

CONFERENCE ABSTRACT

Understanding the outcomes of specialist nursing: the continuing importance of relationships for carers of people with dementia

18th International Conference on Integrated Care, Utrecht, 23-25 May 2018

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Introduction: Unpaid carers are the most valuable resource we have in dementia care, yet little is known about how best to support them.[1] Recent systematic reviews have highlighted a dearth of evidence on the impact of community based case-management services as a means of integrating support for carers of people with dementia^{1,2}. Admiral Nursing is the only specialist nursing dementia service in the UK with a specific focus on carers. In addition to providing emotional support and helping people to live positively with the condition, Admiral Nurses seek to join up different parts of the health and social care system so that needs can be addressed in a coordinated way.

Theory/Methods: We report here the qualitative findings of a study of support for carers of people with dementia which had Admiral Nursing as an exemplar. A limitation of some previous research on interventions for carers has been the choice of outcomes, which have been poorly aligned to the priorities of carers or the aims of the services evaluated.[2] We interviewed and conducted focus groups with 35 carers of people with dementia (half with and half without an Admiral Nurse) to ascertain from their perspectives which outcomes might be influenced by services like Admiral Nursing.

Results: Three key outcome areas were identified by carers that could be influenced by Admiral Nursing: confidence in caring; carer quality of life; and carer physical and mental health. We selected and tested measurement tools aligned to these outcomes.

Discussions: Our findings highlighted the value that carers place on continuity and 'feeling supported' as dementia progresses. Having an ongoing relationship with a specialist in dementia who knew them and their situation well gave them the confidence to continue caring in spite of the difficulties and uncertainties they faced. These findings resonate with the author's previous research into support for people with complex needs and long-term neurological conditions.

Conclusions: Confidence (or self-efficacy) and how well-supported service users feel, are outcomes rarely measured in evaluations of dementia case-management. Yet successive qualitative research suggests that these outcomes, which are potentially influenced by having an ongoing relationship with a professional with condition specific expertise, are important

to people with complex needs and may well be influenced by the quality and availability of support services.

Lessons learned:

- Carers of people with dementia place a high value on having an ongoing relationship with a specialist in dementia
- Such support could influence carer self-efficacy and quality of life

Limitations: This was small-scale qualitative research, focussed on the UK system

Suggestions for future research: There is a need for quasi-experimental research to measure the impact of different models of case-management (in different contexts) on these outcomes.

References:

- 1- Parkinson, M., Carr, S. M. Rushmer, R. and Abley, C. Investigating what works to support family carers of people with dementia: a rapid realist review. *Journal of Public Health* 2016;38(3)
- 2- Thomas S, Dalton J, Harden M, Eastwood A, Parker G. Updated meta-review of evidence on support for carers. *Health Serv Deliv Res* 2017;5(12)

Keywords: dementia; case-management; specialist nursing; outcomes; qualitative
