

Marie Curie Research Grants Scheme

Dr Nathan Davies, University College London

Nutrition, hydration and care for people with dementia at the end of life: How can we best support family carers? (Nutri Dem).

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Research abstract

Background

Dementia is characterised by cognitive and functional decline and often accompanied by other health problems. As someone with dementia approaches the end-of-life some symptoms may become especially distressing to family or friends providing care (carers). Difficulties with nutrition and food intake are common among people with dementia. These problems have multiple causes, including: decreasing ability to recognise food, appetite loss, difficulties self-feeding, apraxia or swallowing problems. As dementia progresses these usually become worse and hard to manage. Swallowing problems may lead to malnutrition, dehydration and risk of aspiration. The consequences of these may be pneumonia, urinary tract infection and falls, all of which are common reasons for hospital admission in people with dementia. Carers supporting a person with dementia at home have reported particular difficulties helping their relative with eating, drinking and swallowing. Many worry that their relative maybe starving and/or dehydrated and that this is decreasing their quality-of-life or even hastening their death. Carers sometimes report a lack of information regarding end-of-life care, particularly about nutrition and hydration. They may ask about artificial nutrition and hydration; however, there is no evidence that these benefit someone with dementia and are often not advised, highlighting the importance of informing carers of suitable options. Professionals do not know what carers would see as better or more information regarding nutrition and hydration when caring for a person with dementia, and do not know if it is possible to provide good information that does not further increase carer stress and possible feelings of guilt.

Aims

The aims of this study are to 1) explore carers' understanding of how best to manage nutrition and hydration at the end-of-life for someone with dementia, identifying possible gaps in knowledge and potential gains of receiving more information, and 2) if the data suggest that further resources would be helpful, to develop a carer information resource.

Objectives

1. To understand how carers currently manage nutrition and hydration at home for people with dementia at the end-of-life
2. Identify what, if anything, carers would like to know more about nutrition and hydration for people with dementia being supported at home
3. Understand what practitioners advise carers to do to manage nutrition and hydration
4. Consider the needs, aims and resources required to develop tailored information for carers caring for someone with dementia at the end-of-life
5. Develop (if needed) a co-produced applied and pragmatic manual about nutrition and hydration for carers supporting someone with dementia at home at the end-of-life.

Method

Design

1) Mapping of existing information resources for carers; 2) semi-structured interviews; 3) co-design the development of an information resource for carers.

Participants

We will purposively sample:

1. Up to 20 family or friends caring for someone with dementia at the end-of-life at home
2. Up to 20 people with mild dementia
3. Up to 20 practitioners from a range of disciplines and agencies (community nurses, Admiral Nurses [specialist dementia nurses], home care workers, palliative care nurses/doctors, speech and language therapists) working with carers.

Procedure

Phase 1: A scoping review of existing resources and guidelines focussing on information about nutrition and hydration for carers and practitioners.

Phase 2: Semi-structured interviews with carers, to explore what information they receive about nutrition and hydration for someone with dementia who is at end-of-life, if this helps with areas of concern and distress, how they interpret and use this information. Semi-structured interviews will also be conducted with people with mild stage dementia, to explore what information they think is important to relay to carers. Focus-groups/interviews with practitioners to learn what information they convey to carers and what areas are of most concern to carers.

Phase 3: Findings from phases 1 and 2 will be synthesised and presented to a co-design group to help identify if a new resource is needed and if so to develop such resource. The group will consist of practitioners, people with dementia, and carers, meeting on up to 3 occasions.

Outcomes

The outcome of this study will be an understanding of whether there are information gaps for carers around nutrition and hydration at the end-of-life, better understanding of current practice and, if needed, a carer information resource. If it is not needed we will produce a comprehensive yet accessible map of services and resources available.