fusebrief

Fuse - Centre for Translational Research in Public Health

- A partnership of public health researchers across the five universities in North East England
- Focused on working with policy makers and practice partners
- A founding member of the NIHR School for Public Health Research (SPHR)
- A UK Public Health Research Centre of Excellence

What works to support family carers of people with dementia?

The prevalence of dementia in the UK is spiraling, making reliance on family care essential. However, the unique challenges dementia presents to family carers can place their health in jeopardy and require special individual support. Fuse researchers at Northumbria University are identifying solutions that are sensitive to this context.

Dementia presents novel and distinctive challenges to family carers in comparison to other diseases such as cancer. The challenges include the lengthy time course of dementia, the inevitability of an irreversible decline in health for the people with dementia (PWD) and the unpredictability of the disease's day-to-day manifestation. These challenges give rise to significant health inequalities for many family carers of PWD.

A recurring theme in family carer research is the polarity of carer response to the challenges of taking on the role: while some carers become overwhelmed by the experience, others appear to not only maintain stability but may even report improvements over time.

What helps those carers who succeed in maintaining and sustaining long-term care of PWD and how can this knowledge be used more widely to benefit other family carers, particularly those who feel overwhelmed? Researchers from Fuse, the Centre for Translational Research in Public Health, are undertaking a two year realist evaluation (to explain what works for whom, how and in which circumstances) to investigate this burgeoning issue as part of a four phase project, funded by the Medical Research Council.

The initial two phases have been completed and comprised a review of relevant research from the past decade to investigate the key factors, strategies, interventions, contextual factors and mechanisms that support family carers of PWD. This generated several theories about how carer support might be maximised. The remaining two phases will include a realist evaluation to examine these theories in relation to family carers' own views concerning what helps or hinders the long-term care of people with dementia.

Key Findings

- Maintaining and building resilience is crucial to the long-term family care of people with dementia.
- However, resilience lacks a clear definition in the literature and research tends to focus on a single factor that oversimplifies how the concept operates in adult health.
- We propose a definition that is context sensitive in order to be useful for policy and practice partners by taking into account:
    a. External resources that are available to the family carer from vital support services
    b. Internal resources that are available to the family carer, such as carers' physical health status, and
    c. How both resources combine to influence the carers' quality of life.
- Five areas were identified as critical to supporting carers of people with dementia:
    1. Carers' social assets
    2. Carers' psychological resources
    3. Their physical health status
    4. Their quality of life, and
    5. Access to external resources.

Policy relevance and Implications

- Researchers and commissioners of services for people with dementia need to take fuller account of the many ways in which the resilience of family carers can be strengthened so that they are better equipped to deal with the challenges they face.

Local authorities can increase the five identified support areas for carers of people with dementia by:

- Extending carers' social assets.
- Strengthening key psychological resources available to carers, such as self-efficacy and coping strategies.
- Maintaining carers' physical health, including enabling regular physical activity, promoting a healthy balanced diet and monitoring carers' perceived quality and quantity of sleep.
- Safeguarding carers' quality of life by creating frequent opportunities for positive experiences via engagement in enjoyable activities.
- Ensuring the timely availability of key external resources, such as respite care that is tailored to individual needs and mindfulness training.

> *"No one should have to face the confusion, loneliness and isolation…"*
> *Tommy Whitelaw, Awareness Campaigner*

BRIEF DESCRIPTION OF THE RESEARCH

There is a lack of knowledge concerning how family carers of people with dementia (PWD) can best be supported to carry out this essential long-term role. Allied to this is a burgeoning need to more fully comprehend how the potential of resilience can best be harnessed and manipulated to bolster adult health. Researchers from Fuse, the Centre for Translational Research in Public Health, are currently undertaking an evaluation to understand how, when and in which circumstances family carers might best be supported to maintain and sustain the long-term care of people with dementia. This work is supported by The Medical Research Council.

FURTHER INFORMATION

Professor Susan Carr, Northumbria University
Email: sue.carr@northumbria.ac.uk
Telephone: +44 (0) 191 215 6217

Fuse is one of five UKCRC Public Health Research Centres of Excellence. It brings together public health researchers from across the five universities in North East England.

Website: fuse.ac.uk/research/briefs
Blog: fuseopenscienceblog.blogspot.co.uk
Facebook: facebook.com/fuseonline
Twitter: @fuse_online
Email: info@fuse.ac.uk
Telephone: 0191 222 729

Photograph 'Care in the home' (4398796876_f21cb735a6_b) by British Red Cross via Flickr.com, copyright © 2004: https://www.flickr.com/photos/britishredcross/4398796876

fuse The Centre for Translational Research in Public Health

All Fuse briefs produced by Mark Welford, Fuse Communications Officer, in conjunction with the academics involved in the research. Email: m.welford@tees.ac.uk or Tel: 01642 342987 for details.