

The nutritional care of people living with dementia at home: a protocol for a scoping study

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Abstract

Introduction

The symptoms associated with dementia can result in adverse nutritional consequences, including increasing malnutrition risk. Many people are living with dementia in their own homes, and nutritional needs are often supported by family or friends providing care, and/or formal domiciliary carers. Direct and indirect interventions to improve nutritional status in dementia have been explored, however many of these take place in a care home or hospital setting. We intend to address this gap by reviewing interventions and other literature associated with managing the nutritional status of people living at home with dementia.

Methods and Analysis

It is intended that this scoping study protocol will outline the planned stages prior to conducting a full scoping study using the Arksey and O'malley (2005) six-stage framework to identify existing literature relevant to the nutritional care of people living with dementia in their own homes. Thematic results of the literature search will be combined with the outputs from stakeholder focus groups, and key themes and ideas for future interventions discussed.

Ethics and Dissemination

The scoping study will use robust methodology to search for interventions and other literature focused around managing the nutritional status of people living with dementia in their own homes. A stakeholder group including representatives from patients, carers, and primary healthcare professionals will be involved as part of the final stage of the scoping study process, and appropriate ethical approval will be sought following approval of this protocol. The findings of this scoping study will also be published in a relevant peer reviewed journal for dissemination, and form part of future seminar presentations.

Contents

| | |
|--|----|
| 1.0 Background..... | 4 |
| 2.0 Methods | 6 |
| 2.1 Objectives..... | 6 |
| 2.2 Inclusion and Exclusion criteria..... | 6 |
| 2.3 Study selection | 6 |
| 2.4 Extraction Method..... | 7 |
| 2.5 Quality Assessment..... | 8 |
| 2.6 Presentation of results | 8 |
| 2.7 Stakeholder Consultation..... | 8 |
| 3.0 Conclusion | 9 |
| 3.1 Funding | 9 |
| 3.2 Competing Interests | 9 |
| 4.0 References..... | 10 |
| 5.0 <i>Appendix A</i> – Preliminary Search Strategy (for Medline OVID) | 12 |

1.0 Background

There are an estimated 850,000 people living with dementia in the UK , and it is forecast that this could increase to over 1 million in 2025 (Prince et al., 2014). The behavioural and psychological symptoms of dementia (BPSD) may be caused by a number of progressive diseases, the two most common being Alzheimer's disease (AD) and Vascular Dementia (VD). The BPSD have been documented (van der Linde et al., 2014) ,however there is acknowledged heterogeneity in symptom presentation amongst individuals as the disease progresses. The average duration of the disease from diagnosis to mortality is around ten years, however it is purported that many people will have been living with dementia for years prior to symptom recognition (Alzheimer's Society, 2016). Two thirds of people with dementia are thought to be living at home, with an estimated 670,000 family and friends taking the role of primary carer (Prince et al., 2014). This role includes meeting the individual's health, emotional and social needs, which will become more complex and demanding as the dementia progresses, and can have profound impacts on the individual and their family (Fauth and Gibbons, 2014).

The nutritional needs of an individual with dementia are an integral consideration of the holistic care provided at all stages of the disease. Maintaining an individual's nutritional status includes preventing unintentional weight loss (fat and muscle), and meeting fluid and micronutrient requirements. The inter-dependant relationship between the decline in nutritional status and cognition has been explored (Lee et al., 2009, Spaccavento et al., 2009), and this decline can begin in the early stages of the disease (before formal diagnosis), which if not addressed can increase the rate of progression to mortality, as well as increasing the risk of clinical vulnerability e.g. risk of falls, infections and pressure sores. Across all care settings, the main symptoms of dementia that can affect nutritional status include: memory decline, loss of motor skills, visuospatial ability, taste changes, changes in appetite, and swallowing problems. The management of these symptoms (and others) will vary dependant on the care setting, and previous systematic reviews have focused on Randomised Controlled Trials (RCT's) carried out across all care settings (residential homes, ward environments and own homes), but including minimal analysis of studies specific to a 'own home' setting (Bunn et al., 2016, Abdelhamid et al., 2016). Carer surveys have indicated that there is a need for increased primary care support relating to the nutritional needs and consequences associated with dementia in those living at home (Alzheimer's Society, 2012). Domiciliary care may form part of the support that the person with dementia receives, and therefore plays a significant role in helping maintain an adequate nutritional status. Best practice guidelines have been published to support

managers of domiciliary care agencies (Skills for Care, 2014), however there is limited literature that evaluates the nutritional care that these agencies provide.

This scoping study intends to address this gap, by mapping what is currently known about the nutritional care of people with dementia living at home, including any interventions that may have been trialled or implemented, and the views of patients and carers (family and domiciliary). The scoping study will use the Arksey and O'malley (2005) staged framework which includes identifying the research question, searching for relevant studies, selecting studies, charting the data, and collating, and summarising and reporting the results (Levac et al., 2010). The final element of the framework will also be included, which will involve consulting with key stakeholders to validate findings and facilitate opportunities for knowledge transfer and exchange. The outcomes of this scoping study will inform future research, and assist in the development of interventions in this study area. This approach was chosen, due to its promotion of including a wide range of study types to answer a range of questions related to a broad topic to engender conceptual clarity. This scoping study will not intend to rate the quality of evidence found, however will include descriptive numerical summary analysis, qualitative thematic analysis and interventions will be critically appraised.

The research question for this scoping study is:

- What is known about managing the nutritional status of people with dementia living at home?

Additional sub-questions to be addressed include:

- What interventions have been trialled in this setting to improve or maintain nutritional status?
- What are the difficulties with maintaining and/or preventing decline of nutritional status experienced by people with dementia who live at home?
- What is known about the nutritional consequences of dementia by patients and/or formal and/or informal carers?
- Where would carers of and/or people with dementia living at home (formal and informal) go to seek help regarding difficulties with eating and drinking?

2.0 Methods

2.1 Objectives

The objective of this scoping review is to examine how the nutritional status of people living at home with dementia is managed, the difficulties associated with enabling this, and the involvement of carers and other healthcare professionals.

Preliminary searches of key databases returned no evidence of existing scoping studies in this field of study. Currently, two review protocols are listed on the Prospero and Cochrane Systematic Review database; one is focused on conducting an 'umbrella' review of current systematic reviews of RCT's, and intends to investigate nutritional interventions for individuals over the age of 80 years living with dementia (however excludes mild cognitive impairment, which could be an indicator for dementia and have nutritional consequences), and the other is concerned with the effects of environmental or behavioural modifications on food and fluid intake and nutritional status in people with dementia across all care settings, and is concerned with patient-related outcomes only (i.e. excludes impact of RCT interventions on carers or other stakeholders) (Burckhardt et al., 2014, Herke et al., 2015).

2.2 Inclusion and Exclusion criteria

The scoping study methodology encourages finding a breadth of literature, therefore the following will be included:

- Any interventions (using any research approach) aimed at maintaining or improving the nutritional status of individuals (no age restriction, male and females) with dementia or mild cognitive decline, who live at home alone, or with formal and/or informal carers.
- Any literature where carer or patient knowledge of nutrition and dementia and awareness of available support has been explored.
- Any literature exploring the nutritional consequences of dementia.

Any literature conducted in nursing/residential care homes, or an acute setting will be excluded, however studies conducted with patients using day-centres or short-term respite care will be included.

There will be no restrictions imposed on the outcomes of studies and quantitative (e.g. body weight, blood markers, and hand grip strength) and qualitative (e.g. themes, concepts, case-studies, perceptions and experiences) outcomes will be included.

2.3 Study selection

At least two reviewers will be involved in the initial searching of titles and abstracts, and will meet at regular intervals to corroborate and make iterative refinements to the search

strategy. Bibliographic information will be downloaded using EndNote X7.5 (Thomson Reuters, 2016). In case of disagreement a third independent reviewer will contribute to discussions. The preliminary search strategy is detailed in *Appendix A*, and will be adapted as required for searching each database. The following sources will be used to search for literature:

- Database search: Electronic databases will be searched from data of inception to present, and the search syntax will be modified as appropriate for use in the following databases:
 - MEDLINE (OvidSP)
 - The Cochrane Library
 - EMBASE
 - TRIP
 - PsycINFO
 - CINAHL

This scoping study will only include literature published in English, due to the resource implications associated with translating literature written in other languages.

- Citation search: Forward and backward citation searching will be conducted on included articles for further material. In the absence of required information, the first authors of studies will be contacted to request additional related material either unpublished or in press.
- Experts in the field: Experts in the field and corresponding authors of included studies will be contacted to gather further information.
- Grey literature search: To minimise the impact of publication bias, grey literature sources will be searched for unpublished material. Examples of this type of material include government reports, policy documents, dissertation theses, book chapters and research reports. Searches for grey literature will be conducted in the Health Management Information Consortium (HMIC) and the Social Policy and Practice (SPP) databases, both of which will be accessed via OvidSP. Web of Science will also be searched for further material (e.g. conference proceedings) relevant to this scoping study.
- Search engines will also be used with keywords relating to the research questions to find any further relevant grey literature for inclusion (e.g. guidelines, and surveys).

2.4 Extraction Method

Full text reviews will be conducted by at least two independent researchers. A data charting form will be developed to include standard information (e.g. author, year of publication) and

further detailed information in order to answer the research questions. This will be subject to iterative amendments as reviews progress to ensure that relevant contextual information is captured. The initial data charting form will be validated by two reviewers to corroborate consistency, as recommended by Daudt et al. (2013).

2.5 Quality Assessment

An element of quality appraisal will be involved in this study, however, unlike a systematic review approach all studies will be included in analysis as may contribute to the knowledge base even if they are of questionable quality. Daudt et al. (2013) recommend using a validated tool for the quality assessment and for the present scoping study reviewers will use the Mixed Methods Appraisal Tool (MMAT), as it allows for quick assessment of qualitative, quantitative and mixed method studies in one tool (Souto et al., 2015, Pace et al., 2012).

2.6 Presentation of results

Included studies will be synopsised using descriptive numerical summary analysis, and a PRISMA diagram (Moher et al., 2009) will be used to convey the flow of inclusion upon completion of the review. Qualitative thematic analysis will be used to identify the key themes and topics, which will then be presented in a summarised format.

2.7 Stakeholder Consultation

This scoping study will include the final stage of the Arksey and O'malley (2005) framework, which involves consulting with key stakeholders. Preliminary findings from the literature search will be shared in a focus group format, with participants representing patients, informal carers, domiciliary carers and healthcare professionals. The focus group will be recorded for future qualitative analysis and the outcomes integrated with the outcomes of the literature search. Following this, a further stakeholder engagement session will be held with the intention of sharing the emerging themes from the overall scoping study, and promoting opportunities for knowledge transfer and exchange. The positive impacts of patient and participant involvement (PPI) in health and social care research have been identified as enhancing the quality and appropriateness of research (Brett et al., 2014). Levac et al. (2010) state that stakeholder consultation should not be a required component of scoping studies as it adds 'methodological rigour'. The authors of this scoping study acknowledge the complexities of involving focus group participants with dementia, however will accept the inclusion of 'study partners' (often carers) who can act as informants and provide comfort and reassurance to the participant (Black et al., 2014). The findings of this scoping study will also be published in a relevant peer reviewed journal for dissemination, and form part of future seminar presentations.

Appropriate ethical approval will be sought from Plymouth University prior to involving stakeholders.

3.0 Conclusion

This document has outlined the protocol for a scoping study which intends to map the existing literature regarding the nutritional status of people with a diagnosis of dementia living at home. Due to the number of people currently living with dementia, and the projected increase in diagnoses by 2025, it is important to increase the knowledge base of the impacts upon nutritional status and appropriate interventions for people residing in their own homes. The output of this scoping study will inform future research in this area, and provide a broad review of available literature and stakeholder views.

3.1 Funding

This research is funded by the National Institute of Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care, South West peninsula (PenCLAHRC). The views expressed are those of the author and not necessarily those of the NHS, the NIHR, or the Department of Health.

3.2 Competing Interests

None

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5.0 Appendix A – Preliminary Search Strategy (for Medline OVID)

| # | Searches | Results |
|----|---|---------|
| 1 | exp dementia/ | 273445 |
| 2 | dement*.ti,ab. | 117843 |
| 3 | (living adj2 dementia).ti,ab. | 903 |
| 4 | alzheimer*.ti,ab. | 143554 |
| 5 | 'mild cognitive impairment'.ti,ab. | 15964 |
| 6 | 1 or 2 or 3 or 4 or 5 | 312065 |
| 7 | home.ti,ab. | 225574 |
| 8 | 'own home'.ti,ab. | 1265 |
| 9 | 'patient* home'.ti,ab. | 2340 |
| 10 | 'own house'.ti,ab. | 107 |
| 11 | non-institutional*.ti,ab. | 2485 |
| 12 | 'sheltered accom*'.ti,ab. | 106 |
| 13 | community.ti,ab. | 424379 |
| 14 | domestic.ti,ab. | 65261 |
| 15 | caregiver.ti,ab. | 23712 |
| 16 | 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 | 703818 |
| 17 | nutrition*.ti,ab. | 274361 |
| 18 | nutrient*.ti,ab. | 122154 |
| 19 | exp Meals/ | 17411 |
| 20 | food.ti,ab. | 378570 |
| 21 | meal*.ti,ab. | 74422 |
| 22 | breakfast*.ti,ab. | 10922 |
| 23 | lunch*.ti,ab. | 7485 |
| 24 | dinner*.ti,ab. | 4047 |
| 25 | snack*.ti,ab. | 7195 |
| 26 | eat*.ti,ab. | 95461 |
| 27 | drink*.ti,ab. | 144946 |
| 28 | hydrat*.ti,ab. | 54666 |
| 29 | feeding.ti,ab. | 181867 |
| 30 | tea.ti,ab. | 29089 |
| 31 | diet*.ti,ab. | 556751 |
| 32 | vitamin*.ti,ab. | 221385 |

| | | |
|----|--|---------|
| 33 | supplement*.ti,ab. | 311327 |
| 34 | ingestion*.ti,ab. | 74982 |
| 35 | cooking*.ti,ab. | 12305 |
| 36 | appetite.ti,ab. | 28444 |
| 37 | 17 or 18 or 19 or 20 or 21 or 22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 | 1876303 |
| 38 | 6 and 16 and 37 | 2139 |

Search Strategy for EBSCO (and PROQUEST) Databases:

(AB(dement*) OR TI(dement*) OR AB(alzheimer*) OR TI(alzheimer*) OR AB('mild cognitive impairment') OR TI('mild cognitive impairment')) AND (AB(home) OR TI(home) OR AB('own house') OR TI('own house') OR AB(non-institutionalised) OR TI(non-institutionalised) OR AB('sheltered accom*') OR TI('sheltered accom*') OR AB(community) OR TI(community) OR AB(domestic) OR TI(domestic)) AND (AB(nutrition*) OR TI(nutrition*) OR AB(nutrient*) OR TI(nutrient*) OR AB(food) OR TI(food) OR AB(meal*) OR TI(meal*) OR AB(breakfast*) OR TI(breakfast*) OR AB(lunch*) OR TI(lunch*) OR AB(dinner*) OR TI(dinner*) OR AB(snack*) OR TI(snack*) OR AB(eat*) OR TI(eat*) OR AB(drink*) OR TI(drink*) OR AB(hydrat*) OR TI(hydrat*) OR AB(feeding) OR TI(feeding) OR AB(tea) OR TI(tea) OR AB(diet*) OR TI(diet*) OR AB(vitamin*) OR TI(vitamin*) OR AB(supplement*) OR TI(supplement*) OR AB(ingestion*) OR TI(ingestion*) OR AB(cooking*) OR TI(cooking*) OR AB(appetite) OR TI(appetite))