

CoMPASs: IOn programme (Care Of Memory Problems in Advanced Stages of dementia: Improving Our Knowledge): protocol for a mixed methods study

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ABSTRACT

Introduction: Approximately 700 000 people in the UK have dementia, rising to 1.2 million by 2050; one-third of people aged over 65 will die with dementia. Good end-of-life care is often neglected, and detailed UK-based research on symptom burden and needs is lacking. Our project examines these issues from multiple perspectives using a rigorous and innovative design, collecting data which will inform the development of pragmatic interventions to improve care.

Methods and analysis: To define in detail symptom burden, service provision and factors affecting care pathways we shall use mixed methods: prospective cohort studies of people with advanced dementia and their carers; workshops and interactive interviews with health professionals and carers, and a workshop with people with early stage dementia. Interim analyses of cohort data will inform new scenarios for workshops and interviews. Final analysis will include cohort demographics, the symptom burden and health service use over the follow-up period. We shall explore the level and nature of unmet needs, describing how comfort and quality of life change over time and differences between those living in care homes and those remaining in their own homes. Data from workshops and interviews will be analysed for thematic content assisted by textual grouping software. Findings will inform the development of a complex intervention in the next phase of the research programme.

Ethics and dissemination: Ethical approval was granted by National Health Service ethical committees for studies involving people with dementia and carers (REC refs. 12/EE/0003; 12/LO/0346), and by university ethics committee for work with healthcare professionals (REC ref. 3578/001). We shall present our findings at conferences, and in peer-reviewed journals, prepare detailed reports for organisations involved with end-of-life care and dementia, publicising results on the Marie Curie website. A summary of the research will be provided to participants if requested.

ARTICLE SUMMARY

Article focus

- This article describes a mixed methods study to gain an in-depth understanding of the end-of-life experience of people with advanced dementia and their carers.

Key messages

- By 2050, it is anticipated that one-third of people aged over 65 will die with dementia.
- This research will provide evidence from multiple perspectives on the main components of good end-of-life care that are currently often neglected in dementia.

Strengths and limitations of this study

- To our knowledge the quantitative data from the cohort studies will be the first of this nature to be collected in the UK.
- The workshops and interactive interviews will provide richness and background to this quantitative data, allowing it to be placed in the context of a complex health and social care system.
- This research does not address the palliative and end-of-life needs of those dying at earlier stages of dementia from other comorbid conditions.

INTRODUCTION

Approximately 700 000 people in the UK have dementia. This will rise to around 840 000 by 2026 and 1.2 million by 2050.¹ One-third of people aged over 65 in the UK will die while suffering from dementia.² In 2005, it was estimated that 24.3 million people worldwide had dementia with 4.6 million new cases occurring every year, mostly in developing countries. People with dementia have significantly increased death rates³ and even minor cognitive impairment is a strong independent predictor of mortality.⁴ Dementia typically involves a long, gradual decline in cognition, behaviour and function. In this research we consider

people in the advanced stages of this disease who are approaching death.

Challenges

Essential components of good end-of-life care are often neglected in dementia, and referral to palliative care is rare.⁵ Fewer than 1% of hospice patients in Europe have a neurological diagnosis.⁶ Despite concerns about prognostic uncertainty, behavioural problems or communication difficulties,^{7 8} most symptoms such as pain or difficulties swallowing could be managed with good generalist care.⁹ Providing care at home is an aim of the UK Government's End of Life Care Strategy; while benefitting patients and carers it aims to save National Health Service (NHS) costs by avoiding acute hospital admissions.⁹ A recent National Audit Office report indicated that about 50% of care home residents who died in hospital could have died at home.¹⁰ In dementia, research has tended to emphasise specific interventions such as pain control, or the withdrawal of care, for example, *not* prescribing antibiotics or withdrawing feeding.¹¹⁻¹⁵ However, good care may require a more rounded (but cost effective) palliative approach, tailored individually to address patient symptoms and the needs of informal carers, particularly in the terminal phase and in bereavement.

Clinical picture

Advanced dementia can be defined using the Functional Assessment Staging Scale (FAST) level 7 and above¹⁶: the person cannot dress themselves, is doubly incontinent and speaks only a few words. With a median survival of 1.3 years, life expectancy is similar to metastatic breast cancer.¹⁷ A retrospective UK study of the last year of life showed that symptom burden and care needs were comparable to those in cancer; in particular 64% of dementia patients experienced pain (compared with 59% with cancer), dyspnoea (46%), pressure sores (39%) and difficulty swallowing or loss of appetite (86%).^{17 18} However, detailed research to define the symptom burden and needs of people with advanced dementia at the end-of-life and their informal carers has not been conducted in the UK.

Care Of Memory Problems in Advanced Stages: Improving Our Knowledge programme

In this paper we describe the first 12-month phase of the three-year Care Of Memory Problems in Advanced Stages: Improving Our Knowledge programme which takes place in the UK. We shall use mixed methods to collect fine-grained qualitative and quantitative data on the experiences of people with advanced dementia and their carers as death approaches and in bereavement. Findings will inform the development of a new model of care (intervention) in the next phase of this research (figure 1). This work responds to the UK government initiatives to provide rigorous evidence to improve the experience of people with dementia and their carers around death and in bereavement.^{9 19 20} The research has been adopted onto the portfolios of the National Institute

for Health Research Clinical Research Network (NIHR CRN)—Primary Care Research Network (PCRN) (Refs. 12621; 12623) and the Dementia and Neurodegenerative Diseases Research Network (DeNDRoN).

METHODS

Aim

To understand the end-of-life experience of people with dementia and their carers and to generate information on how this could be improved.

Objectives

1. In people with advanced dementia we will study in depth their clinical symptom burden and health and social care needs, and pathways of care as the end-of-life approaches.
2. In informal family carers to understand in depth their needs and experiences in the period before bereavement and in the months after their loss.
3. To gather views from professional and informal carers on how care could be improved.

Literature update

We shall begin by updating existing reviews of the international literature on end-of-life interventions for people with advanced dementia and their carers and carer bereavement.^{5 12 21 22}

Cohort studies (quantitative data)

We shall conduct prospective cohort studies of people with advanced dementia and their carers.

People with advanced dementia

Study population

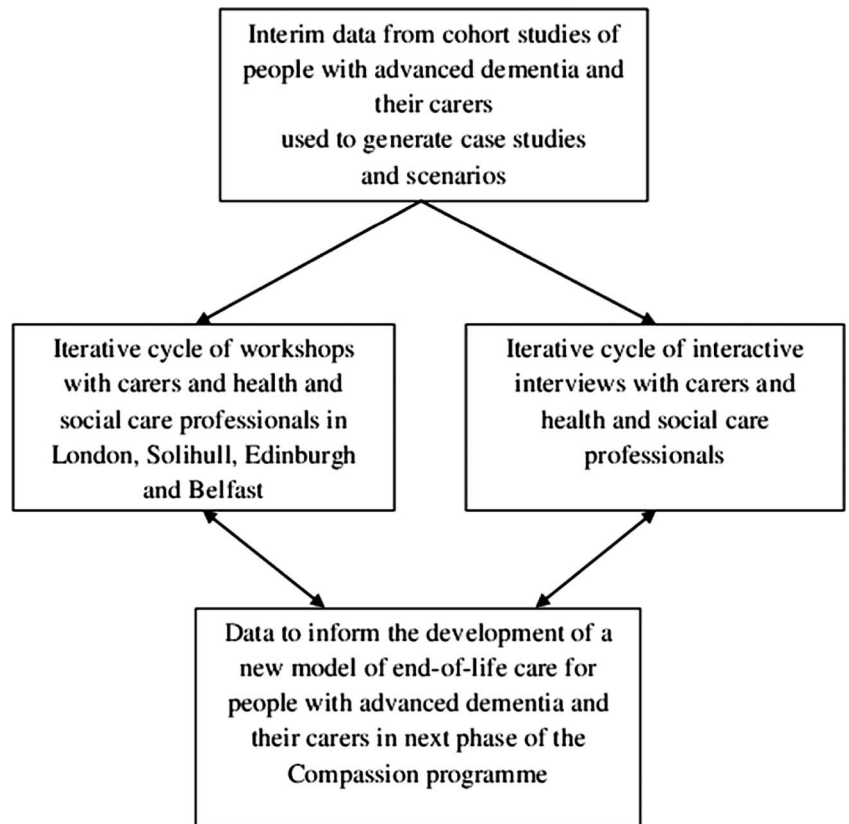
With assistance from the PCRN we shall recruit 100 people with advanced dementia, 50 in patient-carer dyads, 70% residing in care homes and 30% in their own homes¹ from 10 boroughs in London, UK. We shall purposively select 10–20 care homes served by general practices (GP) linked to the PCRN that are representative of variations in quality, number of beds and type of ownership.

We will include people over 65 years of age with a clinical diagnosis of dementia (DSM-IV criteria),²³ at the FAST grade 7c and above¹⁶ (unable to walk, all intelligible speech is lost and doubly incontinent). As people with advanced dementia will be unable to give informed consent; we will gain assent from a carer ('personal consultee') or professional consultee who is able to give assent. We will not include those who indicate either verbally or non-verbally that they do not wish to participate, those who are moribund, comatose or where there are clinical concerns that may preclude them being considered for inclusion.

Consent and recruitment procedure for people with advanced dementia

We have obtained approval from a Research Ethics Committee specialised in considering research on adults

Figure 1 The Care Of Memory Problems in Advanced Stages: Improving Our Knowledge programme, first phase.



who lack capacity. We shall gain assent from the next-of-kin, unpaid carer or close person to act as a ‘personal consultee’ according to the Mental Capacity Act (UK) 2005. If no ‘personal consultee’ is available the research team will nominate a clinician to act in this capacity as a ‘professional consultee’, defined according to current guidance⁹ as a ‘professional who is not directly involved in the research or the care of the person with dementia’. To ensure collection of maximum data, consultees will be asked for consent for the research team to access health and social care records across primary and secondary care. We have used similar processes in earlier work funded by the Alzheimer’s Society and BUPA Foundation (BePaid grant ref. 131).²⁴

Data collection

We will collect demographic information at baseline including information obtained from GP notes such as medications; acute hospital admissions and the reasons for these; and ‘sentinel events’, defined as ‘new medical conditions that have the potential to lead to a significant change in health status and a shift in the goals of care’, for example, pneumonia and hip fracture.¹⁷ The sources of data are summarised in [table 1](#). Patients will be reviewed every 4 weeks for a maximum of 9 months or until death. We will document the presence of advance directives, care plans and specific requests regarding hospitalisation and resuscitation.⁹

Health economics

We will calculate costs for the last 6 months of life. We will combine the volume of resource use data obtained for people with advanced dementia and their carers with unit costs data from published sources^{37 38} in order to calculate costs per patient from NHS, personal social services and societal perspectives.

Data analysis

Interim descriptive analyses will be conducted at 6, 12 and 24 weeks which will inform our understanding of patient outcomes, symptom burden, mortality, patient pathways, case studies and scenarios. After full data collection, we shall present the cohort demographics, the symptoms experienced and calculate symptom rates over the follow-up period (with CIs), taking into account repeated measures. We shall explore the level and nature of unmet needs, describing how comfort and quality of life change over time and differences between those living in care homes and those remaining in their own homes.

Sample size

Numbers are chosen pragmatically, guided by the literature,¹⁷ and the anticipated feasibility of recruitment rates and survival times of people at FAST stage 7c.

Table 1 Summary of assessments for people with advanced dementia

Measure/author	Purpose	Source*	Time of assessment
Functional assessment staging scale (FAST) ¹⁶	Describes a continuum of seven stages of functional impairment	2	Baseline
Diagnostic statistical manual of mental disorders (DSM-1V) ²³	Diagnostic criteria for dementia	2	Baseline
Charlson co-morbidity index ²⁵	Calculates severity of chronic comorbidities	2	Baseline
Waterlow scale ²⁶	Risk for developing pressure sores	2,3	Baseline/monthly
Sterling wound assessment scale ²⁷	Assesses extent of wound damage	2,3	Baseline/monthly
Bedford Alzheimer nursing scale (BANS) ²⁸	Used to stage levels of severe memory impairment in dementia	2,3	Baseline/monthly
Confusion assessment measure (CAM) ²⁹	Measures confusion and diagnoses delirium and distinguishes between delirium and dementia	1,2,3,4	Baseline/monthly
The neuropsychiatric inventory (NPI) ³⁰	Assesses behavioural and psychological symptoms in dementia	2,3,4	Baseline/monthly
Cohen Mansfield agitation inventory (CMAI) ³¹	Measures a range of agitated and potentially challenging behaviours	2,3,4	Baseline/monthly
Pain assessment in advanced dementia (PAINAD) ³²	Observational pain tool used to measure pain during care tasks and at rest	1	Baseline/monthly
Symptom management at the end of life in dementia scale (SM-EOLD) ³³	Assesses comfort and pain in the prior 30 days	1,2,3,4	Baseline/monthly
Quality of life in late stage dementia scale (QUALID) ³⁴	Quality of life in the prior week	3,4	Baseline/monthly
Painful interventions Scale ³⁵	Lists painful interventions, eg, insertion of nasogastric tube	2,3,4	Baseline/monthly/post death
The resource utilisation in dementia questionnaire (RUD-LITE) ³⁶	Formal and informal health and social care resource use	2,3,4	Baseline/monthly/post death
Client services receipt inventory (CSRI) ³⁷	As above but more financially based	2,3,4	Baseline/monthly/post death
Comfort assessment in dying (CAD-EOLD) ³³	Comfort assessment in dying with dementia	2,3,4	Death

*1, Patient; 2, patient primary care records; 3, care home staff; 4, informal carer.

Informal carers

Study population, consent and recruitment procedures

We will recruit 50 informal carers of people with advanced dementia, defined as unpaid informal carer (eg, family member or friend in regular contact and who is the next of kin or a 'key decision maker'). They will require English language sufficient to complete the study ratings. We will exclude carers where there are clinical concerns that may preclude them being approached. Carers will be informed that some patient and carer experiences may be used to generate patient pathways, case studies or scenarios. Carers will be invited to take part when approached about considering the participation of their relative or friend in the patient cohort study. They will give informed consent according to usual ethics procedures.

Assessments

We shall collect data during face-to-face interviews at baseline and every 4 weeks by post or over the telephone. At baseline we shall collect demographic data including relationship to the person with dementia, the number of years spent caring and any other caring

responsibilities. All other carer assessments are summarised in [table 2](#).

Data collection in bereavement

If the patient dies, carers will be interviewed in a place of their choice at 7 months post-bereavement to consider complicated grief which requires 6 months of symptoms, using the Inventory for Complicated Grief.⁴³ If complicated grief is identified, participants will be supported to access appropriate services. We shall undertake interviews which we will analyse using qualitative methods, to gain a deeper understanding of the circumstances surrounding the death and the views of the carer on which aspects of care were or were not satisfactory.

Data analysis

We shall describe the demographic characteristics of carers and their well-being at study entry and explore descriptively the trajectory of carer well-being in tandem with patient data and how this changes if the person with dementia dies. Data will include carer outcomes as listed in [table 2](#).

Table 2 Summary of assessments for carers

Measure/author	Purpose	Source*	Time of assessment
Brief COPE ³⁹	Measures coping strategies used	4	Baseline
Zarit burden interview ⁴⁰	Reflects feelings about caring, measures carer burden	4	Baseline/monthly
Short form 12 health survey questionnaire (SF-12) ⁴¹	Measures health related quality of life over eight domains	4	Baseline/monthly/2 and 7 months postdeath
Hospital anxiety and depression scale (HADS) ⁴²	Anxiety and depression	4	Baseline/monthly/2 and 7 months postdeath
Inventory of complicated grief (ICG) pre-loss ⁴³	Assesses prevalence and severity of carers' anticipatory grief	4	Baseline
Inventory of complicated grief (ICG) pre-loss (ICG-R) postloss ⁴³	Identifies symptoms of complicated grief	4	2 and 7 months post death
The resource utilization in dementia questionnaire (RUD-LITE) ³⁶	Formal and informal health and social care resource use	4	Baseline/monthly/2 months postdeath
Client services receipt Inventory (CSRI) ³⁷	As above but more financially based	4	Baseline/monthly/2 months postdeath
Satisfaction with care at the end of life (SWC/CAD-EOLD) ³³	Assesses the carers' level of satisfaction with care in advanced dementia	4	Baseline/monthly/2 months postdeath

*4, Informal carer.

Workshops and interactive interviews (qualitative data)

We shall hold an iterative cycle of workshops and interactive interviews with carers and healthcare professionals to generate hypotheses on how end-of-life care for people with advanced dementia and their carers might be improved. Case studies, scenarios and examples of patient pathways and carer experiences informed by data from the cohort studies will be used to generate discussions. Data generated may challenge existing ideas and will lead to the emergence of new theories for further exploration. Themes explored at the workshops will be revised as the study progresses.^{44 45}

Workshops with health and social care professionals

Participants

We shall purposively recruit participants from a range of statutory and private providers, and professionals from a variety of disciplines for example, general practitioners, district nurses, speech and language therapists, palliative care specialist nurse/doctors, psychiatric nurses, psychiatrists, geriatricians, Admiral nurses, ambulance staff, social workers, care home staff and commissioners. Potential participants will be sent a study information sheet stating that they have been identified as a person who currently or previously has shown interest in providing end of life care for people with severe memory problems and their carers. They will give informed consent before taking part. Workshops will be facilitated by two members of the research team. A total of 12 workshops will take place over 6 months each with a maximum of 10 participants.

Location

To understand and consider regional variation in resources, services, needs and policy we shall purposively

select providers and commissioners of health and social care in primary, secondary and tertiary settings from four areas of the UK (London, Belfast, Edinburgh and Solihull).

Workshops with carers

Workshops will be conducted with past and present informal carers of people with advanced dementia.

Recruitment and consent

To ensure our population is representative, carers of people with advanced dementia will be recruited from across London. Seventy per cent of people with advanced dementia reside in care homes and 30% at home and we shall stratify our sample to reflect this. Carers will be acting in an unpaid informal role and will be identified by GP linked to the PCRN or by care home managers.

Inclusion criteria

Those eligible for inclusion will be main informal carers of people with advanced dementia (eg, family member or friend in regular contact who is either next of kin or a 'key decision maker') with English language skills sufficient to participate in workshops or interactive interviews. We shall not include carers under the age of 16 or those for whom there are clinical concerns that may preclude them from being approached such as severe physical or mental illness or lack of capacity to give informed consent.

Workshops with people with early stage dementia

We shall conduct up to two workshops with people with early dementia.

Recruitment and consent

People with early stage dementia who have a Mini Mental State Examination⁴⁶ of 20 and above and who are under the care of a specialist memory clinic will be recruited to participate in workshops using the North Thames DeNDRoN research register (DemReg), a database of patients from memory clinics and old age psychiatry services who have given signed consent to be approached to participate in research studies. We will not include people if there are clinical concerns precluding them from being approached, those who lack capacity to consent at the outset and those who are unable to communicate in English to a degree whereby they would be unable to participate in the workshops. Using a four-point framework (Mental Capacity Act, 2005; p45), the researcher will make an independent assessment of the capacity of the person with dementia at the point of recruitment. To participate, they will be able to: (1) understand (relevant) information about the decision to be made; (2) retain this; (3) use or weigh the information as part of the decision-making process and (4) communicate their decision.

Data analysis

One researcher will take detailed field notes during the workshops to record the setting, the activities that took place, who participated and their role in the activities and exact quotations or close approximations of important comments made. We shall use flip-charts to record key elements of discussions. All data will be entered into a qualitative software programme, Atlas-ti and analysed for thematic content emphasising emerging hypotheses on how care may be improved.

Interviews with carers and healthcare professionals

Unstructured interactive interviews are appropriate for understanding complex issues that are relevant to healthcare settings.⁴⁷ Such interviews provide participants considerable control over the interview process⁴⁸ and are similar to guided conversations.⁴⁷ We shall conduct individual interactive interviews with carers and healthcare professionals. As with the workshops, discussions will be facilitated using case studies and scenarios of patient and carer experience. These interactive interviews take an account of the natural interaction between researcher and participant through which each unconsciously considers underlying hypotheses and contextualises responses. Our approach will be underpinned by critical realism attempting to uncover influential processes, policies, perceptions and events that often determine health and social care outcomes. A maximum of 10 interviews will occur only in London at 8, 14 and 30 weeks from the start of the cohort studies, giving 30 interviews with healthcare professionals and 30 interviews with carers. Themes explored during the interviews will be revised as the study progresses.

Health and social care professionals

As with the workshops, interviews will be conducted with a wide range of health and social care professionals to provide an overall perspective. Topics may include discussion about health and social care professionals' roles and responsibilities for patients with advanced dementia. We shall explore what they perceive as the good and bad things about their role and their relationships with other professionals in the field. This will lead to discussions about what an ideal model of care would look like, how this compares with what actually happens now and how improvements might be achieved. We shall also explore how people respond to things that go wrong in everyday practice.

Carers

Interviews will be conducted with current and past carers of people with advanced dementia. We shall explore in depth the complex and potentially contested layers of patient and carer experience and how changes in the management of advanced dementia could improve care pathways. More specifically, topics may include illness beliefs and the illness journey, carer needs along the journey, communication and information needs, the carers' role in decision making, attitudes towards end-of-life care and palliative care principles.

Data analysis

Interviews will be audio-taped, transcribed verbatim and entered into Atlas-ti. The transcripts will be combined with field notes, memos and any relevant policy documents to reflect upon our initial hypotheses. Thus, we shall identify and clarify the barriers to the provision of good health and social care by revealing underlying, often unseen, factors and processes. With the support of diagrams and charts, the analysis will detail and explain the complex linkages between actors and agencies, structural and cultural factors. We shall explore the best way of providing a clear description of key issues that can be fully appreciated by a range of professionals and carers. For example, while we shall undertake a thematic analysis of the data we shall also seek to describe particular barriers through a revision of the case studies and vignettes in a way that accommodates the new explanatory information in an accessible way. While we shall look for patterns or commonalities of behaviour and events we shall also examine and explain irregular cases. The analysis and findings will allow us to build a comprehensive set of recommendations to be incorporated within the development of our intervention. This will also stand alone as a significant contribution to the evidence base of end-of-life care.

Patient and public involvement

We are experienced in involving people with dementia and their relatives in research.^{49 50} We shall involve people with early dementia, carers are included in

workshops across the UK and an expert by experience joins our steering group.

Expert steering group

An expert steering group will meet three times per year. The group is composed of stakeholders with expertise in end-of-life care and dementia including service providers and policy makers from statutory and voluntary bodies. The group will monitor the progress of the research, review interim findings and ensure the appropriate media and policy profile of the work as it unfolds.

ETHICS AND DISSEMINATION

We have obtained approval from NHS ethical committees through IRAS for studies involving people with dementia and carers (cohort studies REC ref. 12/EE/0003; workshops and interactive interviews REC ref. 12/LO/0346), and from university ethics committees for work with health and social care professionals (REC ref. 3578/001).

We shall prepare documents for dissemination by end-of-life and dementia care organisations such as Marie Curie Cancer Care, BUPA, Dementia UK, The Alzheimer's Society, National Council for Palliative Care, National End of Life Care programme and the government special advisor for dementia including detailed reports, scientific presentations at conferences and papers for peer reviewed journals, and publicise our findings on the Marie Curie website. A summary will be provided to all participants who would like to receive this.

DISCUSSION

Combining the quantitative and qualitative data from this study will enable us to gain a greater and more detailed understanding of the clinical and social care needs of people with advanced dementia and their carers as they face death, and for carers into bereavement. Data will inform explanations of the barriers to good care and generate hypotheses on how these can be challenged in new ways to provide innovative solutions. We shall be able to report in detail on the clinical symptom burden of people with advanced dementia living in care homes and their own homes and on their survival. We will gain an in-depth understanding of the complex interactions between the patient experience of care, the involvement of carers and the health and social care systems in which care is delivered and received.⁴⁵ Our mixed methods in-depth approach will enable us to consider factors that might affect the implementation of an intervention from the outset.^{51 52}

Further work

We have received funding from Marie Curie Cancer Care for subsequent research in which we shall use these data to inform the development of a complex intervention. We shall collect data on its acceptability, feasibility and potential costs by piloting the intervention in one

healthcare economy before proceeding to further testing in an exploratory randomised controlled trial.

Strengths and limitations

While there have been some prospective cohort studies in other countries⁵³ to our knowledge our quantitative data will be the first of this nature to be collected in the UK population. We are attempting to ensure that we recruit a representative sample of people with advanced dementia and their family carers, and have used professional consultees so that people with advanced dementia who may not have a relative to assent for them can still be included in research. Using qualitative research methods will provide a richness and background to this quantitative data, allowing it to be better placed in the context of a complex health and social care system. While dementia is a terminal disease in its own right, our research does not address the palliative and end-of-life care needs of those dying at earlier stages of dementia from other conditions.

CONCLUSION

We know that as the numbers dying with dementia continue to increase, this programme will be of importance to health and social care service planners. The analysis and findings will allow us to build a comprehensive set of recommendations to be incorporated within the development of our complex intervention. Policy in this field is rapidly developing and we shall report findings as soon as they are available to ensure that the insights we gain enter the public domain as quickly as possible.

Contributors LJ and ELS devised the programme of research and secured the funding; LJ, ELS, SS and JH wrote the study protocols. LJ, ELS and JH drafted the manuscript. All authors critically revised the manuscript for important intellectual content. All authors read and approved the final manuscript.

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Competing interests None.

Ethics approval NHS Ethics Committees and UCL Ethics Committee.

Provenance and peer review Not commissioned; internally peer reviewed.

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