Protocol for a systematic review on the experience of informal caregivers for people with a moderate to advanced dementia within a domestic home setting

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Protocol

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Abstract

**Background:** The knowledge about the experience of informal caregivers who provide care to people with moderate to advanced dementia in a domestic home setting is limited. A consequence of long hours of caregiving in addition to dealing with normal challenges of daily living is their experience of a poor quality of life. Some of their experiences may be described in terms of a feeling of powerlessness to make changes during care provision. This feeling may also suggest an experience of moral distress. This protocol aims to explore these experiences.

**Methods:** This review adopts a narrative synthesis approach. A search will be conducted for studies written in English language in the bibliographic databases MEDLINE Complete, CINAHL, EMBASE, PsycINFO, Web of Science, and Academic Search Complete covering periods from 1984 to present. The search terms will be related to dementia and caregivers, and the process will be focused on dementia at the moderate to the advanced stages. Reference lists of included papers will also be searched for additional relevant citations. Search terms and strategy will be checked by two independent reviewers. The identification of abstracts and full texts of studies will be done by the author, while the quality and the risk of bias will also be checked by the two independent reviewers.

**Discussion:** Psychological distress is cited as an experience reported within informal caregiving. For the caregiver, it is associated with a negative impact on general health. To date, no synthesis exists on the specific experience of informal caregiving for people with moderate to advanced dementia within the domestic home setting. This review considers that variation of accounts contributes to how the informal caregivers’ general experience is explored in future research. This may enable gaps in current knowledge to be highlighted within the wider context of caregiving in the domestic home setting.

**Systematic review registration**

This review has been submitted for registration at PROSPERO (crd.york.ac.uk/prospero/).

**Background**

Dementia has been described as a progressive disease which affects cognitive abilities and leads to deterioration of daily functional capabilities [8,12]. It is also regarded as a disease with increasing public health concern as cures or effective prevention are currently unknown [30]. In 2014, the epidemiology of the disease in the UK showed that about 850,000 people were affected [15]. Of this population, 1 in 6 people was 80 years of age, and over 40,000 under the age of 65 years were also affected [15]. The total number of people affected, regardless of age, was projected to increase to over 2 million by 2051 [15], unless a cure is found [19].

Much advancements have been made in recognition of the symptoms and diagnosis of the disease. Evidence suggests that caring for the people diagnosed is mostly done by their family [7]. This fact is further supported by a UK statistic by [11] which suggested that approximately 670,000 acts as family
caregivers for people with dementia. Findings by [21] however conclude that the amount of care provided by these caregivers increases as severity in dementia increases. As a result, the burden of care also increases over the disease trajectory [21].

Compared with other terminal diseases, such as cancer, prediction of life expectancy in dementia is difficult [4,13]. In most cases, up to 10 years after diagnosis is a common assumption [39]. It is possible that during this period, the burden of caring is also experienced for longer by the informal caregivers. Hence, [7] conclude that although caring at home for people in the later stages of dementia may be preferred, most informal caregivers would choose to rather employ someone else to provide the care required. Understanding ways by which the effects of their negative experiences may be reduced for an improvement to their quality of life is therefore necessary.

Given evidence suggests that for every 1000 people with dementia cared for within the domestic home setting, around 850 informal caregivers provide round-the-clock unpaid care [7,16,26]. It is recognised that in their unpaid capacity, informal caregivers’ save the UK economy about £132 billion annually [18]. Sometimes referred to as the ‘invisible second patients’, the informal caregivers often experience a poor quality of life due to the long hours of caregiving in addition to dealing with normal challenges of daily living [7]. The implication for their wellbeing, as a result, suggests that psychological distress impacts negatively on their general health [37, 17, 6, 24].

Emotional distress, depression and increasing feeling of isolation have been reported as a direct impact on informal caregivers’ health. Physical illnesses relating to the heart and other chronic conditions have also been reported [7]. By adopting different methodologies to arrive at their conclusions, some studies have however argued that caring may be described in terms of the informal caregivers’ sense of satisfaction at facilitating a good end of life for a family member [7,36]. Examples of positive experiences have been given, which suggest that continued provision of care may be described as the informal caregivers’ personal choice [3]. It is also clear, however, that regardless of these reported cases, the number of informal caregivers caring within the domestic home setting continues to increase.

[6] highlight that due to the negative experiences of psychological distress encountered, some informal caregivers have considered placing the person requiring care in other care environments than the home. [34] also identify that institutionalisation may be considered at a stage in the disease trajectory when behaviours become unmanageable. With these insights, it is considerable that the willingness of the informal caregiver to continue providing care within the domestic home setting may be described in terms of performing a moral obligation. It is also plausible to consider the negative experience reported as a resultant influence from the psychological coercion borne out of a devotion or a feeling of loss of a loved one. Such feeling has been highlighted in terms of a personal tragedy and associated with a disability such as dementia [27][28][1]. Alternatively, it may also reflect the internal conflict encountered while caring at the end of life [10].

Different studies have adopted varying methodologies to show that informal caregivers have both positive and negative experiences in caring for people living with dementia. acknowledged that while
positive accounts may be given as part of the experience of caring for people with dementia, the impact of caring has resulted in a poor quality of life while caring in an unpaid capacity. A consensus for understanding the methodologies already used in this area of interest is however required for describing the experience of care provision for people with moderate to advanced dementia. Specifically, this review seeks to understand the current knowledge about the experience of informal caregivers for people with moderate to advanced dementia within the domestic home setting. The gaps that remain in knowledge will also be explored.

**Review mapping**

The overall review methodology and findings will be reported following the ENTREQ guidelines [35].

**Methods**

This review adopts a narrative synthesis approach. Narrative synthesis, according to [29], approaches systematic reviews by using words and texts to synthesize and explain findings from a combination of disparate study designs. As a systematic approach which favours presentation of findings from empirical literature in established theory within the area of interest, it is useful in summarising the current state of knowledge about the review question [29]. This review aims to identify any existing literature and current knowledge about the experience of informal caregivers who provide care to people with moderate to advanced dementia.

In consistency with addressing areas within the scope of interest, exploration of the key review question will be conducted within the contexts of dementia, informal caregivers and domestic home setting. The main findings from the synthesis of identified studies will then be used in exploring these experiences within the moderate to advanced stages of the disease. dementia within the domestic home setting. As highlighted by [29], the adoption of an iterative approach in the process will map the link between the data from the findings and the individual studies identified. The criteria for identifying which studies to include will also be guided by the different components within the review question.

**Review aims and question**

The aim of this review is to explore informal caregivers’ experiences of home-based caregiving for people with a moderate to advanced dementia. A review question is therefore defined as: “*How do informal caregivers describe their experience of providing home-based care for people with moderate to advanced dementia?*”. Many tools have been suggested on how reviews such as this may be conducted. This review seeks to explore a broader account of informal caregivers’ experiences of dementia home-based caregiving. As such, the question coverage needs to be extensive within this scope of interest [25]. The SPIDER (Sample, Phenomenon of Interest, Design, Experience, Research type) approach, a qualitative tool for evidence synthesis will therefore be used in question definition and systematic literature interrogation. The selection of this tool is based on its specificity in investigating a defined sample’s experience of a phenomenon [22], and the possibility of achieving results of more heterogeneous nature [9].
Inclusion and exclusion criteria

Domain

Studies will be included if they are related to dementia.

Study characteristics

This review will consider all research types including evidence from qualitative, quantitative and mixed-methods studies. No exclusion will be defined based on study type. All research evidence published in the English language from 1984 to present will be eligible for inclusion, given the reported increase in the diagnosis of dementia within that period. However, the possibility of achieving review objectives is dependent on the development of a clear review question and setting inclusion criteria [2, 31, 33]. Precision in framing the question therefore ensures that the population of interest are included [5], and the review question coverage is broad and extensive within the scope of interest [25]. See table 1.

Sample

Informal caregivers are described as the family members, friends, relatives or anyone who provide significant care for an ill person [38]. These may be people related through committed heterosexual or same-sex partnerships, birth or adoption and others who have strong emotional and social bonds with the person receiving care. Only those acting as caregivers in an unpaid capacity will be considered. Other carers who may, or may not be family members, will be defined as lay, unpaid people in a close supportive role, who share in the illness experience of the person receiving care. Literature on other carers who do not fall within this broad definition will be excluded.

Phenomenon of interest

The context of interest is specific to dementia caregiving at the moderate to advanced stage within a domestic home setting. As such, it is necessary to distinguish between the home setting as a place where the person with dementia lives primarily, and other establishments where care provision may also be given, such as care homes. For the review, the informal caregiver may or may not be co-resident with the person with dementia within the home setting. Therefore, only literature on informal caregivers caring for people with a moderate to advanced dementia within this defined setting will be reviewed.

Design

Qualitative evidence collected from interviews, observations and surveys from studies adopting either a qualitative or mixed-method design.

Experience

Subjective experiences, such as views, opinions, attitudes and informal caregivers’ reasons for continued caregiving within the home setting for people with a moderate to advanced dementia will be explored.
Accounts of the duration of time spent caregiving and caregivers’ feelings or emotions during care provision will also be of interest. Examples of these may include the duration of time spent providing care, relationship-based factors, isolation and feelings of guilt experienced. Only those experiences relevant to caring for people with moderate to advanced dementia will be reviewed and other experience aimed at the general population or other illnesses will be excluded.

**Research type**

Research adopting either a qualitative or mixed methods design which is described in terms of exposure to specific elements of caregiving responsibilities leading to a noticeable change in behaviour or wellbeing of the sample [32]. For example, this may include an indication of the duration of the exposure to which the informal caregivers were subjected, which may or may not cause a change to their health status.

**Data sources**

An initial scoping search of potentially relevant literature will be conducted to determine the distribution of relevant studies from available sources. Additional search will be conducted to identify literature in the following databases: MEDLINE Complete, CINAHL, EMBASE, PsycINFO, Web of Science, and Academic Search Complete from 1984 to present. Reference lists of included papers will also be annually searched for additional relevant citations.

**Search strategy and process**

A search will be conducted by the author. The search terms and strategy will be checked by two reviewers (CW and KF), who are familiar with the domain of dementia and care provision. The search strategy will be tailored for use with each database, using Boolean operators, truncations and Medical Subject Heading (MESH) as appropriate for each database. This strategy will use a combination of relevant keywords and period covered in all searches will be from 1984 to the present day (see table 2). The search terms used are shown in table 3.

**Study selection process**
The criteria for paper selection will follow the stipulated inclusion and exclusion criteria. Only the author will be involved in the initial paper selection. All citations will be imported to Endnote and duplicates removed before screening. Identified studies will be screened by the two reviewers, CW and KF to ascertain that the stated inclusion criteria are met. Reviewers will not be blinded to the author's detail and further assistance will be sought from the librarian at Lancaster University if required. Titles and abstracts will be screened in the first stage of the selection process, to exclude ineligible studies and remove duplications. Full text of identified papers will then be retrieved by the author, and a PRISMA-P (Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols) flowchart (Fig 1) will be generated as recommended by [23], which is a comprehensive approach for showing the different stages of searches and how papers were selected for inclusion in the review.

Data extraction

Guidance from [29] will be followed in data extraction as well as in appraising the quality and robustness of the synthesis. In line with the search process, the decision on which data to extract would be guided by the review question, as the definition of these elements differentiates between interpretations across disparate settings and populations [29]. Key data such as author's name, publication origin and year, setting, population and sample size, aim and objectives, illness stage, research design, data collection method and main findings, which clearly show the caregivers' actions would be extracted from each paper selected by the review author as in table 4. A narrative summary of the synthesis will also be given as a critical reflection on the findings of each study. This would include the methodological approach followed in the synthesis, as well as the quality of data used. Any assumptions made would also be declared to ensure the credibility of the review findings.

Quality and bias appraisal

Selected studies will be appraised by the author using the [14] protocol to evaluate the risk of selection bias. [29] consider that conclusions reached in reviews may be influenced by the results of individual studies. It is suggested that grounds for appraising the quality of individual studies considered for review may, therefore, be defined by individual reviewers. The Hawker tool is selected based on its non-discriminatory capability in assessing the quality of included papers, as well as the adaptability of its structure to a variety of methodologically distinctive designs. It uses a checklist of 9 categories for assessing the quality of selected papers. The first 7 categories evaluate the trustworthiness of the paper being assessed, while the last 2 represent individual paper's relevance. The score allocated to each study represents its weight and demonstrates the relevance, validity and appropriateness of each paper in comparison to others also selected.

On the Hawker tool, a maximum of 36 points is possible as a range for categorising and determining paper's quality according to their methodological rigour. Each paper will be assigned a rating of ‘good’ (4 points), ‘fair’ (3 points), ‘poor’ (2 points) or ‘very poor’ (1 point) in the nine categories. It is considered that allocating the ratings as ‘A’, ‘B’, ‘C’, and ‘D’ instead will bring more clarity. As suggested by [20], a high-quality paper may be rated ‘A’ and scored between 30 and 36 points, a medium-quality paper may be
rated ‘B’ and scored between 24 and 29, and a low-quality paper may be rated ‘C’ and scored between 9 and 24. To reduce ambiguity in this review, however, grading for a low-quality paper will be modified to a range between 9 and 23. It is not envisaged that this adaption will impact on the gradings as originally guided by [14] (see Additional file 1). The two reviewers, CW and KF will check the result of the appraisal process to ensure the appropriateness of this tool.

**Data synthesis**

This review adopts a narrative synthesis approach following the guidance by [29] for all study types identified. The use of Nvivo software will be enlisted to manage the synthesis of the data into themes. Narrative description of patterns derived from the findings from reviewed literature will be used in understanding what influences the descriptions attributed to the experiences of informal caregivers. This will involve grouping of studies and making commentary comparisons between them, using their characteristics such as their data collection methods, authors, aims and their reported findings. For clarity, the steps to undertaking the narrative synthesis by [29], suggests that the synthesis of literature be conducted by (a) identifying the review focus, (b) specifying the review question, (c) identifying studies to include (d) data extraction and quality appraisal (e) synthesising of the findings and (f) reporting of findings.

**Data management**

Endnote bibliographic management software will be used in managing all searches. Using this software, all identified papers can be directly imported and duplicates can be easily identified and removed.

**Potential strengths and limitations**

This review considers that variation of accounts contributes to how the caregivers’ experience is explored in future research. As such:

1. This may enable gaps in current knowledge to be highlighted within the wider context of caregiving in the domestic home setting.
2. As a qualitative endeavour, the review will provide a rich understanding of people’s accounts. Transferability of those accounts across clearly defined settings and contexts may therefore be appropriate
3. Full justification of accounts may be difficult as accounts of experiences will be extrapolated from a wider context of discussions within the reviewed literature.
4. Generalisation of findings at either of the moderate or the advanced stages may also be difficult.

**Discussion**

The focus of this review is to explore informal caregivers’ experiences of home-based caregiving for people with a moderate to advanced dementia. Psychological distress has been cited as one of their
experiences and this has been associated with a negative impact on their general health. It is thought that their accounts may also suggest the experience of moral distress, which is a feeling generally associated with the powerlessness to act in situations where one knows the right thing to do. Subjective experiences, such as the informal caregivers’ views, opinions, attitudes, duration of time spent caregiving and the associated reasons for continued caregiving within the home setting will be explored. Only experiences relevant to caring for people with moderate to advanced dementia will be reviewed and other experience aimed at the general population or other illnesses will be excluded. By examining any existing knowledge within the wider literature, gaps within the wider context of caregiving in the domestic home setting will be highlighted. This may also aid further understanding and enable a proposal of interventions or support which lead to better health outcomes and quality of life for informal caregivers within the home setting.

Declarations

Acknowledgements

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Authors’ information

a) Charles James (CJ) (orcid: 0000-0002-8537-1403) is a PhD student in the Faculty of Health and Medicine at Lancaster University. The protocol has been developed as part of an ongoing PhD study titled “Moral Distress in Moderate to Advanced Dementia Care: An Exploration of Informal Caregivers’ Experience of Home-Based Care Provision at End of Life”.

b) Professor Catherine Walshe (CW) is the Head of Department for the Faculty of Health and Medicine at Lancaster University and CJ’s primary PhD supervisor.

c) Professor Katherine Froggatt (KF) was a Senior Lecturer in the Faculty of Health and Medicine at Lancaster University and CJ’s secondary PhD supervisor.

Contributions

CJ was responsible for conceptualising and developing the focus and methods of this review protocol. The protocol has been produced as part of CJ’s ongoing PhD study into the experience of moral distress of informal caregivers for people with a moderate to advanced dementia in a domestic home setting. CJ wrote all the drafts and is the guarantor of the review. CW and KF independently reviewed all drafts of the protocol and provided guidance and correctional input into its planning and presentation. CW and KF also provided feedback which led to the preparation of this final draft.

Ethics approval and consent to participate
Not applicable.

**Consent for publication**

Not applicable.

**Availability of data and materials**

No datasets were generated or analysed during this development of this protocol. Data sharing is therefore not applicable to this article. However, the findings will be disseminated as part of the PhD thesis and published as a peer-reviewed manuscript.

**Competing interests**

The authors declare that there are no competing interests.

**Funding**

No funding has been sought or received for this review.

**Abbreviations**

SPIDER: Sample, Phenomenon of Interest, Design, Experience, Research type; PRISMA-P: Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols; NVIVO: Qualitative Analysis Software Package by QSR International; MEDLINE: Electronic database of medical journal citations and abstracts for global biomedical literature; MeSH: Medical Subject Headings; CINAHL: Cumulative Index of Nursing and Allied Health Literature; PROSPERO: International Prospective Register of Systematic Review; ENTREQ: Enhancing Transparency in Reporting the Synthesis of Qualitative Research.

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Tables

Table 1: Inclusion and exclusion criteria

| Inclusion Criteria                                                                 | Exclusion Criteria                                                                                                                                 |
|-----------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------|
| **Type of papers:** peer-reviewed empirical papers, qualitative papers including case studies and mixed-methods (both telephone and postal surveys are acceptable only if open-ended questions are asked) | Papers that are not primary research e.g. systematic reviews, meta-analysis                                                                                     |
| **Language of papers:** English                                                   | Papers in other languages                                                                                                                                   |
| **Date:** published between 1984 and present                                       | Papers were written before 1984                                                                                                                             |
| **Population of focus:** unpaid family members or informal caregiver               | Population of focus relates to other groups of carers e.g. paid carers, professionals                                                                      |
| **Age group:** 18 and above                                                        | Below 18                                                                                                                                                     |
| **Primary illness of interest:** moderate to advanced dementia                     | Other illnesses                                                                                                                                             |
| **Setting:** domestic home-setting, unpaid home-based care                          | Other formal care establishments where care provision is paid for                                                                                         |
| **Focus of papers:** current experiences or views or needs of family caregiver     | Focus on the views of others, or where death has already occurred                                                                                         |

Table 2: Search strategy
Table 3: Search terms

| Caregiver terms | Dementia terms |
|-----------------|----------------|
| Carer*          | Dementia       |
| Caregiv*        | Dement*        |
| Care-giver      | Alzheimer*     |
| Spouse-caregiver* | Lew* bod*     |
|                 | FTLD           |
|                 | FTD            |
|                 | Frontotemporal |

FTLD: Frontotemporal lobar degeneration; FTD: Frontotemporal dementia

Table 4: Data extraction table
| Field                                      | Description                                                                 |
|-------------------------------------------|------------------------------------------------------------------------------|
| Author, date, country                     | - First author’s name, date of publication and country of origin              |
| Setting                                   | - The setting of care provision                                               |
| Population/sample size/sampling method/illness stage | - Caregiver’s distinctive characteristics of - Sampling method - Stage of illness |
| Aim/ Objectives                           | - Stated aims and objectives of the study                                    |
| Research type/ research design            | - Research design type                                                       |
| Data collection & analysis                | - Data collection method employed                                             |
| Findings                                  | - Study findings showing caregiver’s actions                                 |

**Figures**
Figure 1

PRISMA-P Flowchart for paper selection process (adapted from Moher et al., 2015)

Supplementary Files

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- Additionalfile1Qualityandbiasappraisal.docx