Global Interventions at the End of Life

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Four main areas of academic interest over last 25 years

- Policy, evaluation and implementation in hospice and palliative care
- Global development and mapping
- Sociology and anthropology of death and dying
- History of hospice, palliative care and related movements
Some books since 1993 ...
Current study: Global interventions at the end of life

How and with what consequences is the field of end of life care emerging in the global context?

How are specific end of life interventions formulated and delivered in different settings and with what consequences?

How can social science, frame the issue in ways that lead to greater efficacy and sustainability?
The team on 1\textsuperscript{st} March 2015
The team today
Global death in the 20th century = 5.5 billion
Global trends

- Currently c.56m deaths per year in the world; 85% in developing countries
- Estimate 91 million deaths in by 2050, most growth in LMICs.
- Global projections indicate that the number of people aged over 80 worldwide, will increase from 102m in 2009 to 395m in 2050.
- Implications for developing countries of deaths associated with new infectious diseases, HIV/AIDS, multi drug resistant TB, complex humanitarian emergencies
- By second half of the century some half a billion each year will experience the death of a person close to them.
21\textsuperscript{st} century challenges

- End of life care will have major global importance in the 21\textsuperscript{st} century, as the world population ages and grows
- As individual patterns of disease, symptoms and disability in later life become more complex
- As the social circumstances and communities to support dying become either more enabled or more impoverished
- Paradox: incommensurate level of global interest; but in rich world especially, how we die is increasingly \#contested space
- How will death and dying on this scale and complexity be supported?
- \textit{What is the global future of dying?}
- \textit{When will we reach ‘peak dying’?}
Theoretical perspectives

- Globalisation
- Policy transfer
- Post colonial studies
Culture and globalisation

- A ‘stretching’ process in which individuals of different cultural backgrounds interact with each other across spheres of life and more intensively than before
- Exposing us increasingly to different ways of thinking, cultural values, beliefs and living arrangements.
- Growing sensitivity to cultural difference co-incides with diminution of difference as the world becomes smaller
- Understanding of difference changes from ‘national character’ – to ‘gender’, ‘identity’, politics, ethnicity, religious and new social movements
- In what ways are we experiencing the globalisation of dying?
Policy transfer

• Process in which knowledge about policies, administrative arrangements, institutions and ideas in one political setting is used in another.

• Dolowitz and Marsh (2000) - who is involved, what is transferred, from and to where, constraints on transfer, and success once transferred?

• More recent focus (Stone 2012) on role of two way communication – ‘policy mobilities’ and efforts to acknowledge the ‘indigenization’ of policies as they are modified and adapted to context

• What is the relevance of this to the ‘roll out’ out palliative care globally?
The underlying assumption is that the rest of the world should ‘catch up’ with the developed world at some point.

A narrative of transition, which reproduces ‘European’ archetypes and where the ‘subject’ is always perceived in terms of lack, absence, incompleteness.

Implications for the ideologies of end of life care?
The approach

The project seeks to understand how end of life interventions are developed, implemented and assessed - and with what consequences.

Takes a global perspective to examine interventions of varying types and characteristics, across differing resource settings, geographies and cultures.

Its method is first to build a *typology* of interventions and then to conduct *case studies and reviews* of selected examples.
‘Interventions’, focus and locus

Our definition of interventions - *Organised responses to end of life issues*

- **Focus** This refers to the *character* of the intervention. It concerns the elements found within it, the field of objects to which it is addressed and the related purpose of intervening. Focus is about the content, the orientation, and the qualities of the intervention. It can also include the goals and ambitions of those who construct and deploy the intervention. The focus of any intervention may change over time or as it shifts from one locus to another.

- **Locus** This refers to the *geographical* scope (and spread) of the intervention
Relationships …

<table>
<thead>
<tr>
<th>Locus</th>
<th>Focus</th>
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<tbody>
<tr>
<td>Transfer</td>
<td>Translation</td>
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Ten categories of interventions at the end of life

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
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<tr>
<td>Policy</td>
<td>Decisions taken or rules adopted by governing authorities to deliver, facilitate, monitor or regulate end of life issues</td>
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<tr>
<td>Advocacy</td>
<td>Expressions or actions on end of life issues/care that aim to influence decisions of the institutional elite and/or promote the interests of specific populations, groups or individuals in particular contexts</td>
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<tr>
<td>Cultural</td>
<td>Initiatives taken to influence patterns of shared knowledge and symbolic meanings in particular communities, through which people perceive, interpret, express and respond to end of life issues</td>
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<td>Ethico-legal</td>
<td>Frameworks included within laws, guidelines or ethical codes that relate to issues at the end of life and which permit, facilitate or require specific courses of action</td>
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<td>Educational</td>
<td>Development of knowledge, skills, good judgment and character required for the delivery of appropriate end of life care</td>
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<tr>
<td>Research</td>
<td>Systematic enquiry on end of life issues for the purposes of establishing new knowledge and understanding by description, prediction, improvement and/or explanation</td>
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<tr>
<td>Service</td>
<td>Medical, nursing and other services for the prevention, alleviation and/or reduction of suffering at the end of life through inpatient, outpatient, home care or other forms of services</td>
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<tr>
<td>Clinical</td>
<td>Medical, nursing, allied health and psycho-social procedures at the individual level to relieve symptoms and sufferings associated with advanced illnesses and when death is imminent</td>
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<tr>
<td>Intangible</td>
<td>Actions to promote the recognition and significance of aspects of human existence that have intrinsic value at the end of life</td>
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<tr>
<td>Self-determined</td>
<td>Actions, decisions or choices made by individuals to engage in or refrain from something that has implications for them at the end of their life or the life of another</td>
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Case study methods

**Level of conceptualization**

- **Documentary analysis:**
  Analysis of any organizational document, guidelines, leaflets, published scientific paper

- **Key informant interviews:**
  Interview with the policy makers of the project

**Level of provider experience**

- **Key informant interviews:**
  Interviews with the implementers, end of life care providers

**Level of community experience**

- **In depth Interviews:**
  Community members, Clients Stakeholders

- **Participant observation:**
  End of life care practices in the community
Examples of initial case studies

- Declarations as advocacy: palliative care, assisted dying, older people, pain management
- The spread of Neighbourhood Networks in Palliative Care
- Emergence of the death café movement
- Housing with care: interventions for older people
- The role of ‘public health’ in the global spread of palliative care
- ‘Integration’ of assisted dying and palliative care
- End of life care in the urban slums
- The Liverpool Care Pathway: global reach and national demise
- Migration and end of life care
Zaman with the volunteers and in a patient’s house in West Bengal, India – collaboration with Dr Devi Vijay
A community volunteer in Nadia, West Bengal

All my life I was involved in party politics. And in my political career I always had enemies and had to follow some one else’s order. I have left politics and joined the project as palliative care volunteer. For the first time in my life I realized that I do not have any enemy and I don’t need to follow any one’s order but my heart’s.
Public health

- Approach begins with WHO in early 1980s – starts with cancer pain, moves on to definition of palliative care
- Embodied in the WHO ‘foundation measures’
- From late 1990s appeals to the language of public health become more explicit
- Now we ask – which public health is relevant to palliative care and why?
- One aspect of this is in the practice of declarations …
The rise of palliative care declarations

Mapping the rise, spread, content and purpose of end of life care declarations in the global context - as markers of ‘the field’
Timeline of palliative care declarations

- 33 declarations
- 1983 – 2016
- 2011 – 2015 maximum activity (n=15)
Purpose

- Set out recommendations
- Call others to action
- Convictions of representing organisation
- Action plans for members to undertake
- Draw attention to specific issues through description
- Expressions of commitments by member organisations
Geographic reach and issues addressed

- 16 global
- International
  - Europe, Latin America, Developing countries (2 each)
  - Eastern Europe, Sub Saharan Africa, Selected European countries (1 each)
- National
  - UK (3), India (2), China (1)
- Regional
  - Ontario (1)
  - Kerala (1)
Key immediate goals

• Series of ‘concepts’ papers – on ‘the waiting room’, public health and palliative care, taxonomy of interventions, definition of palliative care, history of end of life care in the 20th century

• Case studies on: NNPC and related community approaches; declarations; death cafes; self directed interventions; ‘integral’ palliative care

• Forming academic partnerships with other researchers around the world

• Promoting wider public engagement with our work …
Public engagement - a strategic approach

Combining a communications and public engagement strategy from the outset of the project
Website
glasgow.ac.uk/endoflifestudies
Community participation in palliative care: A conversation with Dr Devi Vijay and Dr Shahaduz Zaman

As a medical anthropologist on the Wellcome Trust funded project, Global interventions at the end of life, I am interested in community participation in palliative care. In our study we are investigating the transfer and translation of a range of end of life interventions, across cultures and settings. One of these is the Neighbourhood Networks in Palliative Care [...]
Social media

@endoflifestudy
facebook.com/endoflifestudies
Video
Podcasting

soundcloud.com/endoflifestudies
Events
Teamwork culture

Communicating effectively as colleagues:

- Respect and kindness
- Regular contact
- ‘Curated’ meetings
- Getting out and about
- ‘Coffee and Chakrabarty’
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