

PhD Project Proposal - Living well with dementia: a PhD programme to develop a complex intervention that integrates healthcare for people with dementia

1. Background to the study

There are 800,000 people living with dementia in the UK and this is expected to rise to over a million by 2021¹. The costs of caring for this population have been estimated currently to be around £8 billion for direct healthcare, rising to over £20 billion if full societal costs are taken into consideration, which is more than the combined costs of cancer and heart disease². The majority of these costs are for long term residential care (40% of total costs) and informal carers (55% of total costs), with only 5% of costs going on primary and secondary care². Since the prevalence of dementia increases sharply with age, these costs are set to increase sharply in coming years due to the aging of the population.

Care for people with dementia frequently falls short of best practice, as outlined in a number of high profile government reports and recent clinical guidance documents²⁻⁴. Dementia sufferers and their carers frequently fail to access recommended care and support in a timely fashion, and, when they do access care, the varying components of health and social care are fragmented and poorly coordinated. As a result dementia sufferers and their carers experiences of care are less than optimal, outcomes are worse and health and social care costs are greater than necessary. In 2007 and 2010 the National Audit Office concluded that dementia services offered poor value for money due to patchy implementation of services, poor coordination of care, leading to avoidable hospital admission, prolonged stay in hospital and increased use of residential care^{5,6}. Consequently, there is considerable scope to improve the quality and efficiency of dementia care; for example it has been estimated that 20% of the costs of dementia could be saved through early diagnosis leading to reduced use of later residential care homes and up to £700 million if hospital stays could be shortened by up to 2 days per stay².

2. Problem or issue to be investigated

This PhD will investigate how best to improve the quality of care for people with dementia, to ensure that appropriate care is accessible to dementia sufferers and their carers and that the various components of physical, psychological and social care are coordinated and integrated, with the aim of improving the experience of care, improving health outcomes and to reduce unnecessary costs for patients with dementia and their carers. Such an integrated approach to the provision of services is fundamental to the delivery of high quality care for dementia⁷.

3. Hypothesis, aims and objectives

The aim of this proposed PhD will be to develop a feasible, acceptable and evidence-based complex intervention, to improve the coordination and experience of care for dementia sufferers and their carers, improve health outcomes and reduces unnecessary costs.

To achieve this aim the specific objectives of this PhD will include:

- i) To determine the outcomes, key characteristics and barriers and facilitators for complex interventions that coordinate and integrate physical, psychological and social care for people with dementia by conducting a mixed methods review of existing literature.
- ii) To develop a theoretically and empirically based prototype novel complex intervention, including training materials, to coordinate and integrate the physical, psychological and social needs for people with dementia based on this literature review and other reviews of coordinated care.
- iii) To ascertain views on the design of the prototype intervention, the likely acceptability and utility of the different components, and the feasibility of its implementation from in-depth interviews with a range of stakeholders with experiences of dementia and dementia care, including patients, carers, health service providers and commissioners.
- iv) To test the feasibility, acceptability and normalization potential of the complex intervention for people with dementia, their carers, the professionals delivering the intervention, and other service providers involved in the integrated model of care for people with dementia, by conducting a feasibility study.

- v) To select suitable process and outcomes measures and to evaluate the feasibility and acceptability of completing such assessments at baseline and during follow-up.

The PhD will address the following questions:

- i) What are the characteristics, barriers and facilitators of a potential integrative complex intervention to coordinate care for people with dementia and their carers from the perspectives of existing literature, implementation theory, people with dementia, their carers, providers and commissioners of health and social care?
- ii) What is the feasibility, acceptability, and normalization potential of the complex intervention for people with dementia, their carers, the professionals delivering the intervention, and other service providers involved in the integrated model of care for people with dementia?
- iii) What is the feasibility and acceptability of training materials and processes for identified healthcare professionals to deliver the integrated physical, psychological and social care intervention?
- iv) What are the most appropriate measures of process and outcomes for the intervention for use in subsequent trials of the intervention?

4. Proposed methodology

Our proposed PhD programme will follow MRC guidance on the development and evaluation of complex interventions.

Phase 1 of the PhD (Months 0 to 12) will involve a mixed methods review to investigate the characteristics, range of potential outcomes, barriers and facilitators of interventions that coordinate and integrate the physical, psychological and social care for people with dementia.

The review will be a 'contingent' mixed methods review⁸ using both qualitative and quantitative data⁹. This method requires flexibility in defining questions and data extraction, such that emerging findings feed back into questions, searching, data extraction and analysis. Findings from both types of literature will be used to develop iterative loops of evidence that inform the ongoing development of the review. The review will make use of and, where possible, merge the findings of both strands of evidence in each of the review phases. The review will use a three step method¹⁰.

Step 1 will identify initial review questions and the contextual factors that will assist in developing the review questions further and then move to define the core review questions. A broad scoping review of the literature will be used to develop a conceptual logic model to outline a theory of change to underpin the mixed-method review, as well as identify potential moderator variables that are known to impact on interventions evaluated. In addition, the scoping exercise will identify potential subgroups that need to be considered in the effectiveness review and address issues of meaningfulness of potential interventions from the perspective of people with dementia, their carers and those delivering candidate interventions.

Step 2 will shift activity from the conceptual scoping level to an exploratory level using a standard systematic approach. Inclusion and exclusion criteria will be defined, search strategies developed and literature screened for inclusion. Search strategies for a range of electronic databases, from inception to present day, will be constructed to identify trials of complex interventions for people with dementia and descriptive studies canvassing the views of people on integrative dementia care coordination. Electronic searches will be supplemented by hand-searching, by backwards and forwards citation searching and by contacting experts. Titles and abstracts will be screened by two independent reviewers to identify potentially relevant studies. Full texts of potentially relevant papers will be inspected by two independent reviewers.

A core set of effectiveness studies will first be identified. Data on the characteristics of the trial participants, the nature of the intervention, the trial outcomes and the quality of the trial will be extracted using standardized data extraction sheets. Quality appraisal of included studies will be conducted by 2 independent reviewers, using the CASP checklist (Critical Appraisal Skills Programme, Public Health Resource Unit, 2006). Evidence from both

effectiveness and descriptive qualitative studies will be reviewed and further review sub-questions developed based on emerging findings. Further searches and data extraction of identified studies pertaining to these factors will be undertaken. This stage of the review may identify additional important information on the type of moderators and facilitators that may impact on the intervention. Both qualitative and quantitative data on the conditions and circumstances that may impact on the outcome of the review may reveal conflicting or contradictory evidence for which an analytical strategy will be developed. Data on applicability and feasibility will be actively sought including aspects of process, implementation, and barriers and facilitators of interventions.

Step 3 will involve the calculation of pooled estimates of effectiveness or, in the absence of a statistical meta-analysis, a narrative summary of the results of individual studies. Qualitative research evidence that explores reasons for potentially unexpected results and heterogeneity in results will be presented aligned to the effectiveness results. Issues of relevance and applicability expressed by those delivering or experiencing coordination programmes will be presented to identify which elements have been helpful, advantageous or less so. Feasibility, acceptability and implementability data from both effectiveness and qualitative studies will be integrated to update and clarify the original logic model. Candidate intervention components and their relationship to likely effectiveness will be the principal outcome of the review. The review will be reported in accordance with the PRISMA statement¹¹.

Phase 2 (Months 11 to 16)

Based on the review above, the student will develop a theoretical model to describe the intervention, identifying the optimal place in the care pathway where the intervention should be offered, the components of the intervention and how these will work together to best integrate physical, psychological and social care. Whilst the exact nature of the intervention will be determined by the first phase of the PhD, we expect that it will be a multicomponent intervention, characterised by care that i) is proactive, ii) is patient-centred and iii) will act to integrate physical, psychological and social care. It will reflect the qualities of Whole-Person care as described in the recent report of the Institute of Public Policy Research¹².

Once these preliminary components of the intervention have been assembled and described, the student will conduct in-depth interviews with a purposive sample of approximately 20 stakeholders (including approximately four each of the following groups: patients with dementia, their carers, health and social care professional delivering care to people with dementia, providers and commissioners of physical, psychological and social care), from across the South West, identified through contact with local charities and service user organizations and health and social care provider and commissioner collaborators. During these interviews, stakeholders will be asked about their understanding of current service delivery for people with dementia, the need for alternative models of care, and the issues that such new models of care would need to address. To test the intervention theoretically, the different components of the intervention and how they work together will be described to the stakeholders who will then be asked to comment on the different components, how they would fit together, the likelihood that they will achieve the intended objectives, based on their experience of dementia or dementia care. In addition, potential facilitators and barriers to implementation will be elicited. These interviews will be directed using an interview schedule designed in-team. Interviews will be recorded and transcribed verbatim and analysed using a framework perspective. Based on the feedback on the intervention, the theoretical model will be modified and the student will design an intervention manual and develop support materials necessary for the delivery of the complex intervention. Based on these materials a training manual (to support training of healthcare professionals) will be developed.

Phase 3 (Months 15 to 30)

Study participants

Whilst materials for the trial are being developed the student will work with local providers and commissioners of services to identify four healthcare professionals working in the community with dementia sufferers and their families, to undergo training in the new intervention. Previous similar training of healthcare professionals in collaborative care (a specific model of integrative care originating from the Chronic Care Model in the US) has

required two to five days of training, and it is expected that the current training will require similar. Devon Partnership Trust currently provides community and hospital based care for people with dementia in Devon and Bristol. Following diagnosis, dementia sufferers are appointed a “Dementia Navigator”, a named individual to act as single-point-of-contact and coordinator of care for the remainder of the dementia sufferer’s life. This is predominantly high volume and low intensity work, and when crises intervene the Dementia Navigator will engage Community Mental Health Team (CMHT) staff for more intensive support. Devon Partnership Trust Old Age Psychiatry services (via Dr. Colm Owens, consultant old age psychiatrist) has agreed to collaborate in this work and have agreed to help identify suitable healthcare professionals for training nearer the time. Based on preliminary discussions with the dementia team it seems likely that our complex intervention would best be delivered by staff in the CMHT. However, other non-NHS staff or staff from other NHS funded organisations may be more appropriate. Phase 2 of this study will help us in the selection of appropriate staff groups for phase 3.

Each health or social care professional will be required to identify between three and five patients with dementia (12-20 patients in total) living at home. The professional will use the components of the developed complex intervention. Since the aims of this study are to assess the feasibility and acceptability of the intervention, we have not attempted to conduct formal power calculations, but have chosen four healthcare professionals and between 12 and 20 patients to provide sufficient experience and feedback on the processes involved in training and delivering the intervention, and also on the likelihood that the intervention could be implemented, but which are also deliverable within the limited resources of a PhD.

Study procedures

Each healthcare professional will each identify and approach between three and five people with dementia from their patient lists and from new people with dementia referred to the CMHT, for involvement in the clinical study. Dementia patients and their carers will be asked to consent to involvement in the study, they will undergo a standardized baseline assessment and will be subsequently managed according to the integrative complex intervention model.

If time and resources allow, at this point we will also consider identifying a non-randomized comparison group of untrained healthcare professionals from the same professional group and a similar number of comparable dementia patients who do not receive the complex intervention, to enable us to establish professionals’ usual work patterns and clinical work load, and among untreated patients and their carers to establish what constitutes usual care, key outcomes and moderators of care. Inclusion of this component will add value to the PhD but is not essential for the successful completion of the PhD.

Assessments of training

Following training (within 2 weeks) trained healthcare professionals will undergo a brief (up to 30 minute), semi standardized telephone interview (schedule developed in-team) to gather feedback on training, specifically what worked well, what did not work well and whether any additional material is required. Telephone calls will be recorded and transcribed verbatim and subject to thematic analysis. This feedback will be used to modify training for the subsequent pilot study.

Assessments of intervention

Acceptability and feasibility of the intervention will be assessed using in-depth interviews with the four healthcare professionals delivering the intervention, and with approximately 20 other purposively sampled stakeholders, selected from dementia sufferers, carers, other healthcare professionals and provider and commissioner organizations engaged in the provision of care to the recruited dementia patients (where appropriate) . An interview schedule, developed in-house will be used to structure the interviews, which will be conducted at varying times following engagement in collaborative care, to capture people’s experience/opinion on care at varying points during the treatment. Since the aims of this small clinical study are to assess the feasibility and

acceptability of the novel complex intervention there is no primary outcome as such. However, standardized quantitative assessments will be conducted at three and six months to assess study outcomes. The student will assess satisfaction with care of patients, carers, healthcare professionals and representative from provider and commissioning organizations (as appropriate) using the Assessment of Chronic Illness Care ¹³. Acceptability of the intervention will be further assessed by determining the extent to which patients are retained in the intervention. Further quantitative measures will be conducted at baseline, and at follow-up to assess i) healthcare processes, including but not limited to the following: number and length of contacts with healthcare professional delivering intervention, the number of contacts between person delivering the intervention and other healthcare professionals, number of times professional delivering the intervention receives supervision, whether a care plan was drawn up, who was involved in developing the care plan and ii) health outcomes including but not limited to: the following, measures of quality of life (for patients and carers) , anxiety and depression (patients and carers) , healthcare utilization, (e.g. GP visits, home visits by nurse/GP/medication/urgent ambulance calls/hospital visits/admission rates/lengths of hospital stay) and admissions to care or nursing homes.

Analysis

In-depth interviews will be recorded, transcribed verbatim and analyzed using framework methods to identify themes concerning what was liked/disliked about the intervention, what seemed to work/not work and what could be done differently, with particular focus on the various components of the intervention, including the timing of the intervention, the route of referral into the intervention, the skills of the staff delivering the intervention, the processes involved in the intervention and the assessments of process and outcomes. Findings from this analysis will be used to modify the intervention (and the training if necessary). Simple descriptive analyses will be performed on the quantitative measures to identify approximate changes in scores, with variances using means/standard deviation, median/interquartile ranges, numbers/percentages, as appropriate.

Phase 4 (Months 1 to 36)

Writing up thesis

5. Relevance/significance

The lack of coordination and integration of care has been identified as leading to avoidable hospital admission, prolonged stays in hospital and increased use of residential care. Our proposed innovation will benefit people with dementia and their carers who receive health and social care in primary care and community settings in Devon, where the challenge of improving dementia care is considerable due to the high rates of dementia and a population which is geographically dispersed. It is intended that our intervention will address the need to integrate the various components of care.

Reference List

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