Dignity at the end of life in old age

Liz Lloyd
School for Policy Studies

Research Workshop
Institute of Advanced Studies
Law, Ethics and Palliative Care
21st February 2008

University of BRISTOL

- To look at different approaches to understanding dignity in research
- To look at the contemporary UK policy context
- To identify key issues for research and policy

Woolhead et al (2004): Dignity: A multi-faceted concept

- **Dignity of identity** – as it affected 'the self' respect, esteem etc. Could be jeopardised by suffering.
- **Human rights**; intrinsic dignity within the human being. Treated as an individual. Right to choose – eg how to live, where to die, decisions on euthanasia.
- **Autonomy** independence, control over own lives - for as long as possible. Can become undignified by 'hanging on to independence for too long'.

Nordenfelt (2004): Varieties of dignity

- **Dignity as merit**: Excellence, distinction. Related to rights and respect.
- **Moral Stature:** Dignified conduct *eg in the face of adversity.* Respectful of others, self-respect.
- **Dignity of identity:** Autonomous human beings, individual history and future,, relationships with others. *An objective reality?*
- **Menschenwurde:** dignity of human beings. Basic 'human' rights.

Pleschberger (2007) Residents' views of dignity and dying in nursing homes

- Intrapersonal and relational aspects of dignity
- Discourses of 'burdensomeness' of older people and impact of residents' sense of self-worth
- Need for help and care and absence of spouse/family support constrains expectations of dignity
- '*People matter as individuals for who they are and not what they can do'.*

UK Dept of Health ‘Dignity in care campaign’

- ‘Dignity champions’ publicising good practice
- Social Care Institute for Excellence: services should…
  - have a zero tolerance of all forms of abuse
  - support people with the same respect you would want for yourself or a member of your family
  - treat each person as an individual by offering a personalised service
  - enable people to maintain the *maximum possible level of independence, choice and control*

Etc……

A dignified policy approach?

Dignity in Care: Example of good practice:

- ‘Greenwich Macmillan Palliative Care Support Service
- Aims to *maximise choice* for patients at the end of their lives, allowing them to die at home, if that is their wish, in maximum comfort and with maximum dignity. It also offers support to carers’
- ‘Provide *support 24 hours a day, seven days a week* to ensure maximum flexibility to patients and carers; this is the key to enabling patients to die at home if this is their wish’.

  (funded by Macmillan Cancer Support and Greenwich Teaching PCT)

Key issues raised by Greenwich service

- The promotion of dignity at the end of life cannot be separated from questions about resources

- Providing this high standard of care for older people when they are in the ‘palliative’ category is in stark contrast to the standard that is evident in the long term care category.

Understanding the limitations of the policy context

- **Minimalist view of dignity**: *absence* of degrading treatment and stereotyping
- **Unrealistic aspirations:** Greenwich palliative care service – a good example of dignity in care but how widely could this be replicated?
- **Categories of welfare:** separation of long term care for older people from palliative care/care for the dying

Moral and ethical issues in the policy context

- Failure to link moral agenda regarding dignity with the political agenda of resources, service organisation – challenges dignity of identity
- Individualism in welfare services to the detriment of social needs – intrapersonal *vs* relational dignity
- Objectification of weak/vulnerable people. In old age, the need for care is often understood as 'what *we* should do to *them'* – challenges dignity of identity, self-worth and human rights

Relational dignity

- Intrapersonal dignity challenged in context of failing health and decline through extended dying trajectory
- Relational dignity *(*recognition of *menschenwurde,* intrinsic human value, 'personhood') could be applied in services for older people throughout extended and complex dying trajectories….
- …. but this would have significant implications for welfare resources and the organisation of long term care services