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**Research with family carers of people living with dementia: recruiting during the pandemic**

The [UK Government stated](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/780777/dementia-2020-challenge-2018-review.pdf) that by 2020 it wanted to see [an increase in the number of people with dementia living and receiving care at home](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/780777/dementia-2020-challenge-2018-review.pdf). The majority of home-care in the UK is currently provided by informal carers – the Alzheimer’s Society estimate that over [670,000 unpaid carers](https://carers.org/downloads/wales-pdfs/caring-for-someone-with-dementia-eng.pdf) provide support for a person living with dementia within the UK. In this blog, we use the term ‘carers’ to refer to unpaid informal caregivers who support a family member or friend living with dementia, whether they live together or apart, and whether the person with dementia is living in a private household (their own or a family member's) or in a place offering residential care. COVID-19 is [linked to increased deaths](https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvingcovid19inthecaresectorenglandandwales/deathsregisteredbetweenweekending20march2020andweekending2april2021) in people living with dementia and is exacerbating existing inequalities. Yet [very little is known about the experiences of these carers](https://journals.sagepub.com/doi/full/10.1177/1471301221990504), [especially during the pandemic](https://www.medrxiv.org/content/10.1101/2021.08.20.21262375v1).

In seeking to explore these experiences, research teams from University of Manchester and Staffordshire University found that we faced similar barriers in the recruitment of participants to our studies during the COVID-19 pandemic. This encouraged us to consider collectively what the implications of these barriers to recruitment are for knowledge generation, and ultimately, for policy and practice. We wanted to share experiences for the benefit of similar teams and projects, and we would be really interested to hear from anyone with experience or insight into these issues. In discussing our cumulative experiences, we hope we can shine a useful light on this topic and break down some of these barriers.

**In this blog, we outline the research aims and methodologies of our three studies, reflect on our experiences of the research process for our individual studies, before drawing together the implications of these experiences. We close with some recommendations for future studies with this population and collaborative practice.**

**Study outlines**

**Study 1. The impact of Care Act Easements under the Coronavirus Act 2020 on co-resident carers, over the age of 70, with partners living with dementia**

In response to the pandemic the UK government introduced the Coronavirus Act 2020, which included the unprecedented power for local authorities to suspend the majority of their adult social care duties required under the Care Act 2014. These suspensions were known as “easements”. Eight local authorities introduced easements at the initial peak of the pandemic, whilst many others adapted or suspended services, including respite, day centres, and domiciliary support. This NIHR-funded research project, which is ongoing, aims to investigate the consequences of the Care Act Easements for older carers (age 70+) supporting partners living with dementia at home. The study was designed to focus upon this particular group of carers because they are understood to be an invisible group that have received scant recognition during the pandemic despite the considerable increase in caring responsibilities that many have faced.

Our initial research design includes 48 in-depth semi-structured interviews over the telephone with co-resident carers aged 70 or over who have been supporting their spouse or partner with dementia to live at home during the pandemic and live in one of four local authority areas; two of which invoked easements and two that did not. The recruitment strategy drew upon the research team’s extensive networks. This includes two leading national dementia care project partners, the support of two national dementia and carer organisations, established links with local networks in each area, and adoption by Join Dementia Research and the Clinical Research Networks.

**Study 2. Carers’ experiences of caring for a friend or family member living with dementia during the COVID-19 pandemic**

Carers experiences are influenced by [multiple interlinking factors, such as the availability of, and access to, social and professional support, their physical and mental health, and their relationship with the person with dementia](https://www.sciencedirect.com/science/article/pii/S1552526017300018?via%3Dihub). Research has also shown that psychosocial resources, such as [resilience](https://journals.sagepub.com/doi/10.1177/0269215512457961?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed) and [hope](https://pubmed.ncbi.nlm.nih.gov/19485053/), are important in the mental and physical health of carers. The focus of this study was toexplore unpaid carers’ experiences of supporting a family member or friend living with dementia through the COVID-19 pandemic, and to investigate the role of hope and resilience during this time. To capture experiences of changing COVID-19 guidance, a qualitative longitudinal research design was adopted. Carers of a family member or friend living with dementia were interviewed at two time points (roughly eight weeks apart). Participants had to be 18 years old or over, be an unpaid carer of someone living with dementia during the COVID-19 pandemic and live within the UK. The research was advertised through several channels, including carer organisations, support groups, the researchers’ social media, “Join Dementia Research”, and word of mouth by participants.

Semi-structured interviews informed by a topic guide were conducted between June and September 2020. Interviews took place remotely using either Microsoft Teams, Skype, Zoom, or telephone. Interviews were digitally audio recorded, transcribed verbatim, and anonymised. Data were analysed using an inductive, semantic, and realist approach to [reflexive thematic analysis](https://www.tandfonline.com/doi/abs/10.1080/2159676X.2019.1628806).

**Study 3. Using photo-elicitation to investigate the experience of informal older carers of people with dementia living in rural and semi-rural community settings during COVID-19 restrictions.**

This study explored the experience of being an informal carer to community-dwelling people living with dementia in rural settings, [where access to support services may be limited](https://policy.bristoluniversitypress.co.uk/remote-and-rural-dementia-care) . This ongoing project used participatory arts based, qualitative methodologies to engage informal carers over 60 years old in rural and semi-rural communities in the Calder Valley, West Yorkshire, to explore and document the impact of COVID -19 restrictions on informal carers of people living with dementia in the community and compare their experiences with UK government guidelines on support for informal carers and people living with dementia during COVID-19 restrictions.

We aimed to recruit a minimum of six participants and train them in photo-elicitation research methods, which can be used to [uncover what is important to participants](https://books.google.co.uk/books?hl=en&lr=&id=PMVGBQAAQBAJ&oi=fnd&pg=PT10&dq=GC+Stanczak+-+Visual+research+methods:+Image,+society+and+%E2%80%A6,+2007+-+Sage+London&ots=5Qi99P3oN8&sig=5i-v-PKmHD2LUGrhrA2brbbenG4#v=onepage&q&f=false) and [empower them](https://experts.illinois.edu/en/publications/social-ethics-of-landscape-change-toward-community-based-land-use). Using smart phones, they were to record aspects of their day-to-day caring responsibilities and interactions with the people they care for and the wider community. These photographs were then used in interviews as a prompt for further exploration of the issues, providing a rich narrative describing the experience of this group during COVID-19 restrictions. The experience of the participants would then be compared to government guidelines on informal carers and people living with dementia during COVID-19 restrictions.

**Reflections on the research process**

**Study 1:**

The impact of the pandemic, including the closures of day centres, social groups and support services, amid indications that older people are not necessarily returning to services as they re-open, plus the additional stresses that this group of carers are facing, has created substantial difficulties with recruitment and threatened the progress of the project. In response, we sought ethical approval from the HRA SC-REC to expand our carer recruitment beyond our initial geographical areas of interest, retaining methodological integrity by continuing to seek carers from all eight easement areas and comparators from other local authority areas in England. This has relieved some of the pressure on the project but even with our experience as a team, we did not anticipate the difficulties that we have had recruiting carers.

**Study 2:**

Data for this study needed to be collected within a certain time period (during COVID-19 restrictions), it was therefore frustrating to experience early challenges with recruitment. Face-to-face carer support groups, a useful source of recruitment, were no longer running in response to the COVID-19 restrictions. Instead, recruitment relied upon care organisations advertising this research to those who contacted the organisation directly (via telephone) for support (e.g., advice for caring for someone living with dementia during COVID-19) or on a page on their website. Only two participants were recruited in the first month of the study. Consequently, we decided to amend our ethics to broaden our recruitment scope to also include carer groups on social media. Local carer support groups were contacted through their Facebook or Twitter page, and several offered to advertise the research. This resulted in further participants being recruited. However, it was not long before we were again struggling to recruit carers. After much searching for new sources, we came across the “Join Dementia Research” website and decided again to amend our ethics application to recruit using this resource. After months of intensive effort, and no new enquiries for 6 weeks, we decided to end recruitment with 13 participants. The amount of work required to recruit dementia carers was beyond the capacity of a small team without research funding.

**Study 3:**

Our project funding was only for 6 months, and similar to other projects, recruitment has been very challenging as a result of lockdown due to carers’ isolation increasing during the pandemic, and support organisations closing or moving online leading to gatekeepers having less opportunity to promote the project. As a result of this and in discussion with the research team which included members with lived experience of being a carer, we amended our ethics approval to extend the time for data collection and expand our geographical criteria to rural areas in the whole of the UK, and our age criteria to over 50 years old. Despite these changes, we were still only able to recruit three participants. We also decided to extend our participant criteria to include people running support groups and organisations for carers and people with dementia to supplement the information we have collected from carers. This work will be unfunded as it extends beyond the period of the grant. The recruitment of gatekeepers is ongoing but is also proving to be difficult.

**Overall Implications**

The individual and shared challenges experienced by each of the projects in terms of recruiting carers of people living dementia have several potential implications that warrant consideration:

1. **Under-representation of carers in research**

An underrepresentation of the direct experiences of older carers within the research literature and an overreliance on the views and perceptions of third-party stakeholders in research concerning the impact of policy change on this particular group of carers may mean that the voice of older carers is missing within discussions and decision making concerning relevant policy and practice, both now in terms of urgent priorities and in the event of a future pandemic.

1. **Implications for future funding**

Evidence that research projects are experiencing widespread challenges with regards to the successful recruitment of participants may create barriers to receiving funding and ethical approval for future studies focused upon older carers due to concerns regarding successful completion and the methodological robustness underpinning subsequent findings.

1. **Ethics approval processes**

The unexpected challenges in recruitment led all three studies to apply for ethics amendments, which can take considerable time and resources. In a short study such as Study 3, this can have implications on the time available for the core study activities.

1. **Recruitment and interview methods**

**The loss of face-to-face opportunities**

The opportunity to recruit via the face-to-face approach and the loss of the ‘personal touch’ in building rapport with participants, was undoubtedly a significant hindrance in recruitment to studies 2 and 3. This is however, not viewed by us necessarily as a negative, as it has provided the opportunity to explore, with key stakeholders, their own experiences and experiences of their service users during the pandemic. It has still given us some insight and it has also allowed us to establish connections with these stakeholders and given us opportunity to discuss various other barriers with them too. It is essential though, that these barriers are broken down so that the voices of those caring for people living with dementia can be heard.

**The move online**

The need to move to online recruitment and online or telephone interviewing may have impacted participant demographics, deterring participants with limited digital literacy and hearing or visual impairments. For example, study 2 reported that only five participants were 60 years old or over, and Study 3 reduced their age criteria to 50 in an attempt to recruit more participants. However, using online and telephone interviews may also have enabled us to reach groups we would not have been able to using face-to-face interviews, for example, those who are unable to access relief care or are unable to travel.

There is a further need to consider the digital literacy and accessibility of particularly older carers in recruitment to such projects. We know that n[ot everybody is able to access the internet](https://policyatmanchester.shorthandstories.com/on-digital-inequalities/) and indeed, the older and more deprived you are, the less likely you are to be digitally engaged, with lower socio-economic groups more likely to face barriers to getting online and less likely to have the skills to use digital devices.

**Recruitment through partnerships**

The easing of restrictions may mean that research teams can now advertise their research in person and offer face-to-face interviews, therefore overcoming the digital barrier. However, not all carer support groups have restarted, and some have also opted to remain online. Not having access to support groups can present challenges when trying to recruit a broad sample and sufficient participants. Though online social media groups may offer an important route to addressing this challenge, if most or all participants are recruited through online sources, such as social media, it is even more important to reflect upon the participant demographics.

**Recommendations**

We would recommend starting the recruitment process with a “wider net,” and where possible utilising both face-to-face opportunities, and the growing online carer community through social media. Anticipating recruitment difficulties and including these different options within ethics applications from the start would reduce the need to make amendments. Participants should be able to choose the format of their interview. Providing the choice of an online, face-to-face, or telephone interview would make recruitment more inclusive, providing a more holistic understanding of experiences.

Working collaboratively with other research teams at a different university has given us the opportunity to share our experiences of recruitment and our resources. We therefore recommend a dementia research forum, which would be composed of multiple groups, including researchers and people with lived experience of dementia and their carers, to develop connection and opportunities, and to discuss strategies to overcome barriers. This would improve and strengthen the quality of our research. Such forums may already be available, and if so, it would be great to hear more about them (please contact daniel.herron1@staffs.ac.uk and Jessica.runacres@staffs.ac.uk). We would also urge that this is something that does not repeat the exclusions to engagement and recruitment, by ensuring that face-to-face events are available and would suggest that a key strategy noted in the broader literature on reducing digital inequalities is to ensure this by incorporating known places of support such as libraries and support groups. This dementia forum could also be embedded within other existing structures such as the NHS Widening Digital Participation Programme.

As ever, there is a need to connect the silos wherever possible and we would welcome any suggestions for known dementia forums or similar platforms to the above that may assist us in helping ensure those who are particularly isolated, such as informal carers in rural and semi-rural settings, and older carers, have an opportunity to connect and share their experiences (please contact elizabeth.dalgarno@manchester.ac.uk and annie.harrison@manchester.ac.uk).

**Study 1 is ongoing and will be recruiting interview participants until the end of December 2021. If you would like further information about the study, please contact** **jayne.astbury@manchester.ac.uk**.

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**References**

Department of Health and Social Care. (2019). Dementia 2020 Challenge: 2018 Review Phase 1. Available at: <https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/780777/dementia-2020-challenge-2018-review.pdf>. Accessed on: 22nd Nov 2020.

Alzheimer’s Society. (2014). *Dementia UK: An update*. London, UK: Alzheimer’s Society.

Office for National Statistics (ONS) (2020). *Deaths within the care sector involving COVID-19, in England and Wales* . London, UK.

Dalgarno, E. L., Gillan, V., Roberts, A., Tottie, J., Britt, D., Toole, C., & Clarkson, P. (2020). Home care in dementia: The views of informal carers from a co-designed consultation. *Dementia*, p1471301221990504.

Akafekwa, T., Dalgarno, E., & Verma, A. (2021). The impact on the mental health and well-being of unpaid carers affected by social distancing, self-isolation and shielding during the COVID 19 pandemic in England-a systematic review. *medRxiv*.

Farina. N., et al. (2017). Factors associated with the quality of life of family carers of people with dementia: A systematic review. Alzheimer’s and Dementia,13(5), pp572-581. /doi.org/10.1016/j.jalz.2016.12.010

Simpson, G. & Jones, K. (2012). How important is resilience among family members supporting

relatives with traumatic brain injury or spinal cord injury?. Clinical Rehabilitation, 27(4), 367–377. doi:10.1177/0269215512457961

Duggleby, W., & Wright, K. (2009). Transforming hope: how elderly palliative patients live with hope. Canadanian Journal of Nursing Research, 41(1), pp204-217. Retrieved from: <http://cjnr.archive.mcgill.ca/article/viewFile/1944/1938>.

Braun, V. & Clarke, V. (2019). Reflecting on reflexive thematic analysis. Qualitative Research in Sport, Exercise and Health, 11(4), 589–597. doi:10.1080/2159676X.2019.1628806

Innes, A., Morgan, D., & Farmer, J. (2020). Remote and rural dementia care: why is this important for policy, research, practice and the lived experience of dementia?. *Remote and Rural Dementia Care: Implications for Research, Policy and Practice,* 3.

Stanczak GC. (2011). Introduction: Images, Methodologies, and Generating Social Knowledge. In: Stanczak GC,editor. *Visual Research Methods.* Thousand Oaks: Sage.

Glover TD, Stewart WP, Gladdys K. (2008). Social Ethics of Landscape Change: Toward Community-Based Land-Use Planning. *Qualitative Inquiry.* 14(3):384.

Ali, O., Dalgarno, E., Pagliari, C. & Verma, A. (2021). How the digital healthcare revolution leaves the most vulnerable behind. *On digital Inequalities.* Available at:[*https://policyatmanchester.shorthandstories.com/on-digital-inequalities/*](https://policyatmanchester.shorthandstories.com/on-digital-inequalities/)*.* Accessed on 25.10.2021.