Thinking Ahead in Palliative Care

Annual Conference 2011

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Scottish Partnership for Palliative Care
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Advance care planning in dementia – will it make a difference and how?

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Plan

1. How does ACP fit with broader models of dementia care?
2. A review of the literature
3. Personhood in dementia: ethical and practical implications

The starting point

- Advance care planning is a good thing (it's in the End of Life Strategy)

But,

1 How does ACP fit?

The Question is:

- How is the care in advance care planning (ACP) to be characterized?

Or

- How can it be characterized (and does dementia make the characterization more difficult)?

A NICE–SCIE Guideline on supporting people with dementia and their carers in health and social care (2007)

- ‘Dementia care should incorporate a palliative care approach from the time of diagnosis until death. The aim should be to support the quality of life of people with dementia and to enable them to die with dignity and in the place of their choosing, while also supporting carers during their bereavement, which may both anticipate and follow death.’

Four (Broadening) Models

- Biomedical model
- Biopsychosocial model
- Palliative care model (biopsychosocial and spiritual)
- Supportive care model (adds time and depth)

Supportive care

Ahmedzai SH (2005). The nature of palliation and its contribution to supportive care, in Ahmedzai SH, Muers MF (eds) *Supportive care in respiratory disease*, pp. 3–33. Oxford: Oxford University Press.

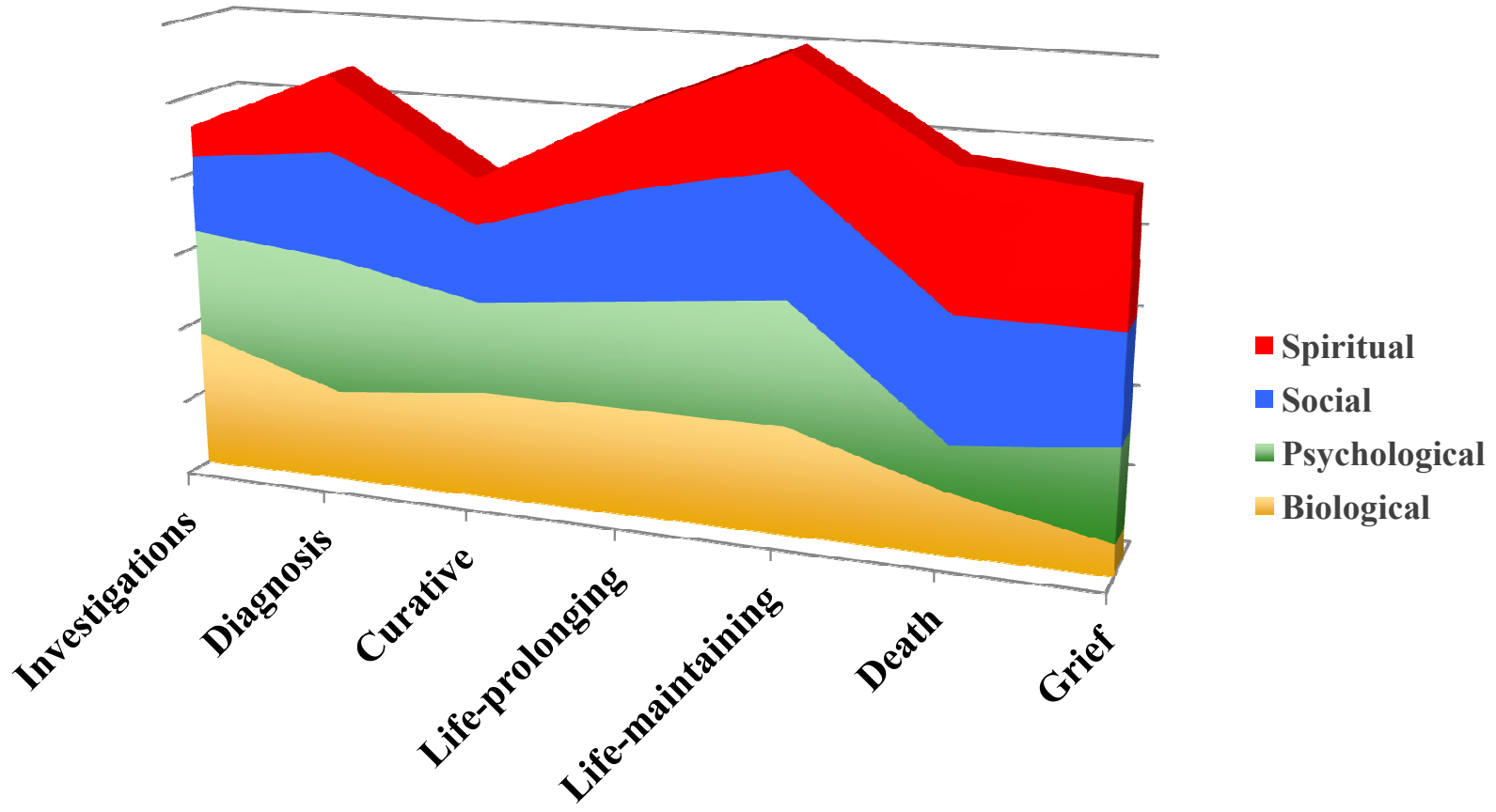
- Multidisciplinary
- Interdisciplinary
- Possibly virtual
- Continuity of care
- No dichotomies:
  - cure/care
  - high tech/low tech
  - biological/social
  - patient-centred/carer-centred
  - ‘being with’/‘doing to’

Supportive care in dementia characterized as:

- '…a full mixture of biomedical dementia care, with good quality, person-centred, psychosocial, and spiritual care under the umbrella of holistic palliative care throughout the course of the person's experience of dementia, from diagnosis until death and, for families and close carers, beyond.' (p. 301)

Hughes, J. C., Lloyd-Williams, M. and Sachs, G. A. (eds.) (2010). *Supportive Care for the Person with Dementia*. Oxford: Oxford University Press.

Supportive care (Figure 32.1 in *Supportive Care for the Person with Dementia* (eds. Hughes JC, Lloyd-Williams M, Sachs GA.) OUP, Oxford)



Four (Broadening) Models and Notions of Care

- Biomedical model
- Biopsychosocial model
- Palliative care model (biopsychosocial and spiritual)
- Supportive care model (adds time and depth)
- Focus on symptom control
- Adds the perspective of the psychosocial context
- The holistic view
- The practical approach: what can we do now?

The problems of ACP in dementia?

- How?
- When?
- Who?
- What?
- With whom?

The issue

- ACP as part of a model of care for people with dementia
  - What is it trying to achieve?
  - How shall we judge effectiveness?
    - Decreasing hospital admissions *vs* nature of human engagement
  - Isn't ACP in essence about a conversation?
  - The issue is to do with formally capturing this person-centred essence

Back to the notion of fit

- ACP as part of an on-going engagement in terms of care
- A broad model of care can accommodate ACP as part of a conversation
- A narrower model becomes legalistic, hung up on capacity
  - The evaluative nature of judgements about capacity in any case

2. Advance care planning in dementia

Advance care planning in dementia

- Lower incidence of advance care directives in dementia compared with cancer (Mitchell et al 2004)
- Older people, with or without dementia, are capable of making decisions about advance care planning (Karel et al 2007; Fazel et al 1999)

Robinson *et al. BMC Geriatrics* 2010, **10**:2
http://www.biomedcentral.com/1471-2318/10/2

BMC Geriatrics

STUDY PROTOCOL Open Access

Patient preferences for future care - how can Advance Care Planning become embedded into dementia care: a study protocol

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Some studies

Caplan, *et al.* **Advance care planning and hospital in the nursing home.** *Age and ageing* 2006; **35**(6):581-585.

- **Study design and setting**:
  - controlled before and after study; Australia; 32 nursing homes & 3 hospitals
- **Health care use:**
  - Annual rate of admission of residents went down by the final year (P<0.0001)
  - Risk of hospitalisation fell (*P*<0.0001)

Molloy *et al.* **Systematic implementation of an advance directive program in nursing homes: a randomized controlled trial.** *JAMA* 2000; **283**(11):1437-1444.

- **Study design and setting:**
  - Randomized control trial; 6 nursing homes (1133 residents) in Canada were randomly allocated to the two trial arms
- **Health care use:**
  - 49% of participants completed advance directives
  - mean hospitalisation rates per patient lower in the intervention group (*P* =0.001)
  - average total cost per patient significantly less in the intervention group (*P*=0.01)

Hanson *et al.* **A quality improvement intervention to increase palliative care in nursing homes.** *Journal of Palliative Medicine* 2005; **8**(3):576-584.

- **Study design and setting:**
  - controlled before and after study; USA; 9 nursing homes with 458 residents
- **Health care use:**
  - DNR orders increased slightly in intervention nursing homes (58% to 65%, P=0.04)
  - significant increase in the intervention group in pain assessment from 18% to 60% (*P*=<0.001); no change in orders for pain medication
  - significant increase in hospice enrolment: 4.0% at baseline to 6.8% post intervention (*P*=<0.01)

Morrison *et al.* **The effect of a social work intervention to enhance advance care planning documentation in the nursing home.** *Journal of the American Geriatrics Society* 2005; **53**(2):290-294.

- **Study design and setting:**
  - non-randomised controlled trial; 4 social workers were randomly allocated to two arms; USA; 139 nursing home residents
- **Health care use:**
  - significant increases in documentation of patient preferences in the intervention group; including artificial nutrition and hydration, intravenous antibiotics and hospitalisation
  - control residents were significantly more likely than intervention residents to receive treatments discordant with their prior stated wishes (p=0.04)

Interventions

- **Caplan**: Education for residents, families, staff and GPs
- **Molloy**: 2 day educational workshop for nurses in nursing homes who then trained other staff and counselled patients
- **Hanson**: Recruitment and training (in palliative care practices) in nursing homes
- **Morrison**: Education, using interactive methods, in ACP for intervention group social workers

Summary

- Some evidence that ACP is effective in dementia (quality of studies?)
- It's mostly education and training (in what essentially?)

Some further studies

Detering *et al.* (2010) The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ*, **340**:c1345

- 309 medical in-patients with capacity
- Randomised to normal care or care plus ACP
- 56 died by end of 6 months
- End of life wishes more likely to be followed in intervention group ($p<0.001$)
- In family carers, less stress, anxiety and depression

Stewart *et al.* (2011) Advance care planning in care homes for older people: a qualitative study …*Age and Ageing*, **40**: 330-35

- Benefits
  - Provides choice and better planning
- Barriers
  - Residents perceived by staff and family to be reluctant
  - Care assistants reluctant
  - Dementia as a barrier
  - Families and medical circumstances seen as problematic

Stewart et al. (2011) continued

- Facilitators
  - Early initiation of discussions
  - Family involvement to establish preferences
  - Residents and staff being well-known to each other
  - Staff training

Sampson *et al.* (2010) Palliative assessment and advance care planning in severe dementia….*Palliative Medicine*, **25**: 197-209

- Emergency hospital admissions with severe dementia and physically frail
- 32 patient participants: 62% pressure areas, all required help with feeding, 95% in pain
- 50% died during 6 months follow-up
- Only 7 carers made ACPs
- Care planning discussion was well-received, but despite intensive support, carers reluctant

Summary

- It may do some good
- Still, dementia is seen as a barrier
- When and whom?

3. Personhood in dementia: ethical and practical implications for palliative care including ACP

The argument

- Models of care broaden – they have to (to approximate to reality)
- Care is aimed at persons and judged accordingly
- Broad care is as broad as persons require
- Care in the future must be as broad as persons require
- But dementia challenges our abilities to judge what the person requires (more than other conditions?)

Old Arguments

- Experiential and critical interests
  - Dworkin, R. (1993). *Life's dominion. An argument about abortion and euthanasia.* Harper Collins, London.
  - Dresser, R. (1995). Dworkin on dementia: elegant theory, questionable policy. *Hastings Cent Rep* 25:32-38.
- Being a valuer
  - Jaworska, A. (1999). Respecting the margins of agency: Alzheimer's patients and the capacity to value. *Philos Public Aff* 28:105-138.

The SEA view of the person

Hughes JC, (2001) Views of the person with dementia. *J Med Ethics* 27:86-91.

- Situated
- Embodied
- Agent

Being an agent

- The demands of autonomy
- The limits of autonomy
- The situated agent
- The frail agent
- The dependent agent

Being embodied

- The need for symptom control
- The meaning of bodily movements and gestures

Being situated

- In a personal history or narrative
- In a family
- In a culture and society
- In a realm of morals and law
- In a spiritual field

ACP is about…

- The narrative account
- The space of values
- Situated agency
- On-going conversations
- Knowing the person through and through (values statements or LPAs rather than ADRTs)
- The embedded knowledge of families and cultures

What have I tried to do in this talk?

- I've emphasized the importance of broadening our models of care and seeing ACP as part of that
- I've considered some of the evidence-base concerning ACP in dementia
- I've wanted to shift our attention to ACP as a matter of conversation or narrative in the context of a human encounters involving persons as such

Thank You