

**“We can’t visit and see what’s going on for her...
it’s like having paper-bags over our heads”:**

**Experiences of infection-control measures on family
and friends of care-home residents during COVID-19**

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Margaret Butterworth Care-Home Forum

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Theme: Visiting in Care Homes during COVID-19

Introduction

- Little research on the impact on care-home (CH) residents, family and friends of residents and CH staff of infection-control measures (ICMs) during the pandemic
- UCAIRE, funded by NIHR SSCR, began June 2021
- *Aim:* identify the lived experiences of infection risk and transmission of those living, visiting and working in CHs, what supports their needs and what will help inform learning for future infectious disease outbreaks

Methods

- Mixed-methods for the UCAIRE study:
 - online staff survey to provide broad insights of the impact of ICMs (autumn 2021) and to gather longitudinal data (spring 2022)
 - online qualitative, semi-structured interviews to obtain in-depth experiences of staff, residents and family and friends of challenges in implementing new ICMs, sources of support, morale, experiences and future needs
 - Aim for variety of age, gender, ethnicity, size of CH, geographical location and (for staff) job role
- ➔ ***Focus of this talk: Family and Friends***

Context – 1st December 2021

Cases

People tested positive

Latest data provided on 1 December 2021

Daily

48,374

Last 7 days

305,252 ↑ 2,181 (0.7%)

► Rate per 100,000 people: 438.9



Deaths

Deaths within 28 days of positive test

Latest data provided on 1 December 2021

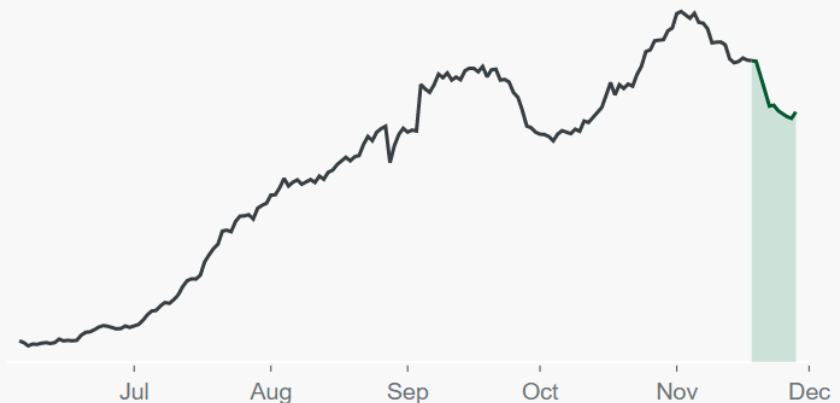
Daily

171

Last 7 days

854 ↓ -72 (-7.8%)

► Rate per 100,000 people: 1.2



Source: UK Summary | Coronavirus (COVID-19) in the UK, last updated on 1 December 2021 at 5:24pm <https://coronavirus.data.gov.uk/> (accessed 02.12.2021 at c.10:50).

Family and Friends of residents

- Recruitment of Family and Friends (F/F) to qualitative online interviews began in August 2021
- Promoted through various channels
 - o local and regional networks; care-home newsletters; ENRICH; PPI/Carers; snow-balling
- Target: 10-12
- Recruited: 11

F/F Participants

- 11 participants (F=9)
- Ages: nine >55 years; one 36-45; one 26-35
- Participant's relationship to resident:
 - Daughter (5); Son (1)
 - Husband (1); Wife (1); Sister (1)
 - Friend (2)
- Recruited from regions across England:
 - East Anglia; Midlands; South-west; Northern England
- Length resident had lived in CH: 3 months to 12 years (average=3.6 years)

Early Findings

Analysis: thematic analysis is on-going (last interview completed two weeks ago)

- Family and Friends [F/F] wanted to stay in touch with their loved one as much as possible and some found CHs very supportive
- F/F faced challenges of lockdown; visiting access to the CH was, for F/F, changing, erratic and unreasonable; observing infection-control measures; variable communication and guidance from the CH; sometimes mixed support in face of distressing or concerning situations

Early Findings – supportive

A few F/F reported effective communication:

- “They locked down two weeks before the official lockdown. They were really very clear and precise; although they didn’t want to have to do that but it was to protect their residents.” (F-03)

Some CHs had “seen what was coming” and ordered extra PPE.

One had remarkable insight into events in China:

- “[The Director of Operations] was front-loading PPE into the care home in January and February.” (F-10)

For one participant, good communication was the main reason the CH had done well in controlling Covid infection:

- “Telling us what happening; explaining. That we’re all in it together and they need us to help – with the knowledge that they couldn’t answer when we’d get back to normal.” (F-08)

Early Findings – supportive

Staff who were very supportive:

- “A staff member would send me a text saying, *is now a good time for you to have a quick catch-up with your mother [on Facetime]?*, and that was wonderful.” (F-03)

CH always being available:

- “If I was worried at any time, I could always phone up and I would get an answer. I’ve always felt welcomed from day one.” (F-08)

Early Findings – challenging

Emotional costs of enforced separation:

- “On 22nd March [2020] I had my last visit with [my wife] before lockdown, not knowing that I would ever see her again.” (F-10)

Lack of communication from the CH:

- “Nobody talked to me ...gave me specific guidance on what they felt was appropriate [ICMs] or my needs.” (F-02)

Prolonged lockdown and variable access to loved ones:

- “I’ve lost part of my mum and I won’t get that back. ...Should we go through this again, there’s got to be a different way for these people with their families. This is the last stop for them.” (F-01)

Feeling helpless in the face of restricted visiting:

- “You cannot do anything. We can’t visit and see what’s going on for [our friend]... it’s like having paper-bags over our heads.” (F-04)

Early Findings – challenging

Lack of support of family members:

- “An online relatives’ forum was mainly them talking to us about what they were doing and how wonderful it all was. ...there was a token “have you got any questions”, but it wasn’t a major part of the forum.” (F-07)

Impact of PPE on residents whose capacity had declined:

- “I hurriedly pulled my mask down when the carer wasn’t looking and said to her, *it’s me, your sister!*” (F-05)

Arbitrary rules causing distress:

- “I have ECG [Essential Care-Giver]; why are they still making visitors wear rubber gloves and aprons when carers go in? If the carer assists my mum with food or drink, they won’t be wearing rubber gloves ...or wearing an apron.” (F-01)

Closing thoughts

- Findings, though incomplete, are increasing our understandings of challenges experienced by F/F of transmission mitigation measures aimed to limit the spread of COVID-19 in CHs and the impact these had
- Looking ahead, F/F suggested:
 - “[Do] PPE in a humane way. So that visitors aren’t gearing up with all masses of kit so that residents wouldn’t know who was behind it.” (F-08)
 - “We’re not going to be rid of Covid for a very, very long time. [CHs] have got to be on their guard all the time.” (F-06)
 - “Keep the structure of activities going, with social interaction, as much as possible.” (F-03)

Closing thoughts

One participant argued for a user group of F/F:

“What about us talking about what it’s like for us to help them get the balance right between infection-control and what F/F can do. ... Let’s work together.” (F-02)

For another participant, relatives and advocacy groups should be involved in formulating public-health guidance for care homes, especially to ensure

“a recognition that compassion is just as important as infection control.” (F-09)

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**Thank you –
your questions and
comments are welcome**

Kathleen,
on behalf of UCAIRE study