients, most of them End-Of-Life Clinic doctors

Appelbaum, 2016
Are Safeguards Adequate?

- Miller & Kim, 2017 examined EAS not meeting ‘due care criteria’ in the Netherlands. (DCNM cases)
- 2012-2016, DCNM cases published on website of the euthanasia review committees. Total 33, 32 cases were included in study
- Substantive criteria breaches: eligibility
- Procedural criteria breaches: consultation with independent doctor and/or due medical care
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Are Safeguards Adequate?

- 22/32 cases procedural breaches
- 10/32 did not meet at least one substantive criteria
- Of these 10 substantive cases, 9 involved patients with non-cancer diagnoses and in non-terminal states (including Huntington’s, Parkinson’s, Alzheimer’s, psychiatric conditions and past CVA with stable recovery)
- In 6 cases (5 substantive and 1 procedural), the patients relied on EAS advocacy organisations to provide EAS instead of their regular doctors
‘Due Care Criteria Not Met’ cases

- Procedural breaches
  - Lack of independence: financial ties to EAS organisation, already knows the case
  - Disagreement between first and second doctor but EAS went ahead anyway
  - Not seeking further consultations
  - Due medical care criterion not met: inappropriate/incorrect use of meds (inadequate dose of coma inducer, wrong medicine used, no coma check, mixed up syringes and gave neuromuscular blocked before the coma inducer)
‘Due Care Criteria Not Met’ cases

- Substantive breaches
  - Unbearable suffering (disregard of communication impairments, inferring from ‘a look in the patient’s eyes’; not finding unbearable suffering at the time, but ‘deducing’ from doctor’s report that there will be unbearable suffering by the time EAS were to be carried out)
  - No prospect of improvement: not arranging nursing home care for Huntington’s patient, rejecting other doctors’ reports, lack of psychiatric consult for a patient
‘Due Care Criteria Not Met’ cases

- Physician behaviour
  - Did not keep medical records for 3 months before EAS
  - Refused to fill in key parts of report form and refused to be interviewed by review committee
  - Amending records when had not seen patient for over 6 months before death
  - IV line inserted even before EAS consultant had arrived
  - Doctor leaving the patient during EAS to get back up drugs from a pharmacy after administering the first set
  - IM administration instead of IV because the doctor did not want the patient’s family to see blood or an IV line
  - Pushing legal boundaries: patient was secretly given sedatives then later held down to administer more when patient showed signs of protesting (Alzheimer’s patient with advance directive)
Is Assisted Death in Psychiatric Patients a Risky Concept?

- Is it ever acceptable to assist people in ending their lives?
- Is it an appropriate role for doctors?
- Will psychiatrists conclude from the legalisation of EAS that it is Ok to give up on some patients?
- Will it induce hopelessness in patients?
- How do we ensure the decision is competently made?
- How do we ensure the rules are followed in implementation?
- How do we ensure there is no abuse?
THANK YOU