BSA Risk Study Group Conference: Risk, Policy and Decision Making 12 April 2011

Risk & dementia

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Risk and dementia: safety first or rights-based decision making?

- Work based on 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
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’

Cigarettes  Alcohol  Food intake
600% 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

OBJECTIVES: To examine the effects of being a spouse with dementia on the caretaker's risk for incident dementia.


SETTING: Rural county in northern Utah.

PARTICIPANTS: Two thousand four hundred and forty-two subjects (2,423 married couples) aged 49 and older.

MEASUREMENTS: Incident dementia was diagnosed on the basis of a structured interview using the Diagnostic and Statistical Manual of Mental Disorders, Third Edition. Informed consent, and a balance of cognitive and functional measures. Additional tests and clinical evaluations for follow-up are scheduled.

RESULTS: A spouse whose spouse experienced incident dementia had a six-times greater risk for dementia at the baseline than a spouse whose spouse was not incident dementia free (odds ratio [OR] = 6.0, 95% confidence interval [CI] = 1.5 - 25.5; P = .01). In a sex-specific analysis, husbands had higher risks than wives (P = .04). Additional tests and clinical evaluations for follow-up are scheduled.

CONCLUSION: The effects of being a spouse with dementia on the caretaker's risk for dementia are significant. Additional tests and clinical evaluations for follow-up are scheduled.

Key words: dementia, caregivers, risk.
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
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
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)
Context

- Cautious approaches to risk
  - Recognition of risk as a danger more than liberating aspects of risk
- Higher eligibility requirements in terms of access to support
  - ‘Managing risk’ now important than ‘meeting needs’ (Manthorpe, 2004)
Remit

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

1. Literature review to identify suitable material

2. Consultation with practitioners, policymakers, researchers, family carers and people with dementia

3. Guidance designed to be used for all agencies involved in supporting people with dementia
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 focussed on the present and the interpersonal domain of risk, for example loss of the partnership role.
- People with dementia appeared most concerned with the biographical domain of risk, for example, the loss of self identity.
Key themes 2: differing perspectives 2

- Gilmour and colleagues (2003) compared approaches of different professionals
  - Community nurses emphasised 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.
Key themes 3: generalised versus personal experiences

- Professionals tend to look at risk in generalised way (Carr, 2010)
- People with dementia and family carers take a more personalised view
  - Frequency of self regulating behaviour (for instance, giving up driving)
Which issues are debated

- ‘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’**

<table>
<thead>
<tr>
<th>Risk of harm or risk to quality of life of individual</th>
<th>Contribution to quality of life</th>
<th>Maximise safety enhancement and risk management – protect the individual and manage the activity</th>
<th>Carefully balance safety enhancement and activity management to protect the person</th>
<th>Minimal safety enhancement necessary – carry out with normal levels of safety enhancement</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td>High</td>
<td>Maximise safety enhancement and risk management – protect the individual and manage the activity</td>
<td>Carefully balance safety enhancement and activity management to protect the person</td>
<td>Minimal safety enhancement necessary – carry out with normal levels of safety enhancement</td>
</tr>
<tr>
<td>Substitute – can the same personal benefit be delivered in a different way – seek different activities?</td>
<td>High</td>
<td>Carefully balance safety enhancement and activity management to protect the person</td>
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<td>Minimal safety enhancement necessary – carry out with normal levels of safety enhancement</td>
</tr>
<tr>
<td>Find alternatives – level of risk is not related to the benefit/value to the person – find alternatives</td>
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<tr>
<td>Challenge real value of the activity to the individual – seek alternatives that are more attractive and lower risk</td>
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<tr>
<td>Undertake the activity or seek alternatives that may provide a better relationship with their needs</td>
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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?
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 with 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?

Find guidance here!
Thank you

- For listening!
- To Claire Goodchild for commissioning the guide
- To Simon Ricketts for help with the framework
- To everyone who commented and gave advice
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