Overview

Risk of suicide and self harm in the terminally ill

Wish to hasten death in the terminally ill
  - Measurement
  - Associations
  - Change over time
  - Treatment of depression and desire for death
  - Examining meanings of desire to die statements

Responding to desire to die statements
8/100,000/year in UK

5th most important cause of life-years lost

More common in elderly, men, physical illness, psychiatric disorders, unemployment

High proportion who complete make contact with medical services in month prior to death (less so for elderly)

### Risk Factors for Suicide

*Boardman, Psych Med, 1999*

<table>
<thead>
<tr>
<th>Risk factor</th>
<th>Odds ratio (95% CI)</th>
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<tbody>
<tr>
<td>Living alone</td>
<td>2.8 (1.7-4.6)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>2.8 (1.4-5.9)</td>
</tr>
<tr>
<td>Recent bereavement</td>
<td>2.7 (1.6-4.7)</td>
</tr>
<tr>
<td>Relationship difficulties</td>
<td>8.2 (4.4-17.0)</td>
</tr>
<tr>
<td>Past psych history</td>
<td>5.3 (3.0-9.9)</td>
</tr>
<tr>
<td>Past DSH</td>
<td>11.5 (5.6-27.4)</td>
</tr>
<tr>
<td>Current medical disorder</td>
<td>10.5 (5.6-27.4)</td>
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</table>
SUICIDE RATES IN TERMINAL ILLNESS

Difficult!!!
• Methodological difficulties
• Definitions
• Assumptions
• Lack of systematic data collection

Attempts by DEMOS and Dignity in Dying via FOI requests to CCGs and Coroners offices. Limitations and interpretations….

Proxy groups?
• Risk of suicide in cancer patients (Robson et al 2010)
  • 17 studies
  • Incidence of completed suicide SMR 1-11
  • Wide variation in methodology
  • Several studies suggest risk decreases with time after diagnosis
  • Suicidal ideation common

SELF HARM

100,000 medical admissions per year in UK

1-2% of patients with SH complete suicide in next year

Risk factors for suicide completion include: males, older patients, drug and alcohol abuse, psychiatric disorders, social isolation

Risk prediction notoriously difficult

Growing evidence that brief psychotherapeutic interventions are effective
The WTHD is a reaction to suffering, in the context of a life-threatening condition, from which the patient can see no way out other than to accelerate his or her death. This wish may be expressed spontaneously or after being asked about it, but it must be distinguished from the acceptance of impending death or from a wish to die naturally, although preferably soon.

The WTHD may arise in response to one or more factors, including physical symptoms (either present or foreseen), psychological distress (e.g. depression, hopelessness, fears, etc.), existential suffering (e.g. loss of meaning in life), or social aspects (e.g. feeling that one is a burden).

44 patient with terminal illness (90% cancer)

34 had never wished death to come early

100% of those who desired death were judged to be severely depressed. Only 1 of 34 who did not desire death had depression.
# Measuring Desire for Hastened Death

<table>
<thead>
<tr>
<th>Desire for Death Rating Scale (DDRS)</th>
<th>Schedule of Attitudes toward Hastened Death (SAHD)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Hierarchy of questions</strong></td>
<td><strong>Series of 20 self rated statements</strong></td>
</tr>
<tr>
<td>7 point scale (observer rated)</td>
<td><strong>Not hierarchical</strong></td>
</tr>
<tr>
<td>Do you ever wish that your illness</td>
<td><strong>True/False format</strong></td>
</tr>
<tr>
<td>progress more rapidly so that your</td>
<td><strong>Items both towards life and towards death</strong></td>
</tr>
<tr>
<td>suffering would be over sooner?</td>
<td></td>
</tr>
<tr>
<td>1 = No DfHD</td>
<td>“I am seriously considering asking my doctor</td>
</tr>
<tr>
<td>2 = Slight desire</td>
<td>for help in ending my life”</td>
</tr>
<tr>
<td>3 = Mild desire</td>
<td>“Despite my illness my life still has</td>
</tr>
<tr>
<td>4 = Moderate desire</td>
<td>purpose and meaning”</td>
</tr>
<tr>
<td>5 = Strong desire</td>
<td></td>
</tr>
<tr>
<td>6 = Extreme desire</td>
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200 terminally ill inpatients

44.5% had occasional wishes that death would come soon

8.5% had serious and pervasive desire to die

Depression in 58.5% of those with desire for death, vs 7.7% of rest
92 terminally ill cancer patients, life expectancy <6m

Administered SAHD and DDRS and measures of physical and psychosocial wellbeing

Average number of SAHD items endorsed 4.72

15.3% endorsed => 10 items

Significant positive correlation with DDRS, depression and hopelessness, physical sx and sx distress, negative correlation with spiritual wellbeing a QoL

Prevalence, course and associations of desire for hastened death in a UK palliative population: A cross sectional study

Annabel Price, William Lee, Lauren Rayner, Laura Goodwin, Rosemary Humphreys, Penny Hansford, Nigel Sykes, Barbara Monroe, Irene Higginson & Matthew Hotopf

BMJ Supportive and Palliative Care 2011;1:140-148
AIMS AND METHODS

Determine the prevalence and remission of desire for death in a large representative sample of patients with advanced illness receiving palliative care in the UK.

Examine the associations of desire for death, particularly the relationship between desire for death, depression and perceived loss of dignity.

Outcome measure: Desire for Death Rating Scale

DESIGN

2 cross-sectional assessments

Time 1

300 patients recruited from new referrals to St Christopher’s Hospice

Interview 1: 1-2 hours

213 patients followed up

Interview 2: 15 minutes

4-week follow-up

Time 2
ASSOCIATIONS OF DHD AT T1

Demographic and clinical factors:
- Only significant factor was disease status: Those with non malignant disease had greater odds of DHD than metastatic cancer (OR 4.15 95%CI 1.56-11.05)
- History of depression or referral for psychological support not associated with DHD
- Nor was being close to death (< 4 weeks)

PSYCHOSOCIAL ASSOCIATIONS OF DHD

- MDD (OR 4.71 95%CI 2.19-10.15)
- Any depressive syndrome (OR 3.85 95%CI 1.80-8.22)
- Suicidal thoughts in past 2 weeks (OR 18.77 95%CI 7.44-47.34)
- ↑Fatigue (OR 6.09 95%CI 2.53-14.67), dyspnoea, insomnia
- ↓Social support (NS)
- ↑Identity, emotion on IPQ
- ↑HH (OR 7.64 95%CI 3.07-18.97), ↑FA ↓FS
- ↑Loss of dignity (OR 5.05 95%CI 2.02-12.67)

↑Odds of DHD
- ↑global QOL, physical functioning, cognitive functioning
- ↑Social support
CHANGE OVER TIME

ROSEN Feld, SOC SCI, MED 2014

128 terminally ill cancer patients completing SAHD at two time points 2-4 weeks apart

Categorised as 'low' 'rising' 'falling' 'high'

Variables distinguishing between those who developed DHD or not: Physical sx distress, depression severity, hopelessness, spiritual wellbeing, hx of mental health tx

High frequency of change in DHD even in final weeks

Mental Disorders and the Desire for Hastened Death in Patients Receiving Palliative Care for Cancer

WILSON ET AL, BMC SUPP PALL CARE 2014

Cross sectional survey of 377 patients with advanced cancer receiving palliative care

Examined relationship between DfHD (DDRS) and depression/anxiety

In the 12.2% with more pervasive DfHD, 52.2% had a mental disorder and had highest scores on measures of distress (physical, social, existential, psychological)

BUT those with no mental disorder had higher scores on measures of distress and suffering than those without DfHD
**Desire for Euthanasia/Assisted Suicide in Palliative Cancer Care**

*Wilson*, *Health Psychol* 2007

- 379 patients receiving palliative care for cancer
- Those who expressed DfHD followed prospectively
- Attitudes toward medically assisted death and personal interest:
  - 62.8% thought medically assisted death should be legalised
  - 39.8% would consider medically assisted death for themselves
  - 5.8% would initiate a request immediately if legalised
- DfHD associated with:
  - Lower religiosity
  - Decreased functional status
  - Dx major depression (p<0.001)
  - Greater distress/symptom concerns

**Impact of Treatment of Depression on Desire for Hastened Death**

*Breitbart et al.*, *Psychosomatics* 2010

- 372 patients with advanced AIDS
- Assessed for presence of major depression (SCID and HAM-D)
- DfHD measured with DDRS and SAHD. Monthly interviews
- If MDD diagnosed started on an SSRI antidepressant (or dose reviewed) and continued with weekly interviews
- DfHD strongly associated with depression compared with non depressed group
- DfHD reduced dramatically in those who responded to antidepressants but little change if no response to AD treatment
QUALITATIVE RESEARCH: MEANINGS

‘MINDFRAMES’ TOWARDS DYING
SCHROEPFER, JOURNAL OF GERONTOLOGY, 2006

• Neither ready nor accepting
• Not ready but accepting

• Ready and accepting
• Ready, accepting and wishing death would come

• Considering a hastened death but no specific plan
• Considering a hastened death with a specific plan
SYSTEMATIC REVIEW OF STUDIES: DESIRE FOR DEATH IN ADVANCED DISEASE

HUDSON ET AL PALL MED 2006

Desire to die statement as:
- An expression of feelings and current reaction to circumstances (not intending to carry out)
- Communication of distress and way of opening up conversation about relieving distress
- Seeking info about assistance to die
- Asking for assistance to die

DESIRE TO DIE STATEMENTS OHNSORGE 2014

- Bio/psycho/social
- Appeal
- Vehicle
- Re-establish
- agency
- Manipulation

Reasons
Meanings
Functions

E.g. Preserve self determination
PESTINGER ET AL, PALL MED, 2015

"The desire to hasten death may be used as an extreme coping strategy to maintain control against anticipated agony."

COMMON CONCERNS

• Balance life time and anticipated agony
• Intrusive images of agony and suffering
• Need for more info about dying process
• Wish for others to respect the wish and not necessarily as an order to hasten death

Fear of future suffering (self and others)
• Fear of a future worse than death itself
• Fear of dying in agony
• Fear of loss of dignity
Loss of autonomy/wish for control

A wish to live but not like this
Perception of burden to others

A wish to live but not like this

18/09/2019
CONCLUSIONS

- Desire for hastened death at the end of life occurs in significant minority
- Severe and pervasive DHD is not common
- Strongly associated with depression also symptom burden, quality of life, functional status
- Overlap with suicidal thoughts but not synonymous
- DHD is often unstable over time
- If depression present, tx for depression reduces DHD
- Qual studies point to nuanced reasons, meanings and functions of DTD statements
- Fear is an important driver

RECOMMENDATIONS

- Explore the statement carefully, reassess over time
- Don’t take at face value
- Look for depression and treat it if found
- Explore symptom control, burden, dignity, QOL, social support, fear of the future, autonomy—much can be addressed
Suggestion that legalisation of PAS might reduce suicide rates and delay suicides that do occur.

Study examining association between legalisation of PAS and state-level suicides in the US.

Legalising PAS was associated with a 6.3% increase in total suicides, 14.5% in over 65s.

No reduction in non-assisted suicide or increase in mean age.