Tittel: Everyday decision-making in dementia: findings from a longitudinal interview study of people with dementia and family carers

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Sammendrag:

Background: Exercising choice and control over decisions is central to quality of life. The Mental Capacity Act 2005 (England and Wales) provides a legal framework to safeguard the rights of people with dementia to make their own decisions for as long as possible. The impact of this on long-term planning has been investigated; everyday decision-making in people's own homes remains unexplored.

Methods: Using a phenomenological approach, we interviewed 12 dyads (one person with dementia + one carer) four times over one year to ascertain experience of decision-making, how decisions were negotiated, and how dynamics changed. Qualitative interviews were conducted in people's own homes, and thematic analysis was applied to transcripts.

Results: Respecting autonomy, decision-specificity and best interests underlay most everyday decisions in this sample. Over time, dyads transitioned from supported decision-making, where person with dementia and carer made decisions together, to substituted decision-making, where carers took over much decision-making. Points along this continuum represented carers’ active involvement in retaining their relative’s engagement through providing cues, reducing options, using retrospective information, and using the best interests principle. Long-term spouse carers seemed most equipped to make substitute decisions for their spouses; adult children and friend carers struggled with this.

Conclusions: Carers may gradually take on decision-making for people with dementia. This can bring with it added stresses, such as determining their relative's decision-making capacity and weighing up what is in their best interests. Practitioners and support services should provide timely advice to carers and people with dementia around everyday decision-making, and be mindful how abilities may change.

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