TO DEATH AND BEYOND: LIVING AND DYING WITH AN INTELLECTUAL DISABILITY

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DEVELOPING A LIFE COURSE PERSPECTIVE

- ID Research - A cradle to grave perspective?
- Living with ID has been well explored to create a representation of a moving and complete life - including positive ageing
- Family life, life course phases and transitions, dimensions of a good life (health, wealth, sexuality, employment, home, friendships, social status, bereavement)
- Dying – one transition too far? What happens to people with ID at the end of their lives?
- Does death bring to an end our research questions? Does our research interest end with the last breath?
POST MORTEM CONCERNS

- Social an biological death may not be simultaneous
- An understanding on end-of-life care must include aspects that relate to the care and treatment of the dead; the ways people are remembered and how, if at all, people with ID have any role to play in shaping their after-life identities
- The need to account for the absence and presence of the dead with ID...... But not this morning
AIMS AND OBJECTIVES

- To use current social theorising and research to provide
  - A view of the importance of issues connected with death and dying
  - Identify the gaps that exist in policy, practice and research
  - To recognise the need to build international links around and perspectives of these hidden ID concerns
  - To develop completeness of a life course perspective in our research questions. What does it mean to have (have had) an intellectual disability from birth to the grave and beyond?
Dying and ageing are becoming more closely intertwined—(the greater the ageing, the greater the dying)

- Although one does not explain the other
- Ageing (positive ageing) is not about dying (but fighting social dying)
- Ageing must embrace an admission of death
Death is no longer a taboo
Only some deaths remain taboo (deaths by suicide, the deaths of devalued groups)
There has been a major change in our thinking about death
The focus has shifted from post to pre-mortem concerns, and from the dead to the living
The situation of with people with ID reflects social ambivalence concerning their lives
DYING AND END OF LIFE CARE

- Across the economically developed world, there is increasing attention being paid to End-of-Life Care
- The Quality End-of-Life Coalition of Canada; Palliative Care Australia, The End of Life Care Strategy in England.
- The Australia and the UK has one of the best systems for end of life care (Economist Intelligence Unit) in terms of access to services, quality of care and public awareness across 40 countries.
- However, the end of life care needs of people with intellectual disabilities are not well recognised in those or other countries.
Around 500,000 people die in England each year.

The vast majority (around 99%) of deaths occur in adults over the age of 18 years, and most occur in people over 65 years.

The majority of deaths occur following a period of chronic illness related to conditions such as heart disease, liver disease, renal disease, diabetes, cancer,
The age profile of people at the time of death and the relative frequency of different causes of death has changed radically since the start of the past century, when infectious diseases were the major killers in this country.

People are dying when they are older and dying is now long enough to constitute a distinct phase of life. There are concerns about the quality of care during this phase of life.

End-of-life care is concerned with making dying more personalised and less institutionalised.
PLACE OF DEATH

- The place where people die has also changed markedly over the past century with most deaths no longer occurring at home but in hospital. In 1900, about 85% of people died in their own homes, (with workhouses accounting for most other deaths). In the early twenty-first century acute hospitals have become the most common place of death. Is the hospital the most appropriate setting for death?
DEATH PROBLEMS

- Some evidence of the magnitude of the problem related to the quality of care given at the end of life comes from a recent survey of complaints within the NHS, undertaken by the Healthcare Commission.
- Its ‘Spotlight on Complaints’ report assessed just over a total of 16,000 complaints made about NHS organisations - 54% related in some way to end of life care.
- The complaints were mainly about poor communication, lack of basic comfort, privacy and psychological care and late or no referral for specialist palliative care.
- Moving death out of hospitals (individual, social, clinical and economic reasons) and revaluing home as a place of dying
Gomes and Higginson indicate that if the trend in home death proportions observed over the last five years continues, less than one in ten (9.6%) people will die at home by 2030. Institutional deaths would increase by over 20%.

At present most deaths in England occur in NHS hospitals (58%), with deaths at home (18%). Hospices account for around 4% of deaths, with around 3% occurring in other locations. and in care homes (17%) (based on ONS figures for 2004).

What is death like in a care home (evidence that it is as poor as death in the hospital).

However, 'care homes' are typically seen as care homes for older adults.
19,834 people live in care homes, 4062 are people with ID (20%).

There were 1572 care homes, 609 for people with ID (39%)

However, end of life care research in care homes does not deal with ID. In addition, ID research on quality of life in ID settings does not include dying.
In much the same way as the Institution is not seen as appropriate ‘place of living’ for people with ID, is it still the most inappropriate place for their dying. Where do people with ID become dead? Where does their dying taking place?

There are growing concerns about the quality of general hospital care for people with ID in the UK. Growing demands for palliative care intervention (National Network for Palliative Care for People with ID www.pcpld.org)

In Wales, reference is made to end-of-life and ID in both EOLD and ID policies, but they lack specificity and depth.

We are at the beginning of this new and emerging concern. This is an area for basic and complex research activities
Two peaks of mortality in the ID population
Substantially higher risk of death for younger people with severe and profound ID, reduces life expectancy estimates for people with ID
In terms of intellectual impairment, the literature suggests that life expectancy is substantially shortened in individuals with more severe intellectual disability
Death in ID has not been pushed back to later life – giving death a distinct profile in ID- parental/family bereavement; death anxiety; special education – that is seldom recognised in the literature
DEATH IN ADULTHOOD

- Median life expectancies of 74.0, 67.6, and 58.6 years for people with mild, moderate, and severe levels of disability (Bittles et al, 2003)
- Death in adulthood, and more so in later adulthood, and for people with severe ID, will be associated with death in non family or care settings.
- As for the general population, these will be deaths that are preceded by a prolonged phase phase of dying
- Can settings that supported living also support dying?
DEATH AND ID

- Rarely discussed together beyond mortality and survival, - defying death - so that dying and care of people of who are dying are seldom discussed.
- Need to promote death awareness in our services and academic activities, and not just in ageing.
- Awareness raising activities are limited without evidence
- Why is there a lack of evidence?
staff in social care settings find death and dying problematic,
lack of service level policies;
people with ID may not experience good dying,
poorly coordinated and inadequate service interventions,
the spectre of social death (isolation/separation) returns
(repeated transfers out);
lack of participation of people with ID in advance planning;
family-care staff tensions;
people with ID are willing to talk about the way death touches them!
RESEARCH AREAS

- Where are people with ID dying?
- What happens to people with ID in the last year or last months of life?
- What are the determinants of care at the end-of-life?
- What happens when someone is deemed to be dying?
- To what extent are people with ID participating in decisions about the end of their lives?
- How are staff/residents supported over dying and death phases?
- How is care maintained after death?
63 deaths across 3 large services providers of small scale settings. This represents a death rate of:

- 1 death for every three residents in ten years
- 17 deaths per 100 residents in five years
- 3.5 deaths per 100 residents every year
- Approx 1 death for every 8 service settings each year
- Male deaths: 31  Female deaths 32
- Average age at death = 61.8 years
- Standard deviation = 16 years
- 75% of deaths were between the ages of 46 and 78 years of age
AGE AT DEATH

AGE DISTRIBUTION:

- Under 30:
- 30-39:
- 40-49:
- 50-59:
- 60-69:
- 70-79:
- 80+:

Graph showing the distribution of age at death.
CAUSE OF DEATH

- Cancer: 14%
- Con. Defect
- Ageing
- Heart
- Organ F
- Epilepsy
- Other
- Dementia
- Resp
PLACES OF LIVING AND DYING

- **Hospital** 71%
- **Other** 21%
- **Home** 8%

- Average length of stay in hospital prior to death – 16 days (range from 1 day to three months)

- Length of stay in supported living setting prior to death
  *Average 8.6 years +/- 3.4 years*  80% of deaths occurred between 5 and 12 years after moving into the service setting

In 2002, the average completed length of stay for long stay residents in homes intended for older people was 2 years and 9 months
SERVICE ISSUES

- Lack of Routine collection of information after death
- No care/management ‘post-mortem’s’
- No Advance care planning in services
- Death but no dying policies
- No Training in and preparation for end-of-life care
RESEARCH ISSUES

- PROSPECTIVE DATA- ETHICS AND OPPORTUNISM
- RETROSPECTIVE DATA - ACCESS TO DATA – RECALL PROBLEMS- INDIVIDUAL EXPERIENCES LOST
- END OF LIFE CARE MEASURES- FOR WIDER POPULATION- FOCUS ON LAST DAYS/HOURS OF LIFE- HIGHLY SPECIALIST
- LAST YEAR OF LIFE-BROAD MEASURES OF SETTINGS, SOCIAL PARTICIPATION, HEALTH INTERVENTIONS; PAIN CONTROL
SUMMARY

- Community living settings are also dying settings
- Inadequately prepared for that dimension of support
- The evidence base is however ‘thin’ and ‘patchy’
- Develop an awareness of the importance of end-of-life care for people with ID
- National and international collaborations in end-of-life AND post mortem care?
- How valued are lives? How do we treat the dead?
HOW DID SHE GET HERE? HOW IS SHE REMEMBERED?