

Managing uncertainty in care for people with dementia at the end of life: The use of heuristics

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Introduction

The end of life for someone with dementia can present a series of challenges for practitioners. Challenges may be eased with the development of heuristics (rules-of-thumb). For example, FAST is used in stroke: **F**acial-weakness, **A**rm-weakness, **S**lurred-speech, **T**ime to call 999. This study aimed to develop a toolkit of heuristics to aid practitioners making difficult decisions when caring for someone with dementia at the end of life.

Methods

A co-design approach with three phases:

- 1) Focus groups and semi-structured interviews with family carers and practitioners, to identify key decisions and how these should be made.

Results were presented to a co-design group consisting of health and care practitioners, and family carers tasked with developing a toolkit of heuristics, through workshops.

- 2) Testing the heuristics in practice for six-months in five clinical settings.
- 3) Evaluation of heuristics through interviews and questionnaires at three and six-months.

Results

Four sets of heuristics were developed; eating/swallowing difficulties, agitation/restlessness, reviewing treatment, and routine care. The heuristics are arranged as flowcharts. Eating/swallowing difficulties have two rules; ensuring eating/swallowing difficulties do not come as a surprise and reflection about 'comfort-feeding' only. Agitation/restlessness encourages a holistic approach, considering the environment, physical causes, and caregivers' health/wellbeing. Reviewing treatment/interventions prompts practitioners to consider the benefits to quality-of-life and comfort. Finally, routine care, such as bathing, prompts practitioners to ensure care interventions have positive impacts on quality-of-life.

Conclusions

Teams liked the simplicity of the heuristics, making their implicit knowledge explicit, enhancing their confidence in making decisions at the end of life.