How do carers decide for their relatives with dementia?

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EviDEM Programme of Research –
Mental Capacity Act
Our study

☐ Five year research programme funded by National Institute for Health Research

☐ Investigating the implementation of the Mental Capacity Act 2005 in England and Wales, and how it applies to people with dementia and their carers
Today’s presentation

☐ MCA provides frameworks to enable people with dementia to make their own decisions

☐ Encourages people to plan in advance and nominate a Lasting Power of Attorney, someone who can make decisions regarding care and treatment on their behalves, if required.

☐ Decisions may include *everyday decisions*, as well as *major decisions about care, treatment and finances*.
Research Question

How does the Mental Capacity Act support and enable everyday decision-making for people with dementia and their carers living at home?
Methodology

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

Four main topics covered:
- Types of everyday decisions
- How were these discussed and negotiated
- Areas of possible tension and
- Relevance of MCA principles in managing them
Underlying principles

- Autonomy
- Decision-specific
- Best interests
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
Supported decision-making

Decision-making discourse

Substituted decision-making
Support decision-making

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

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
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.
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
• Carers tended to fall back on past knowledge of their relative with dementia
• Past preferences, beliefs and habits were key, especially for spouse carers
• Adult children referred to earlier conversations
• Stronger relationships made 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?
Balancing conflict

- How can best interests decisions be weighed up practically? i.e. whose best interests 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 closer to where the carer lives

My doctor’s told me that I need to make sure that my health does not suffer... So sometimes I need to force myself to rest... for his benefit, if you see what I mean? (Wife of husband with dementia)
Decision-making discourse

Supported decision-making

- Mutual
  - Part of regular conversation

- Reductive
  - Providing cues and fewer options

Substituted decision-making

- Restrictive
  - Deciding what can be avoided

- Balancing conflict
  - Whose best interest?

- Retrospective
  - Past knowledge, preferences, conversations

- Negotiating substitute decision-making
Understanding domestic decisions

- Decisions rarely made in isolation
- Carers regularly negotiate decisions
- Mental Capacity Act itself was rarely known or identified but principles of autonomy, decision-specificity and best interests seem relevant to carers
- Carers struggled with deciding for their relatives and lacked support about this part of their role
- Practitioners could discuss day to day worries...
  - How to balance and make best interests decisions
  - How to support joint decisions
Disclaimer:

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Thank you!

For further details

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