Risk and dementia: the amplification of risk or risk reduction?

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Outline
Based on work compiling a guidance document for Department of Health
- What do we mean by risk and dementia?
- What ideas about risk are held by people with dementia, family carers and professionals?
- Which ‘risks’ cause most concern?
- Ways of approaching risk
- Discussion

Evidence of cautious approaches to risk
- Recognition of risk as a ‘danger’ rather than a liberation
- Higher eligibility requirements in terms of access to support from local councils
- ‘Managing risk’ now important than ‘meeting needs’ (Manthorpe, 2004)
- Undertaken at cusp of Labour/Coalition governments
- End to ‘red tape’ and bureaucracy

Part of wider work to inform implementation of dementia strategy
- Emphasis to be on ‘risk enablement’ and ‘positive risk taking’

What we did
- Literature review to identify suitable material
- Consultation with practitioners, policymakers, researchers, family carers and people with dementia
- Guidance designed to be used for all agencies involved in supporting people with dementia

Findings from literature
- ‘Risk’ seen in terms of aetiology
- ‘Risk’ seen in context of where people with dementia ‘should’ be cared for
  - ‘Wandering’ and getting lost
  - Safety inside and outside the home
- ‘Risk’ in terms of impact of diagnosis
  - Efforts to increase access to memory clinics
  - Advances in early diagnosis
**Most often presented in terms of ‘risk of’ developing dementia**

- Link between heavy smoking and Alzheimer’s suggested
- Heavy drinking may be to blame for one in four cases of dementia
- Obesity may be linked to dementia
- Food intake

**Even caring has its risks!**

- 60% greater risk of dementia among spouses of persons with dementia than among spouses of persons without dementia
- Explanations include assortative mating, shared lifestyle, and caregiving
- Obviously needs replicating

**Public preferences for care**

- West and colleagues (1984)
  - Presented a series of vignettes to a random sample of people drawn from the electoral register in Glasgow
  - Vignettes presented different examples of people needing care and support
  - Long term care was always the least favoured option EXCEPT in case of the vignette depicting a person with dementia
- No recent work replicating this study

**Being ‘at risk’ of dementia**

- Corner & Bond (2004)
  - Interviewed 15 people without dementia as part of a wider study of quality of life and dementia
  - Fear of developing dementia was a major theme for them
  - Assumption that long term care was inevitable
  - Assumption that only ‘basic’ care is possible because it is impossible to influence quality of life

**Impact of diagnosis**

- McColgan and colleagues (2000)
  - Use Goffman’s concept of the ‘moral career’ to discuss way in which Iris Murdoch’s life is presented
  - Discussed almost totally in terms of her Alzheimer’s disease
  - People with dementia become the ‘personification of risk’ (Manthorpe, 2004)
Robinson and colleagues (2007) compared the process of risk appraisal by professionals, carers, and people with dementia. Professionals tended to focus management strategies on the future, emphasizing the physical domain of risk, for example falling. Family carers focused on the present and the interpersonal domain of risk, for example the loss of the partnership role. People with dementia appeared most concerned with the biographical domain of risk, for example, the loss of self identity.

Gilmour and colleagues (2003) compared approaches of different professionals. Community nurses emphasized the risks of falling and not having adequate nutrition. Social workers spoke about issues such as dealing with heating, managing money, wandering, and cooking. Care workers’ approach based on situated risk – a man who went for walks outside his own home was less at risk because he had neighbours who knew him and who would take him home if he got lost. By contrast, when he went into a care home he was thought to be at greater risk if he went out walking because he was in a new location situated near a main road.

Professionals tend to look at risk in a generalised way (Carr, 2010). People with dementia and family carers take a more personalised view.

‘Big’ issues
- Around diagnosis
- Around driving
- Around money
- Around entry into long term care

Less on everyday issues
- Leaving a person with dementia alone in the house
- What to do about smoking?

Risk ‘heat map’
- Maximise safety enhancement and risk management - protect the individual and manage the activity
- Carefully balance safety enhancement and activity management to protect the person
- Set realistic safety enhancement necessary - carry out with normal levels of safety enhancement
- Undertake the activity or seek alternatives that may provide a better relationship with their needs

Rights based or safety first?
- Clearer legal framework for actions
- Mental Capacity Act
- Deprivation of Liberty (DoLS) guidance
- Wider community awareness?
- Role of other family members, not primary carers?
- Neighbours?
- But Nuffield Council on Bioethics emphasised most difficulties occurred in ‘in between’ stage in terms of capacity
Discussion (1)
- Consistent with existing literature about risk being situated in own experiences and expectations (Kemshall, 2010) and ‘risk’ as a context specific concept
- Emphasis on risk enablement rather than harm minimisation contrasts with, for instance, alcohol or drugs policies
- Emphasis is still on ‘big decisions’ rather than smaller everyday decisions

Discussion (2)
- Typifies wider debates about rights to take risks versus ‘safeguarding’ of groups deemed to be vulnerable
- ‘Risky’ behaviour especially associated fronto-temporal dementia
- Extent to which dominant notions of risk are shared by people from different ethnic backgrounds
- Differences in views on autonomy and independence?

Discussion (3)
- Wider literature on ‘risk’ generally excludes people with dementia
- How do professionals acquire knowledge about risk
- Social work qualifying education – Task Force evidence focused on child protection
- Focus on early and late stages – by definition this excludes a large group

Discussion (4)
- ‘Risk’ as an agent of policy
- Coalition commitment to reducing red tape and bureaucracy

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