

From Euthinasiasts to Village Elders, the Role of Culture in End of Life Decisions

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The Role of Culture in End of Life Decisions

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Background – The Clash of decision making

The importance of decision making to our end of life culture

Are all cultures valid?

Decision making in a multi cultural world

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What is Culture?

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- The sum total of the way of living; includes values, beliefs, standards, language, thinking patterns, behavioral norms, communications styles, etc. Guides decisions and actions of a group through time.



Hospice Culture

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The challenges of cultural diversity within hospice



- Example – Disease culture
- Hospice in England developed a focus for caring for patients with advanced COPD

Issues?

- Younger patient group
- Steroid taking hungry large volume eating
- Not as grateful or "genteel as cancer patients"
- Used services on a PRN basis
- Didn't accept the hospice patient role
- Volunteers resigned
- Nurses sick leave increased



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Simple Decisions...



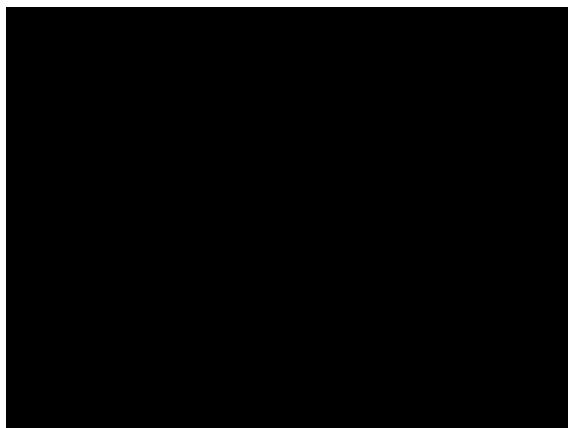

FileJuicer

Simple Decisions...




We are good at seeing everybody else's culture but our own...





Culture and decision making at the end of life





The importance of decision making to our end of life culture




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The Context of CHOICE

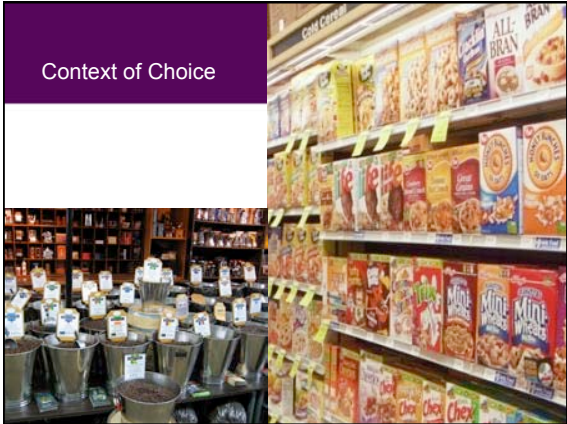



- What you want
- When you want it
- The choice is yours





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Context of Choice



Context of Choice

End of life care choices



- Preferred priorities of care
- Advance care Planning
- Place of death
- CPR or Natural death
- Transfer out or stay
- It's YOUR Choice....




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Ethnic Chinese Population



It was not evident that this group viewed 'having care choices' as the right of an individual or an important part of health care
'We are always very obedient.....we would always listen and do as we are told.' (Woman, Focus group 3)

Beliefs
'I think it is all fate! If it happens it happens; it applies to everything.'

Implications

- Recognizing that the individuals' needs and cultural backgrounds influences their perception of care choices.
- Recognising that a particular model of 'end-of-life care' may not meet the needs or fulfil the wishes of individuals from different backgrounds.
- *How could we have a choice? Older Chinese people's views about cancer, palliative care and end-of-life care presented at European Congress of Palliative Care, 2005, from Sheffield University School of Nursing*





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Is Choice ESSENTIAL



- Should we be sending out Missionaries of autonomy, choice and individual freedom?

Choice and Autonomy are absolute essential to a section of the UK population




Continuous Deep Sedation The alternative to euthanasia?

Seale, C. (2009). "End-of-life decisions in the UK involving medical practitioners." *Palliat Med* 23(3): 198-204.



This study estimates the frequency of different medical end-of-life decisions made in the United Kingdom (UK) in 2007-2008, comparing the prevalence of ELDs with 2869 having attended a hospice, and 2869 having attended a hospital. The prevalence of UK decisions about ELDs showed both non-treatment decisions (21.8%; CI: 19.0-24.6) and double effect measures (17.1%; CI: 14.6-19.6) to be much less common than suggested in earlier estimates, rarely involving intent to end life or being judged to have shortened life by more than a day. Continuous deep sedation (16.5%; CI: 14.3-18.7) is relatively common in UK medical practice, particularly in hospitals, home care settings and with younger patients. Further findings about the distribution of ELDs across subgroups are also reported. Survey research in this area requires careful control over question wording if valid estimates and comparisons of the prevalence of ELDs are to be made. The high rate of sedation compared with other countries may be a cause for concern.

If I cannot choose I stop being...




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For some choice and autonomy is absolutely **essential**







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Alternatives to Euro-American decision making




- Family has obligation to shoulder the burden
- The physician is the expert and should decide
- Truth of diagnosis is harmful or burdensome to patient
- We can't control our fate; it's God's will
- All life involves suffering
- A person's word is all that is needed
- Indirect communication
- Emphasis on present orientation


Dr. Pradeep Vaidya with patient and family in Hospice Naspil.

Family as interface



- In societies with strong sense of family(eg Portugal, China, Spain) autonomy is not regarded as the backbone of biomedical ethics
- Decision making and communication may be more family-based - delegated to another family member (e.g., Mediterranean cultures, south asia)

Daniel Fu-Chang Tsai How should doctors approach patients? A Confucian reflection on personhood *JME*,
 Nunez-Ojarte JM. Cultural Issues and Ethical Dilemmas in Palliative and End-of Life care in Spain. *Cancer Control* 8(1):46-54, 2001); 39; 41



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Culture and decision making at the end of life



Are all cultures valid?



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A culture of pain....

Science Millions Dying in Pain The New York Times

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Unacceptable Culture??

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How do others see our "dying Culture"?

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Ethnic minorities across Ireland

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- Northern Ireland is portrayed as a society dominated by tensions between a majority Protestant and a minority Catholic community
- 60 ethnic minorities live here.
- High levels of racism, xenophobia, discrimination and intolerance are directed at these communities.
- In the last year, the number of racist incidents recorded doubled.^[11]
- A Racial Attitudes Survey suggests racial prejudice is around twice as significant as sectarian prejudice in the attitudes of the population in Northern Ireland.^[12]

^[11] Report of House of Commons Northern Ireland Affairs Committee on 'Hate Crime': the Draft Criminal Justice (Northern Ireland) Order 2004, May 2004, <http://www.parliament.the-stationery-office.co.uk>

^[12] Racial Attitudes and Prejudice in Northern Ireland, P. Connolly, and M. Keenan, (Belfast Northern Ireland Statistics and Research Agency, 2000).

Three Dimensions of Humanness

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Every person is in certain respects:

- like all others, human nature - universal
- like some others, culture - local
- like no other, personality - individual

(Kluckhohn and Murray, *Personality in Nature, Society and Culture*, Knopf, 1948)

Cultural Competency Continuum

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Josephina Campinha-Bacote and Larry Purnell

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- Multiplicity of cultures, faiths and traditions in the same public space, and in health care decision making makes understanding pluralism essential.

Pluralism: a challenge for civil society. Javeed

Cultural competence in end-of-life care

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- Evaluate your own cultural beliefs and practices
- Learn about the specific cultures in your area
- Seek out training in cross-cultural communication
- If in doubt ASK

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The LEARN Model

Berlin and Fowkes

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Listen to the patient's perception of the problem
Explain your perception of the problem
Acknowledge and discuss differences
Recommend treatment
Negotiate treatment

If in doubt ASK

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Culture is constantly Changing

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