

## Meaning of desire for euthanasia in Chinese advanced cancer patients

Dr. Yvonne Mak  
Bradbury Hospice, HK

*This presentation aimed to highlight some of the findings from a hermeneutic study undertaken on Chinese advanced cancer patients having desired for euthanasia [1].*

### Aim

This study aimed to gain deeper understanding into the hidden meaning of desire for euthanasia, in response to the existence of such death wish by a minority of terminally ill despite receiving palliative care. The desire for euthanasia was defined as any patients, who have out of their own initiation, expressed a desire or an actual request for their doctor to terminate their life.

### Method

The methodological framework followed the philosophical underpinnings of hermeneutics according to Gadamer, which allowed in-depth understanding and interpretation of the patients' lived experience within their social and cultural contexts [2,3]. Data collection was holistic including:

- (i) Initial formulation of the researcher's pre-understanding regarding the phenomenon of desire for euthanasia from clinical / research experience and literature review
- (ii) Unstructured interviews with 6 advanced cancer patients having desired for euthanasia whilst receiving palliative care.
- (iii) Review of the 6 patients' medical records
- (iv) Keeping of a reflexive journal
- (v) Use of non-medical literary and artistic sources

As the terminally ill were considered as 'vulnerable', strict ethical considerations were followed [1]. Scientific rigour was established by following the criteria of credibility, fittingness, auditability and neutrality [4].

## Analysis

The data analysis aimed to accurately describe the patients' lived experiences regarding the phenomenon and interpret the phenomenon by going deeper and 'reading between the lines'. Data were formulated into codes, categories and themes and the findings were presented as thematic analysis, exemplars, paradigm cases and concepts. This presentation will focus mainly on the thematic analysis.

## Findings

The findings illustrated the patients' life journey from wellness to death approaching and their rationalization when confronted with an end-of-life existential crisis. Data analysis of their lived experiences revealed 5 major themes and 18 minor themes (Table 1).

**Table 1** Thematic analysis

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Major Themes	Minor Themes
I. Reality	Disease progression <ul style="list-style-type: none"><li>• Inevitability of death</li><li>• Incurable meant hopelessness</li><li>• No longer who I used to be</li></ul>
II. Perception	Current suffering <ul style="list-style-type: none"><li>• Intolerable suffering for self</li><li>• Sense of burden to significant others</li></ul>
III. Anticipation	Dying trajectory worse than death itself <ul style="list-style-type: none"><li>• Witness of poor care</li><li>• Inadequate knowledge</li><li>• Unskillful communication</li><li>• No one would understand</li><li>• Misconceptions</li><li>• Fantasies of a dying process</li><li>• Fear and anticipation</li><li>• Passive resignation to bad destiny</li></ul>

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IV. Desire	Good quality end-of-life care <ul style="list-style-type: none"> <li>• Good death</li> <li>• Attention to needs of patients and relatives</li> <li>• Care from significant others</li> </ul>
V. Holding environment	Care and relational connectedness <ul style="list-style-type: none"> <li>• Good quality healthcare professionals</li> <li>• Supportive significant others</li> </ul>

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## Discussion

From the thematic analysis, the following new dimensions in understanding the meaning of desire for euthanasia emerged:

### A. Significance of Personhood

The findings illustrated the relevance of the themes to Cassell's concept of personhood [5]. Cassell refers personhood as the experience of the 'whole person'. The themes not only related to the disease, but also to the patients' whole lived experience of body, mind and spirit. The themes also revealed a timeline of lived past, present and perceived future. Patients expressed their own values, hopes and desires, their routines, roles and rights. They talked about their existence in relation to the world of objects, events and relationships. They sensed a loss of wholeness or integrity to their personhood.

#### Implications

- Not only attend to suffering of illness but also understand the uniqueness of personhood
- Listen to our patients' narratives

### B. End-of-life Existential Crisis

Patients faced an end-of-life existential crisis as they approached death. They juggled between their lived past, present and anticipated future, rationalising for meaning for continual existence. The first 3 major themes of reality, perception and anticipation portrayed an overall negativistic perceived present and future. The only factors that could minimize their pessimism depended on whether their desires were met and whether their holding environment was effective. Thus care and connectedness were important buffers in sustaining the patients' meaning of existence.

#### Implications

- Attention to illness crisis and life events
- Significance of connectedness
- The need to define what is 'care'
- Provide effective holding environment from time of diagnosis

- Understand their rationalisation
- Awareness of their ambivalence in their decision-making

### **C. Concept of Perceived Reality**

The patients' perception was their 'Reality'. Major themes I (Reality) and II (Perception) represented the patients' perceived present. Patients had to face the reality of disease progression with continual losses and awareness of the inevitability of death. They lived in the presence of suffering for self and for significant others.

Major theme III represented their perceived future with the anticipation of it being worse than death itself. Patients with the desire for euthanasia perceived a 'Medical Hell'. This was derived from what they have been told, witnessed or personally experienced in healthcare and the community. As they had not died before, they could only formulate their anticipated future from the experiences of others dying from cancers. They fantasized their own dying process with horrific complications, further treatments, symptoms and suffering. They anticipated increasing suffering, dependency, burden and future lack of care.

Thus the power of witness of poor healthcare or community care and the power of language from unskillful communication by doctors could greatly contribute to the patients' perceived future with detrimental consequences.

#### Implications

- Holistic care in acute setting with effective communication and pain / symptom control
- Promote a caring society with a positive attitude to death and dying
- Improve community resources so that caregivers become better able to care

### **D. Depth of Meaning of Desire for Euthanasia**

The thematic analysis was also interpreted in relation to how the terminally ill patients usually communicated. They usually expressed their physical and functional concerns before revealing their deeper psychosocial, spiritual or existential issues. Thus overtly, patients might express their desire for hastened death being related to physical and functional disintegration. But if carers explored deeper, patients would express psychosocial suffering, sharing their perception, fears and fantasies. And if carers were able to establish a 'spiritual connectedness' with their patients, patients might express their deepest spiritual / existential concerns, revealing their covert desires and yearnings for care, connectedness and respect.

#### Implications

- Not to take euthanasia request at face value but explore covert desires and yearnings
- The need to establish connectedness with patients
- Focus on healing or restoring wholeness rather than methodical medical interventions

## References

1. Mak, Y. (2001), 'Meaning of desire for euthanasia in Chinese advanced cancer patients: a hermeneutic study', *Department of Palliative Medicine, University of Wales College of Medicine*, pp. 129.
2. Gadamer, H.-G. (1998), *Truth and method*, The Continuum publishing Company, New York.
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4. Sandelowski, M. (1986), 'The problem of rigour in qualitative research', *Advances in Nursing Science*, **8**, 27-37.
5. Cassell, E. (1982), 'The nature of suffering and the goals of medicine', *NEJM*, **306**, 639-645.

