Everyday decision-making among people with dementia and carers

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EviDEM Programme of Research – Mental Capacity Act
Overall study

- Five year research programme funded by National Institute for Health Research
- Looking at the implementation of the Mental Capacity Act (MCA) in England and Wales and how it applies to people with dementia and their carers
- MCA encourages people to plan in advance for later life care and finances
Today’s presentation

How do people with dementia and carers living at home make and sustain everyday decisions?
Methodology

- Qualitative longitudinal study
- Case studies of 12 people with dementia and their carers
- Interviews every 6 month over 1.5 years
- Framework analysis to develop categories

EviDEM
www.evidem.org.uk
Interviews

Four main topics covered:
- Types of everyday decisions
- How were these discussed and negotiated
- Key areas for tension and how were these managed
Underlying principles

- Autonomy
- Decision-specific
- Best interest
Underlying principles

**Autonomy**
- Maintaining autonomy in people’s lives dominant theme
- Aware that likely to deteriorate over time

**Decision-specific**
- All decisions made in context, often as part of everyday conversations and incorporated into lifelong and established routines
  **Types:**
  - Discussing meals at start of day
  - Deciding when to go shopping
  - Planning holidays

**Best interest**
- When making decisions on behalf of relative with dementia, most carers factored in relative’s best interest or well-being
- Often, unconsciously
Decision-making discourse

Supported decision-making

Substituted decision-making
**Mutual decision-making**
Decision-making was undertaken together
Part of shared regular conversations

*I like retirement. I like being at home. We [wife and him] have breakfast together and decide what we’re going to do all day. Mostly we’re together but if she has one of her Ramblers’ outings, I don’t stop her. I’m not that kind of husband! But mostly we do things together.*

(Husband with dementia)
Reductive decision-making

- Carers enabled relatives to make their own decisions by providing cues
  - Such as fewer options when presenting them with a question
- Commitment to engage them in decision-making still remained strong
Decision-making discourse

Mutual
Part of regular conversation

Reductive
Providing cues and fewer options

Restrictive
Deciding what can be avoided

Supported decision-making

Restrictive decision-making

• Carers reduced decision-making opportunities for relatives with dementia by making smaller everyday decisions on their behalves
  • And “saving” their relative's decision-making capacities for bigger, more significant decisions

You have to remember that we’ve been retired for over 20 years now! So it's easy for me to know what he likes for dinner, I don’t bother asking him things like that. Save him for the bigger decisions, if you know what I mean! [Laughs.] But it's true in a way, I suppose, he can’t do everything now so I guess I try to manage our life in that way.
Retrospective decision-making
• If carers had to make proxy decisions for their relatives, they tended to fall back on past knowledge of their relative with dementia
• Past preferences, beliefs and habits were cornerstones of proxy decision-making, especially for spouse carers
• Adult children more likely to base them on conversations they had had
• Stronger relationships appeared to find making proxy decisions easier

Oh I don’t ask her what she wants anymore. I know what she’ll say anyway – “anything you like, you decide”. So I just do what’s best for us both. She has never had sugar in her tea. Never! And lately, she seems to like it. So I let her be, let her have it if that’s what makes her happy. When the sugar runs out, I’ll get some more but I’m not going to break my back getting the sugar for her because she’s never liked it before, you know?
Best interest?

- Challenges remain in understanding how best interest decisions can be weighed up practically i.e. whose best interest if well-being of one (carer) depends on well-being of the other (relative with dementia)?
- Common examples given:
  - Respite care
  - Giving up driving
  - Moving them closer to where the carer lives

My doctor’s told me that I need to make sure that my health does not suffer, and I have started to a bit more. I eat better now. I know I should be doing anything that’s good for him, and I would. But I get so tired these days and I worry… if I go what will happen to him? So sometimes I need to force myself to rest… for his benefit, if you see what I mean? (Wife caring for husband with dementia)
Decision-making discourse

- **Mutual**
  Part of regular conversation

- **Reductive**
  Providing cues and fewer options

- **Restrictive**
  Deciding what can be avoided

- **Retrospective**
  Past knowledge, preferences, conversations

- **Best interest?**
  Whose best interest?

- **Negotiating substitute decision-making**

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Implications

- Not all decisions are made in isolation
- Decision-making discourse suggests that carers in an ongoing and regular way negotiate these
- Principles of autonomy, decision-specificity and best interested, enshrined in legislation like the Mental Capacity Act were applied routinely
- Inequalities in information access common
  - Ways to balance and make best interest decisions
  - Support for making joint decisions with relatives and on their behalves
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Thank you!

- For further details

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