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Living Alone with Dementia in England – Managing without Informal Support to Contact and Navigate Services: A Mixed-Methods Protocol

PROTOCOL

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ABSTRACT

Background: Much of the evidence about good practice and commissioning in dementia services focuses on the person with dementia-carer dyad. We know that people with dementia who live alone and do not have informal support experience worse outcomes, but we know little about the additional support needs experienced by this group, nor do we know about service responses to accommodate any additional or different needs.

Aim: This research aims to understand the needs and experiences of people with dementia who live on their own and do not have someone to help them access services or act as a point of contact. It will also explore whether and how services respond to the unique needs of this group of people with dementia to help them to live at home for as long as possible.

Methods: The project commenced in April 2022 and will report in November 2023. There are four consecutive elements: an on-line audit of social care dementia commissioners in local authorities in two regions of England about services for this client group; in person/on-line interviews/focus groups with people with dementia who live alone and don't have someone to navigate their care; and qualitative case studies of four different service examples. Two stakeholder consultation workshops will be held at the end of the project to identify areas for action and co-design resources for different stakeholders. The findings from each element will inform subsequent ones.

Impact: Feedback loops will be embedded throughout this research to maximise opportunities for rapid action in response to findings. These include regional Sharing and Learning Networks and bi-monthly newsletters. A series of outputs targeted at different audiences, including academic and practice publications and events, and co-produced resources for people with dementia and social care commissioners and providers, will be produced. Dementia-focused networks will facilitate dissemination.

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INTRODUCTION

Living independently is a priority for many people with dementia (Quince, 2011), and current United Kingdom (UK) policy aims to support people with dementia to live in the community for as long as possible. However, achieving this aim often relies on family and friends providing support (Newbrunner et al., 2013), more so as dementia progresses, particularly when people with dementia live alone.

Approximately a third of people with dementia who live in the community in studies in Germany, the UK and the USA live alone (Eichler et al., 2016) and in some cases they have someone who can act as a point of contact for services when needed. However, not everyone with dementia who lives alone has an informal carer. Some have good social networks that assist with shopping or practical support (Duane, Brasher and Koch, 2013) but may be reluctant to help with care decisions (Samsi and Manthorpe, 2013). Evidence on how this group manage their daily lives and access services is lacking, partly because people with dementia are often excluded from research when they do not have a carer to facilitate involvement (Brooks et al., 2017; NICE, 2018).

While there are no clear figures for the number of people with dementia who live alone and have no-one to act as a point of contact, three studies with people who live alone showed that 3% to 9% of participants had no informal caregiver (Clare et al., 2020; Ebly, Hogan and Rockwood, 1999; Eichler et al., 2016).

Existing evidence demonstrates that people with dementia who live alone in the community have an increased risk of unmet needs, particularly around diet, self-care, looking after the home, and accidental self-harm (Miranda-Castillo et al., 2010a); being admitted to hospital or long-term care (Soto et al., 2015); reduced capacity to care for themselves and live safely (Evans, Price and Meyer, 2016); and of only coming into contact with formal services if there is a crisis (Waugh, 2009). Furthermore, a recent study identified that life satisfaction was lower for people with dementia living alone (including those with low support) than for people living with others (Clare et al., 2020). It is likely that these risks may increase further when people living alone with dementia do not have someone to help them navigate services, but there is very little evidence available.

In one study, people with dementia living alone without support were more likely to be male, less likely to have someone who could help them in an emergency and have significantly lower self-perceived social support (Eichler et al., 2016). This group may be at more risk of social isolation (Miranda-Castillo et al., 2010b) and loneliness (London Strategic Clinical Network for Dementia, 2014). In addition, they are less likely to receive a timely diagnosis, and more likely to experience

delayed access to, and challenges navigating, social care and other support. Given the likely delay in diagnosis, this group's initial contact with social care may occur when they already have advanced dementia, and they may be likely to progress to 24-hour care sooner than those with family support (Weimer and Sager, 2009). These inequities can also be witnessed in how services support people who do not have a carer. In the Dementia Enquirers project, people with dementia who attended clinical appointments without an informal carer described clinicians' uncertainty and discomfort with making decisions about current and ongoing support and service delivery (York Minds and Voices, 2021). Practitioners may experience difficulty in understanding a client's background when there are no carers at appointments, while clients may struggle to understand and retain information with no carer to reinforce messages. In these circumstances, people with dementia may be more likely to miss appointments and other opportunities for regular monitoring of support needs. However, there can also be positive aspects to living alone, particularly when this is through choice, and it is important that these are recognised when support is being planned (York Minds and Voices, 2021).

Dementia intersects with different aspects of identity. People in black and minority ethnic groups in the UK are more likely to be unsure about how to access dementia services (Moriarty, Sharif and Robinson, 2011), and to access dementia services later than white people (Mukadam, Cooper and Livingstone, 2011). There are similar impacts for lesbian, gay, bisexual and trans people, who may face discrimination in service provision (Fredriksen-Goldsen et al., 2018). The National Dementia Strategy (Department of Health, 2009) does not mention sexual orientation (Ward, Pugh and Price, 2010), and service providers often fail to recognise sexual diversity in their practice (MacKenzie, 2009). A lack of culturally appropriate service provision may particularly affect those who live alone without informal support. Knowing how these additional challenges impact people with dementia who live alone and do not have carers, is essential to help maximise equitable support and services for everyone with dementia.

STUDY AIMS

This study will provide evidence about the personal assets, natural community, and formal social support used by people with dementia who live alone and have no-one to help navigate or act as a point of contact to/for services to manage their daily lives. It will identify examples of practice aimed at supporting these clients that can be shared to increase inclusive social care provision.

METHODS

We are using a mixed-methods approach: a service audit, qualitative interviews with people with dementia who live alone and do not have carers, and case studies of exemplar services supporting this client group. The three elements will be conducted sequentially, meaning that later work is informed by earlier elements. The data from across the elements will be compared and contrasted at workshops where priorities will be decided, and resources developed.

BI-REGIONAL SERVICE AUDIT

We will undertake an audit of services for this client group in 34 local authorities in two English regions, Yorkshire and the Humber, and North Thames. These regions have been selected because they offer diversity of council type (namely county councils, unitary authorities and London Boroughs), socio-economic and demographic characteristics, and rural-urban classifications.

All lead commissioners of social care dementia services in these local authorities will be asked to complete a short (around 20 minutes) on-line survey about local dementia services and networks that support this client group, including services/support tailored for this group and generic dementia services that also support this group. At the end of the survey, we will request contact details for the manager of relevant services so we can seek clarifications (if needed) about, for example, client numbers and specific pathways or delivery approaches for this client group. The survey will be cognitively tested and piloted with commissioners in our existing networks before it is distributed.

The lead dementia commissioner in each local authority will be identified via our local contacts, the Association of Directors of Adult Social Services (ADASS), and organisational websites. They will be sent an email invitation with a summary of the research and a link to the survey. Respondents will have two weeks to respond. One reminder will be sent to those who do not complete the questionnaire in this timeframe.

Survey data will be subjected to descriptive statistical analysis to summarise regional service provision. We will also develop service descriptions to identify/confirm options for services to include as case study sites later on the research, to inform topic guides development for the interviews with people with dementia and professionals, and to guide discussions in workshops.

INTERVIEWS/FOCUS GROUPS WITH PEOPLE WITH DEMENTIA

Interviews/focus groups will be conducted with 30 people with dementia who live alone and have no-one to help navigate or act as a point of contact with services.

Purposive sampling, via, for example, the Dementia Engagement and Empowerment Project (DEEP) network, specialist dementia services and voluntary sector groups, will help recruitment, across a range of characteristics (use of social care services, ethnicity, sexuality, and stage of dementia) to reflect diversity of experiences. People with a diagnosis of dementia (reported by either the recruiting organisation or themselves) who can give informed consent and who live alone (including in supported accommodation, but not in residential care) and do not have a family member or friend acting as a point of contact to help them access and navigate services will be recruited.

As this is qualitative research, we are not seeking a representative sample, but we will seek to represent a diversity of voices and experience. We acknowledge that recruitment of this population may be challenging and have therefore, set a pragmatic sample size ($n = 30$) which will enable collation of different service and support context experiences. We will use purposive sampling to recruit across a range of characteristics that might affect experience, for example, use of social care services, ethnicity, sexuality and stage of dementia. We will not use quota sampling, but acknowledging intersectionality, will seek a range of participants from across these groups to elicit a range of views and experiences to help address the research aims.

Potential participants will be offered an individual interview, or a focus group discussion if they are geographically close to other potential participants. Interviews will last approximately 45 minutes, and focus groups (consisting of no more than 4 participants) will last approximately 90 minutes, with breaks. All will take place in a location the participant is familiar and comfortable with. Virtual interviews or focus groups will be possible for participants who request these and who are already familiar with the technology.

An asset-based approach (Glasby et al., 2013) will be used to map the support people use, and what is missing, particularly in relation to social care. Interviews will cover

- Who is in the person's life, and what support they provide (if any)
- Whether the person has any interaction with services, and how this is managed (and if not, why not)

It can be difficult for people with dementia to answer abstract questions, so to facilitate involvement we will use creative approaches within interviews and focus groups, for example drawing maps of local areas or networks of support, or using vignettes. We will use the CORTE approach – gaining CONsent, maximising Responses, Telling the story, Ending on a high – (Murphy et al., 2015) to help manage recruitment and data collection with people with dementia. People with dementia who take part will be given a £20 gift voucher to thank them for their participation.

Initial thematic analysis (Braun and Clarke, 2021) of interviews with people with dementia will create a provisional summary of the findings. Two analysis workshops with people with dementia who live alone without carers will be held to sense-check the initial findings, identify gaps between service provision (covered in the audit) and needs for support and identify key findings to feed into the development of topic guides for the next stage (case studies). These analysis workshops play a key role in ‘following the thread’ of our analysis through the project. Findings from this analysis will help inform the focus of interviews and potential additional stakeholders and/or support services to invite for interview in the case studies of dementia services.

CASE STUDIES OF DEMENTIA SERVICES

A case study approach will be used to examine the different ways social care support is planned and delivered for this group. Case studies allow complex phenomena such as service planning and delivery to be studied in-depth (Yin, 2009) and undertaking multiple and diverse case studies can increase the transferability of data to other situations and contexts (Yin, 2009; Yin, 2013).

Cases will be services supporting the social care needs of this client group and identified via data from the earlier survey. Four exemplar services (two per region) that show different approaches to supporting this group will be selected. Case studies will allow exploration of the service and its context in depth, including service delivery mechanisms and care pathways, approaches for assessing and supporting this client group, and the wider service landscape.

Case study research draws on a variety of data sources to construct a detailed picture of phenomena in their ‘natural setting’ (Bowling, 2002). In each of the four sites, documentary analysis and semi-structured interviews with service providers will be conducted.

DOCUMENTARY EVIDENCE

Documentary analysis is widely used in social research (Prior, 2003; Tight, 2019). Collating and analysing local documents, for example, local strategy and policy documents, relevant service pathways, annual reports, and Board minutes/reports, will help to understand local approaches to planning, delivery and outcome monitoring for this client group and the local service context in which clients live. Relevant documents will be identified by monitoring relevant local websites and asking participants to recommend/provide relevant documentation.

INTERVIEWS WITH SERVICE DELIVERY PROFESSIONALS

Semi-structured interviews, which ensure key topics are addressed but enable flexibility for participants to present other relevant information, will allow in-depth exploration of service components and pathways, local policy, structures and process arrangements, and the interaction between these (Sheppard, 2004).

Telephone/on-line interviews, lasting around 45 minutes, will be conducted with service managers and key personnel working on strategy, commissioning, and service provision for people with dementia within that local authority area. Interviews will be guided by a topic guide, informed by data from the survey and interviews with people with dementia. It will be pilot tested with similar populations before data collection. All potential participants will be sent an information sheet detailing the study aims, the voluntary nature of the research, confidentiality, and limits on this, and what taking part will entail. If they wish to take part, they will be asked to sign a consent form before the interview commences.

Six to eight people per case site ($n = 24\text{--}32$) will be interviewed. Based on our previous work to understand local service commissioning and provision, we expect that this will generate sufficient data to understand the local service landscape (e.g. Aspinal et al., 2014; Aspinal et al., 2023; Gridley et al., 2011).

Documentary and interview data will be subjected to Framework Analysis (Gale et al., 2013; Ritchie and Lewis, 2003; Ritchie et al., 2014). In line with this analytic method, codes and themes will be iteratively developed as the research progresses. Data will be analysed per case site to produce in-depth understanding about the local context of these services and then cross-site comparisons will identify similarities and differences in support for this client group, and help develop possible explanations for these differences.

ETHICAL CONSIDERATIONS

The interview and case study components, including precautions and safety considerations for professionals’ and people with dementia’s involvement, of this research were reviewed and approved by the Coventry & Warwickshire Research Ethics Committee (22/WM/0185). The audit and case study components of this research were also reviewed and approved by the ADASS (11.11.22).

The information sheet will explain the research in more detail, what taking part would entail and that participation is confidential. After reading this, potential participants will have the opportunity to ask questions. If they agree to take part, they will be asked to give informed consent. All interviews will be held in the place/using the format preferred by the participant.

At the start of interviews, all participants will be reminded about the voluntary nature of their participation and their right to withdraw at any time, confidentiality of participation and content (including when this needs to be breached), and anonymity processes that will be used in reporting. All participants will be advised that they can pause or stop the interview at any time.

A 'sensitivity protocol' that addresses the precautions and safety considerations for professionals' and people with dementia's involvement, will be informed by the participant's preference. For example, if a participant becomes distressed or anxious during the interview, we might provide reassurance, and/or pause or terminate the interview, and/or avoid the emotive topic. If the participant wishes to continue with the interview, they will be given the time needed to feel able to continue, including doing so on a different day. For focus groups, a separate quiet room will be available for participants to sit and recover with or without the support of a researcher (depending on their preference), after which they can return to the group discussion or withdraw from the study. Data collected up to the point of withdrawal will be retained with the participant's permission. Participants who become distressed during the interview/focus group will be offered a follow-up conversation with the co-director of Innovations in Dementia, who is a co-applicant on this study and has many years' experience in supporting people with dementia. At the end of interviews/focus groups with people with dementia, participants will be given a 'support leaflet' with details of national and local organisations that provide information, advice and support for people with dementia.

DEVELOPING RESOURCES THROUGH INTEGRATIVE WORKSHOPS

Findings from all elements of the study will be collated and presented at two stakeholder workshops (with relevant professional and public delegates). These workshops will enable different stakeholders to work together to (i) identify key priorities for service planning and delivery and (ii) help co-produce evidence-informed resources for different stakeholder groups so that support can be optimised for people with dementia who live alone and have no-one to help navigate or act as a point of contact to/for services use to manage their daily lives.

PATIENT AND PUBLIC INVOLVEMENT

Patient and public advice is supported by Damian Murphy (Co-Director) of Innovations in Dementia. The advisory group, which will meet throughout the project duration, comprises professional and public members, four of

whom are people with dementia who live alone and who do not have informal carers.

DISCUSSION

This protocol describes a study, funded by the NIHR Research for Social Care, about the social care needs and services in England for people with dementia who live alone and who do not have informal carers. It will combine qualitative and quantitative methods to understand the needs and experiences of people with dementia who live on their own and do not have someone to help them access services or act as a point of contact. It will also explore whether and how services support the unique needs of this group of people with dementia to help them to live at home for as long as possible. The interim and immediate findings will have local significance for the two regions taking part in the study to help understand, and plan for, local need. The study will provide insights into this population's needs, providing information useful to social support service commissioners and providers more widely while concurrently raising the profile of this client group.

A key strength of this study is the collaboration between academia, local service social care organisation and user-led organisations. The collaboration between these groups ensures that people living with dementia are central to the research and how it progresses. The mechanisms developed to share findings as the research progresses means that stakeholders can respond to findings in a timely manner.

Recruitment of people with dementia for this study is potentially challenging. This will be overcome by drawing on a wide network across England, including statutory, voluntary, and user-led organisations. If the desired range of characteristics (use of social care services, ethnicity, sexuality, and stage of dementia) is not achieved after four months of recruitment, the remaining recruitment will focus on anyone who meets the inclusion criteria.

CONCLUSION

This study seeks to understand the unique social support needs of, and specific social service provision for, people with dementia who live alone and do not have someone who can help navigate or access service. The collaborative workshops will help to identify the key priorities for service planning and delivery and help co-produce evidence-informed resources for different stakeholder groups. In doing so, we aim to raise the profile of this group and their unique needs so that they can be enabled to live well at home for as long as possible.

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COMPETING INTERESTS

The authors have no competing interests to declare.

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