

DEMENTIA & RISK: CONTESTED TERRITORIES OF EVERYDAY LIFE

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Dementia and its societal impact

- *'The most significant health crisis of the 21st Century'* (Wellcome Trust 2010)
- 35.6 million people worldwide and rising (Alzheimer's Disease International 2012)
- Dementia costs US\$315.4 billion annually, one third of which is care by families (Wimo et al 2005)
- A key public health concern (WHO 2012)

The Challenge of Everyday Life

- Home – a place that is non-threatening, with habitual routines and without surveillance?
- In the presence of living with a dementia?
 - Risk of adopting the characteristics of a total institution, with mortification of the self, routinisation and surveillance (Askham et al. 2007)
 - The carer as a mediator between private experiences and public services (Galvin, Todres & Richardson 2005)

The Study

- The Construction & Management of Risk in Dementia Care (Health Foundation)
- Multi-phase study including:
 - Interviews with 55 people with dementia (up to 2 interviews each) and their nominated family and professional carers
 - 3 groups: living independently, living with some service support, residential care
 - 3 study areas: NE England, Lothian, North Wales

Analysis

- ◎ Symbolic interactionist frame of analysis
- ◎ Triadic case studies
- ◎ ‘Contested territories’ of everyday living with dementia, their symbolic meanings and practical manifestations
 - > Friendships
 - > Smoking
 - > Going out
 - > Domestic arrangements
 - > Occupation and activity

Exemplar Case Studies

- ◎ **Margaret** – in her 60's, lives alone, nominated her daughter Sarah and OT
- ◎ **Martin** – in his 80's living with his wife Jane in a remote area, nominated Jane and community practitioner
- ◎ **Jack** – in his late 70's, lives with his wife Kath, has several other health problems, nominated Kath and CPN
- ◎ **Mary** – lives with her partner Peter, nominated Peter and day centre staff

Friendship

- ⦿ Making sense of the situation
 - > ‘we can all have a laugh’ (Mary)
 - > ‘she realises she is not alone any more’ (Peter)
- ⦿ Maintaining identity
 - > ‘I feel human’ vs ‘it is always “now don’t do this” and “don’t do that” or “you’ll not like that”’ (Mary)
- ⦿ Supporting activities
 - > ‘always on the lookout for me’ (Martin)
- ⦿ Contraction of friendships
 - > ‘he takes so long to tell his stories I think some people get a little bit bored or intolerant of it’ (Jane)

Smoking

- The paradox
 - ‘Other people would say “well you shouldn’t smoke” but it’s the only pleasure I’ve got, it calms me down’ (Mary)
- Part of social life
 - ‘There’s four of us like to go outside for a cigarette...I can have a cigarette and discuss things’ (Mary)
- A cause of surveillance
 - ‘She’s burning her jumpers...dressing gown, full of holes’ (Peter)

Domestic Arrangements

- Relinquishing responsibilities, maintaining identity
 - ‘I put them (dishes) back all in the wrong places. So he’s has to sort that out. “Will you please leave that alone”, and I feel like I’m not wanted’ (Mary)
 - I used to love cooking...now I can’t, I live out of packets...it’s hard to give the things up, the cupboard’s still full of cooking things’ (Margaret)
 - ‘I mean, when they discovered (the debt) it was quite a shock to the system’ (Kath)
- Surveillance
 - ‘the problem now is watching, wondering what she’s doing now, mislaying things’ (Peter)

Occupation & Activity

- ◎ A sense of purpose
 - ‘when I had to stop (counselling) I felt useless’ (Margaret)
 - ‘I leave her grandchildren with her because one, it alleviates the fact that she feels useless’ (Sarah)
- ◎ Changing social role
 - ‘I used to do all the work (for holidays with friends) but it’s all, had to turn it over to her (wife) you see – who’s really good, I think she’s far better than me actually I ever was’ (Martin)

Going Out

- ◎ Maintaining identify
 - ‘I miss doing things most women do, go shopping...now and again I sneak out...I don’t tell Peter because he’ll go off it’ (Mary)
 - ‘Oh I think it would kill him if they (took away) the driving! Not kill him, but I think that would be terrible! I think he’d deteriorate if he couldn’t drive’ (Jane)
- ◎ (In)dependance
 - ‘I don’t like it, I hate it, I feel a bit vulnerable...I hate depending on other people, and you’re asking people to do things for you’ (Margaret)
 - ‘I was told I shouldn’t drive’ (Jack)
- ◎ Difficulty maintaining friendships
 - ‘she just refuses to go anywhere without anybody so she’s very isolated’ (Sarah)

Everyday Life and Dementia

- Everyday life becomes an unstable structure with competing social expectations of independent adulthood and dementia
- Each member of the triad seeks to build a bridge to each other, recognising their need for each other but also their differences

The Purposes of Contested Territories

- Sense-making
- Maintaining identity
- Claiming and relinquishing decision making
- Creating purpose(lessness)

Contested Territories and the Experience of Risk

- ◎ Everyday life has a dynamic nature, in which a person with dementia, their family carer and practitioners variously seek to amplify or attenuate risk constructions, assessment and management
- ◎ This is critically important in the light of Bond et al. (2002) – diagnosis of dementia may lead to professional judgements about lack of insight, and so to depersonalisation and loss of independence irrespective of the probability of risk.

Risk: Quality of Life or Physical Safety?

- Creating 'silent harms' (Clarke et al 2011)
- Managing risk by attending to physical safety only can lead to (Titterton 2005):
 - Ignoring other needs
 - Denying right to choice and self-determination
 - Loss of a sense of self-esteem and respect
 - A form of institutionalisation with loss of individuality, volition and increase in dependence
 - At its worst, can lead to abuse of vulnerable people.

RISK MANAGEMENT IS ONE OF THE MOST COMPLEX ASPECTS OF PROFESSIONAL PRACTICE

And one that can have an enormous impact on the quality of life of someone living with dementia

Staff managing risk - key messages

- The dilemmas faced by many staff concerned balancing independence and autonomy with exposure to potential harm.
- Maintaining safety and protection from harm is, in the view of some staff, insufficient.
- The dilemmas faced by practitioners and service managers in risk assessment in dementia care are complex, and profoundly influence the nature of care available to people.

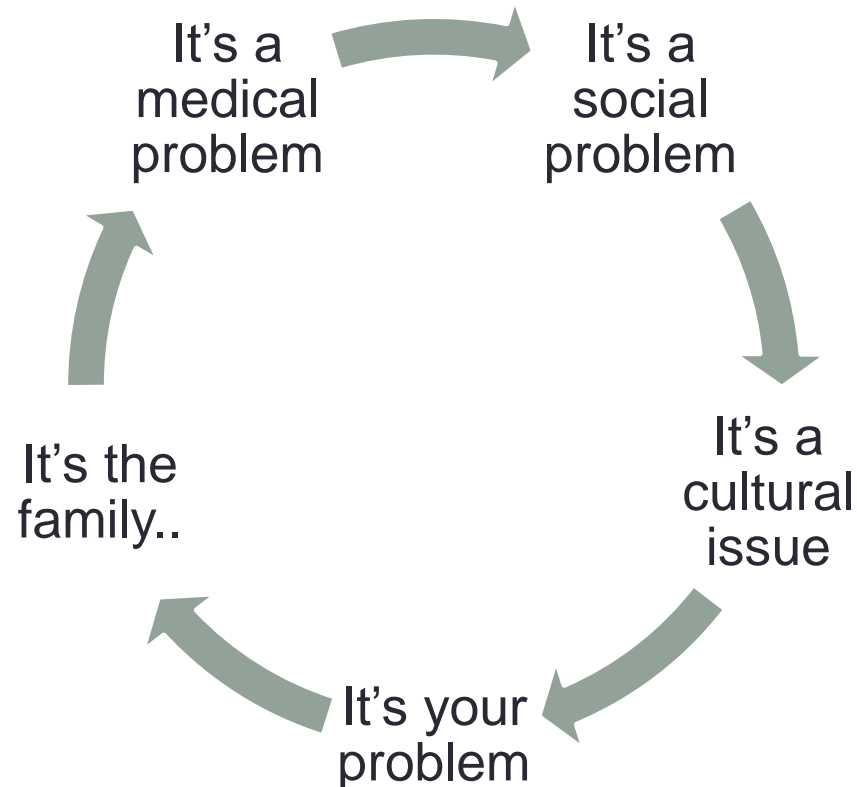
Managing risk - judgments

- Making judgments – being judged
- Making judgments for fear of being judged
- Working with multiple views of the 'right' thing to do
- How to gather and interpret information to inform judgments
- Keeping the person central for person-centred care



Managing risk - team working

- Conflicting views between colleagues, between professions & between sectors



Roles in Risk Management (Alaszewski et al 1998)

- Risk is a hazard
 - and the practitioner is a **hazard manager**
- Risk is potentially empowering
 - and the practitioner is a **risk facilitator**
- Risk is a dilemma
 - and the practitioner is an **dilemma negotiator**

Supporting Quality of Life Through Positive Risk Taking

- Enable people to manage uncertainty rather than create certainty - avoid unnecessary dependence and risk avoidance
- Effective advocacy of the views of the person with dementia – involve them in decisions about risk taking or risk avoiding
- Ensure that assessment includes psycho-social and emotional wellbeing as well as physical safety, and builds on people's existing coping strategies and resilience
- Ensure that there is good communication within and between services.

Framework for Risk Assessment & Management (Clarke et al 2011)

1. Identify risks in the life-context of personal biography & everyday life
2. Identify risk perspectives
3. Weighting of risks
4. Identify current and past strategies for managing risks

Personal Risk Portfolio (Manthorpe & Moriarty 2010)

High Quality of Life	Yellow	Yellow	Green
	Red	Yellow	Green
Low Quality of Life	Black	Yellow	Green
	High risk of Harm	Low of Harm	

Legend:

- Black: Stop
- Red: Substitute
- Yellow: Balance carefully
- Green: Continue

In Conclusion...

- Contested territories are purposeful and dynamic.
- Through these territories, the person with dementia, family and practitioners seek to moderate each other's perceptions of risk, and explain and reconcile the changing family dynamics