

UNDERSTANDING AND REDUCING THE PSYCHOSOCIAL IMPACT OF CORONAVIRUS SOCIAL DISTANCING AND BEHAVIOURAL CHANGES ON FAMILIES OF CARE HOME RESIDENTS IN SCOTLAND



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CONTENTS

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| AIMS | 1 |
| KEY FINDINGS | 2 |
| WHAT DID THE STUDY INVOLVE? | 3 |
| WHAT WERE THE RESULTS AND WHAT DO THEY MEAN? | 4 |
| WHAT IMPACT COULD THE FINDINGS HAVE? | 5 |
| HOW WILL THE OUTCOMES BE DISSEMINATED? | 6 |
| CONCLUSION | 7 |

AIMS

This project examined the impact of social distancing on care home communities as a result of lockdown to minimise threats of COVID-19 with a particular focus on the health and well-being of family carers and investigated measures taken by care home staff to help families to stay in touch with their relatives in care homes.



KEY FINDINGS

- **The Importance of visits:** The experience of being unable to visit their loved ones during the pandemic had a negative impact upon the emotional well-being of the study participants. In our interviews, the inability to touch and see their loved ones caused multiple negative emotions. This was supported by the survey data in which 76% of participants gave responses indicating mental distress.
- **Significance of prior trust:** The pandemic has heightened the significance of prior trust in care home staff and management, and the importance of frequent effective communication building trust and confidence when relatives are no longer in the building and able to see good practice in action.
- **COVID-19 led to creative changes in care home practices:** Care home staff instituted greater pro-active communication with relatives, and staff reported enhanced confidence in their communication with families. Staff also made great use of digital technology to facilitate communication between residents, family carers and themselves. There was a widely expressed belief that many of these changes could be built on to improve care home practices in the future.
- **Maintaining communication is crucial.** Analysis from the survey suggests that respondents who felt they were kept well-informed by the care home on average experienced less mental distress than those who did not.
- **Lack of insight into the impact of lockdown on family carers.** Most policy makers and leading figures in the sector had a superficial understanding of the impact of lockdown on family carers. In particular, there was little acknowledgement of family carers as partners in providing care and the importance of that relationship to both care-giver and care-receiver.
- **Human rights.** There was a widely expressed concern that the human right to a family life had not been adequately balanced against the risks of infection.
- **Impact on marginalised communities.** There was a recognition the pandemic has revealed how little we value older people with dementia within our society and the needs of black and minority ethnic communities.
- **National Guidance.** The mixed economy of care home providers meant that it was extremely difficult to implement national guidance in a manner which was consistent, equitable and appropriate across the whole sector.

WHAT DID THE STUDY INVOLVE?

The study adopted a mixed method design. We conducted 36 in-depth interviews with family carers to understand the impact on them being prevented from visiting their relatives in care homes. Our café style interviews involved five sessions with staff drawn from four separate care homes and explored creative practices used to connect residents with family carers. To help understand measures taken to reduce the impact on family members, we undertook 19 interviews with key stakeholders from the health and social care sector. Finally, using the General Health Questionnaire (GHQ 12), we conducted an online survey of people who had a loved one in a care home, which yielded 444 responses, representing 31 of Scotland's 32 local authorities.

Recruitment of study participants were informed by convenience sampling with maximum variation to ensure diversity of experience to be reflected in the data. All interviews and café sessions were held online (using Zoom or Microsoft Teams) or by phone due to social distancing regulations. All recordings were transcribed by an externally contracted specialist company then anonymised by the research team. Qualitative data analysis was informed by a thematic analysis framework. The GHQ-12 survey conducted using the Qualtrics software (licensed by the University of Edinburgh) was analysed using quantitative data analysis software R. The study secured ethics approval from the ethics committee of the School of Social and Political Science and sponsorship from the Ethics Committee of the University's College of Arts, Humanities and Social Sciences at the University of Edinburgh. The study benefited from the expertise of a Project Advisory Committee drawn from care home sector, academia, policy and practice, care quality and regulation and NHS research and policy. Public involvement in the project came primarily through public participation in the research.

WHAT WERE THE RESULTS AND WHAT DO THEY MEAN?

Although conducted rapidly, the data from the four strands of fieldwork gives us both breadth and depth of insight. The impact on relatives of being prevented from visiting during lockdown was severe and often went unrecognised. It is highly likely that this impact will be felt for years to come, especially in cases where a loved one died or became seriously ill during lockdown. A general breakdown in trust and loss of support for the lockdown measures over time may lead to poor compliance in the future. Conversely, interviewees expressed support and admiration for care home staff, recognising the severe stress they were under. The sector as a whole has much to learn from those care homes that were able to successfully innovate new forms of communication.

WHAT IMPACT COULD THE FINDINGS HAVE?

The policy and practice recommendations below have the potential to reduce inequalities in the impact and mitigate the harms experienced by family carers and care home residents as a result of being deprived of care and support during their visits. All care home residents who rely on visits by their relatives for their emotional wellbeing are detrimentally impacted by regimes which have imposed more severe restrictions on their visits.

- Policies and practices designed to protect care home staff and residents from the introduction or transmission of COVID-19 should be mindful of the differential impact of this deprivation and avoid depriving all care home residents of visits from chosen family or friends for long periods.
- If outdoor visits with appropriate social distance are permitted by local COVID-19 restrictions, then such outdoor visits should be more routinely enabled if these are requested by family carers and care home residents.
- Policy should enable care home managers to routinely discuss and encourage the option of indoor visits by designated friends or family in the case of care home residents who will otherwise be severely impacted by the absence of such visits.
- The impact is likely to be more severe for care home residents who would normally receive several visits in a week from a partner or family member who has been their primary carer and remains a primary social contact and source of support for the resident.
- In addition, particular consideration should be given to care home residents whose physical needs or cognitive impairment means that the absence of indoor visits cannot be effectively mitigated by outdoor visits or internet telephony such as Zoom and its equivalents.
- The experiences of relatives suggest that care-home residents with dementia or other degenerative conditions deteriorate more rapidly without support from family or friends. Consideration should always be given to the views of residents with capacity to express their views and their chosen key family member(s) concerning the necessity of in-the-room visits.
- Given that the impact of reduced visits can be mitigated by virtual communication in some cases, facilitating virtual communication between care home residents and their families should now be standard good practice.
- Consideration should be given to whether funding arrangements for care homes are sufficient for the additional training and staffing needs resulting from COVID-19.
- Because of a sense of isolation and the need for support, relatives of care home residents have started to form informal support systems such as the Facebook group Care Home Relatives. We recommend that care homes combine communicating with relatives of their residents and facilitating informal support communities among the relatives of their care home residents in the way they set up and use virtual groups.
- There needs to be a focus on a human rights-based approach, which addresses both ageism and discrimination experienced by black and minority ethnic communities.
- There is a need for greater stakeholder involvement in shaping policy, including relatives, carers' organisations and care home providers, with a greater emphasis on co-production in the policy-making process.

HOW WILL THE OUTCOMES BE DISSEMINATED?

The research team have developed a robust dissemination plan in consultation with the Project Advisory Committee. This will be led by Iriss and the University of Edinburgh's Centre for Research on Families and Relationship (CRFR) and includes two strands: 1) publications and 2) engagements with a range of stakeholders. Our primary paper is in an advanced stage of completion and a second paper based on the survey data is near completion; while work is progressing on a minimum of two other papers.

The dissemination plan is aimed at a number of different audiences: policymakers; families with relatives in care homes; social care workforce; and academics. Our first dissemination seminar took place on 28 October 2020, led by CRFR and attended by c. 60 participants that included family carers, carer and advocacy organisations, practitioners and other academics and researchers.

We have also developed a project website: www.creativecovidcare.com to share findings and news about the work, which will create links to Policy Brief with recommendations (for policy-makers); FLASH Report with Infographics (public/social services workforce), Presentational slides and other peer reviewed and briefing papers.

CONCLUSION

The severe impact of COVID-19 pandemic necessitated immediate, hitherto untested public health measures to arrest its spread. While speedy responses are vital to curbing the pandemic, care should be exercised in designing such measures to ensure a more rights-based approach is ensued and that people who are directly affected have their wishes heard. Lack of such careful consideration might prove counterproductive to the very principles of existing legislation in Scotland. For example, the Principle 4 of the Adult with Incapacity (Scotland) Act 2000 provides for 'consultation with relevant others' and Carers (Scotland) Act 2016 aimed at supporting carers' health and wellbeing and help make caring more sustainable places a duty to provide support to carers.

Carer's call for greater recognition. Their identity and work as a carer along with their notable contribution to the care sector might be considered for 'key worker' status. To do so, would enable wider consultation and enhance solidarity, necessary at times of crisis for families, including COVID-19.

The coronavirus pandemic has generated an opportunity to reconceptualise care of older people, particularly in care home settings. The use of technology to provide greater connection between families and their relatives in a care home is likely to remain a fundamental aspect of care home life. As we plan ahead, consideration should be given to examine the capacity of care home staff in managing care to ensure connectedness with the families and other relatives and friends of care home residents. This might involve the use of modern communication methods (such as Skype, Zoom, FaceTime, WhatsApp video calls etc.) and provision of resources and opportunities for training staff in the use of such communication methods. In addition, provision of high-speed internet in care settings should be considered as a standard good practice.

This research was completed by a team of researchers from [The University of Edinburgh](#), [University of Strathclyde](#), [University of the West of Scotland](#) and [Iriss](#).

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