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Caring from a distance – carers' experiences of keeping in touch with care home residents during COVID-19 closures.

Abstract

In response to COVID-19 many care homes (CHs) closed to visitors, and new ways for carers and residents to stay in touch were tried. This UK study employed an online survey to explore carer experiences of staying in touch from a distance. The research highlighted the importance of ongoing connections (through visits and remotely); diverse approaches to maintaining contact; concerns about safeguarding and wellbeing. Findings underscore the importance of developing personalised approaches to staying in touch during future CH closures, and for those who require an ongoing approach to remote contact, due to distance, illness, or additional caring responsibilities.

Key words

Family Carers; Care Homes; Remote Contact; Distance carers

Introduction

Family and friends, (referred to as carers throughout this paper) are an important element of care home (CH) life. Carers continue to provide care and support after their relative/friend enters a CH, although their roles and the nature of tasks undertaken may change (Mullin et al, 2011; Hughes et al, 2019). Ongoing support by families has been well documented and includes providing practical and emotional support; overseeing care quality; providing advocacy; helping the person to stay connected to the world beyond the CH, sustaining relationships and reducing the risk of loneliness (Prieto-Flores et al, 2011; Baumbusch and Phinney, 2014; Bigby et al, 2014; Pasque et al, 2018; Hoek et al, 2021; Vereijken et al, 2021). The presence of family and friends has been described as enriching residents' lives, with life 'more colourful and dignified when the family was around' (Lao et al, 2019; 7), and connections with families has been identified by CH residents as important, with visits anticipated, and separation a source of grief (Milte et al, 2016).

For some carers, their main contact with CH residents takes place at the home itself, with some 'highly involved families' visiting daily or at least once a week, contributing a 'constant and purposeful presence' (Baumbush and Phinney, 2014; 80). While such carers may establish roles and a place within CHs, they may also experience difficulties. Visits may be contested territories within which CHs may place boundaries on the carer roles that are accepted and permitted. Carers, despite their self-identified role in monitoring care, appear uneasy about the potential consequences of raising concerns, and may be left out of care decisions; staff may be anxious about interacting with carers and perceive families/friends who raise concerns as 'difficult' (Baumbusch and Phinney, 2014; Dewar and MacBride, 2017; Vereijken et al, 2021). Some carers are unable to visit frequently, for example due to distance, time and costs of travel, their own health problems, or because their relative/friend has been placed 'out of area'(Beadle-Brown et al., 2006; Miller, 2019, 2020, White et al., 2020a). Less is known about the experiences of such carers, how they maintain contact, and their experiences of contact from a distance. Research with 'distance carers' has highlighted difficulties in keeping in touch when apart, which were experienced by people caring for family/friends living in their own homes and in CHs (White et al., 2020a). This reflected care recipients' difficulties in using the phone and/or technology, coupled with a lack of local support; this both disadvantaged carers and those they supported, and called into question the extent to which enabling people to maintain contact with their support networks is perceived as important by care providers and commissioners.

Care homes in many nations were required to implement measures in response to the COVID-19 pandemic. These included restrictions on usual staff and resident activities, and restrictions on CH visiting, both by families/friends and professionals (Sims et al, 2022). In many countries the closures were for extended periods of time, often lasting many months. In the UK lockdown began in March 2020; during this time people were told to stay at home, prior to a gradual easing of restrictions. This was followed by a second lockdown during November 2020, and a third from January – March 2021. CH visits were not subject to government guidance until April 2020 (although many closed to visitors prior to the start of lockdown), when it was recommended that visits from family and friends should be permitted only in exceptional circumstances, such as at end of life; limited visits were recommended from July onwards (House of Commons/House of Lords/Joint Committee on Human Rights, 2021). However, CHs operated diverse policies, and in many instances, remained closed to families and friends, sometimes for considerable periods (Giebel et al, 2021; de Vries et al, 2022). Contact between carers and residents therefore occurred remotely or through socially distanced visits, facilitated by staff. For some carers, this period of CH closures marked a stark contrast to their usual frequent, in-person contact. At this time, all carers were effectively 'distance carers' regardless of proximity to the CH and they shared the challenges of keeping in touch in the absence of visits. The COVID-19 pandemic therefore provided an opportunity to better understand how carers maintain contact with CH residents when visits are not possible; the responses of residents to remote contact; the support required and provided by CH staff; barriers and facilitators to remote contact. An understanding of the needs of carers, residents and staff when remote contact is required is important in ensuring that carers who are separated by distance or other factors such as illness or multiple caring responsibilities are able to stay in touch between visits. Further, although COVID-19 related closures are often referred to as 'unprecedented', CHs do close in order to minimise the spread of infection (McCleary et al, Inns et al, 2018), although for shorter durations than experienced during the COVID-19 pandemic; during such times remote contact is required to maintain links between residents and carers. McCleary et al's (2006) study of a SARS related CH closure in Canada identified practices which helped families, these included receiving reassurance about their relatives' wellbeing; regular updates; contact with a trusted staff member; a 24-hour information line.

The aim of this study was to explore carers' experiences of staying in touch with family and friends in CHs at a time when visiting was not possible or permitted, and to identify facilitators and barriers to staying in touch when unable to spend time in CHs. Although carer experiences of visiting CHs have been previously studied, experiences of contact outside of visits have received less attention, especially prior to the pandemic. The need for research on communication during a pandemic, including communication with relatives, has been identified as a research priority (Richardson et al, 2020). However, we argue that such communication has ongoing relevance for many CH residents, and their families and friends, especially distance carers, beyond the COVID-19 pandemic.

Although the term 'carer' is not one with which all family members/friends identify (Mullin et al., 2013), it is the term we use throughout this paper. This explicitly recognises the significant contributions they make to the lives of many CH residents, and positions them (as has been advocated during the pandemic) as 'more than visitors', in which the language of 'visiting' and 'visitors' fails to recognise their critical roles (Kemp, 2020).

Methods

The study employed an online survey. These facilitate participation among geographically dispersed and sometimes 'hidden' populations, who can participate at their convenience; thus, researchers can readily access diverse perspectives and voices, and a rich source of qualitative, as well as quantitative, data (Braun et al, 2021).

The survey was inclusive of carers in a range of relationships, and included carers of older people, people with learning, physical and sensory disabilities, people with mental health problems, autism and long-term health conditions. For the purposes of this study CHs included residential homes, nursing homes, supported housing, and other staffed services.

The survey

Closed questions were used to gather information about demographic details, information on carer distance from the CH, and, prior to COVID-19, frequency of visits and activities undertaken when in the CH. Open questions were used to explore participants' experiences of CH visits prior to the COVID-19 pandemic, the methods they used to try to maintain contact following restrictions on face-to-face visits, and their experiences of these.

Data collection

A volunteer sample was recruited. To capture diverse perspectives multiple methods of publicising the study were used, including: regular Twitter posts (@dist_care); contacting carer support organisations and other relevant agencies with requests to publicise the research; placing information in University staff and alumni bulletins; discussing the research on a local radio station.

Carers were eligible to participate if:

- They had a family member/friend living in a CH during the COVID-19 pandemic
- Both carer and CH resident were aged 18 or over.

Carers from any country were eligible to participate, although publicity mainly took place within the UK.

The survey was available on the Joint Information Communication Systems Committee (JISC) Online Surveys platform, from June to December 2020.

Data analysis

Quantitative data. Where questions had pre-defined categories, descriptive analysis was undertaken to describe participant responses. Data was organised into frequency (number of responses) and percentages. 'Other' categories were examined and recoded where appropriate.

Qualitative data. Qualitative analysis was undertaken using thematic analysis (Braun and Clarke, 2006). An inductive approach was taken, enabling the development of data driven themes. Initial codes were developed by all four researchers, and the coding framework was applied and refined by one member of the research team, with ongoing meetings of the research team to check and further refine the evolving themes, before developing a narrative on the data.

Ethics

Ethical approval for the study was given by the University of Hull Faculty of Health Sciences Research Ethics Committee.

To minimise risk of distress, care was taken in the design and selection of questions and the survey signposted participants to sources of support.

No personal detail was sought and the survey was completed anonymously, with completion taken to imply consent. Permission was sought for the use of anonymised quotes.

Findings

97 surveys were returned. Of these 7 were excluded as responses were incomplete or did not appear to be from carers.

Characteristics of participants and those they supported are detailed in Tables One and Two.

Table 1 – Participant characteristics

Table 2 – Characteristics of CH residents

Participants were primarily female, and were connected to residents through a range of relationships (the majority of carers being adult children, parents or siblings). A range of descriptors for residents could be selected; all but seven included 'older person', 'person living with dementia' or 'person with learning disabilities' within those selected. A high proportion of carers supported a person with a cognitive impairment; 78.9% of residents were reported to have a learning disability or dementia. While the majority of carers lived in close proximity to the CH, 37.7% were, using our previous definition (White et al., 2020a), distance carers. Further, just over a quarter of carers reported visiting less than once weekly. These findings therefore suggest that a significant proportion of carers are likely to be unable to visit frequently, due to distance or other circumstances, and therefore that keeping in touch from a distance is likely to be an ongoing need beyond the COVID-19 pandemic. All participating carers lived in the UK, primarily in England, but with representation from all three devolved nations.

Male carers, people from minority ethnic groups and spouses were under-represented in the sample.

Through the thematic analysis, six themes were identified.

Theme 1 – Prior to COVID-19 carers undertook multiple roles primarily through visiting

For most participants frequent face to face visits were the norm prior to the pandemic. This enabled them to continue with many aspects of their caring roles, which had not been relinquished on entry to the CH, and some articulated their roles as 'co-workers' or 'part of the team'. Their roles included providing personal care; accompanying residents to appointments; assisting with finances; spending time outside the care home; providing emotional support:

> *Assist with personal hygiene dressing and maintaining his appearance; Assisting with feeding; Keeping his spirits up; Filling the gaps in his memory bridge; Encouraging activities; Chatting reminiscing; Just being there (C79)*
>
> *Allowed in at any time and kept my husband motivated, also taking pressure [off] of the carers who didn't need to watch him or help him while I was there (C61)*

Carers also oversaw and monitored resident wellbeing and care, enabling them to 'trouble-shoot' if they observed problems:

> *Very importantly was frequent and informal interaction with staff so a question/problem/arrangement could be dealt with in a relaxed manner at a time that was obviously convenient to all concerned (C75)*

For many carers, regular visits were valued, and they appreciated being made to feel welcome and having freedom in respect of the frequency and duration of visits:

> *It was lovely to be able to pop in for a couple of minutes or to stay for a few hours, share a meal etc. Lovely to be able to go alone or have several members of the family - and the dog (C75)*

Carers' discussion of pre-COVID contact focused primarily on spending time in the home. For some, there appeared to be little requirement for other forms of contact, due to the frequency of face-to-face visits. Furthermore, for some carers, only visits were experienced as offering meaningful contact:

> *My mum has advanced dementia so keeping in touch between visits is not possible. Only face to face visits allowed contact (C1).*

In contrast to their experiences of visiting, carers did not appear to have enjoyed such positive contact between visits. Some had tried using online calls, with mixed success, or received updates from staff, although these were not always frequently provided:

> *Very supportive of contact with us. Our son is non-verbal so we rely on news from staff between visits. This isn't always as frequent as it is promised (C69).*
>
> *The care home is good in many ways but communication with relatives has never been great unless there were problems/issues…..[However] staff were very welcoming and visiting felt like a very positive experience (C40).*

Overall, carer responses suggest that in-person contact often worked well (or at least worked well in contrast to subsequent pandemic experiences), and was the preferred option for many, with remote contact used less and with more mixed success.

While most carers had some experience of their relative/friend's CH before the pandemic, some admissions had occurred during lockdown; in such instances carers lacked pre-existing relationships with, and knowledge of, the CH, and their experiences of remote contact came at a time of heightened stress for both CHs and carers.

Theme 2 – Carers employed diverse strategies for keeping in touch from a distance during COVID-19

Following CH closures, carers employed a range of strategies for staying in touch. Figure One indicates that posting cards and gifts, talking to CH staff, online calls and email were all used more frequently during this time. Additionally, some CHs introduced garden or window visits which provided opportunities for socially distanced visits. Participants provided information about their experiences of the different communication methods adopted or tried.

Figure one here…..

Technology

Digital technologies, such as online platforms and apps, were used to interact with residents or contact staff. For some, the experience of online calls was positive and enjoyable, and some relatives living at a distance were encouraged to adopt online platforms for the first time. The multi-sensory nature of online calls was beneficial; being able to see their relative and perceive how they were was helpful for carers, and could facilitate communication:

> *My brother finds communicating easier when he can see who he is speaking with. Using visuals has been revolutionary for his communication (C27).*

However, others found online communication unsatisfactory or impossible. Some CH residents experienced calls as disorientating, confusing or distressing. Consequently, some abandoned these, or carers decided not to continue their use:

> *Mum cannot understand or cope with skype FaceTime or thinks i am in the room looking around for me (C58).*

The use of digital technologies placed demands on CHs, staff, residents and carers. Stable internet connections were required, but were not always available, and some staff lacked skills in using online technologies:

> *When family members have tried to make contact with her using this type of technology, staff have often not been able to utilise it themselves (C90).*

Phone calls

Phone contact offered a means of alleviating loneliness:

> *Short calls every day have been good for my mother and I think these have reduced the extent she has felt isolated (C70)*

Phones are widely available and a familiar and established means of communication, and this familiarity may have enabled some residents to use them independently, and initiate calls themselves. However, for others, phone contact had become difficult. Physical, cognitive and hearing impairments all contributed to challenges using the phone, and staff support was not always available:

> *He just about manages on the phone because of hearing loss. No support offered (C80)*

Physically distanced visits

Some CHs enabled ‘window’ visits, meetings in the CH grounds, or created ‘safe visiting’ spaces, for example, using Perspex screens to prevent close contact. Such visits, albeit in unusual contexts, were enjoyed by some:

Outside visits have really helped. Mum is so much happier seeing us face to face (C26).

However, such visits took placed within changed settings and with physical distancing requirements in place. These could be confusing for residents:

> *Window visits allowed on a few occasions but these distressed my husband. He wanted us to come in out of the pouring rain (C79).*

Carers and residents with sensory impairments could especially struggle with the constraints of the new visiting arrangements, in which background noise, distancing and the requirement to wear face masks were all barriers to contact and communication:

> *She was inside 2m away behind a table. I was outside with a mask on. Her vision and hearing are very poor and shouting through a mask is exhausting (C60).*

Carers' use of the term 'prison visits' indicates that, in addition to the physical discomfort experienced due to the weather and sensory challenges, physically distanced visits could also be emotionally uncomfortable. Further, for those who travelled long distances, the time taken to travel could be disproportionate to the amount of time they could spend with their relative/friend in this highly regulated context.

Post

Carers posted letters, cards, gifts and photos to residents. These enabled them to let the person know they were thinking of them, ensure they had familiar items around them, and to connect them to memories and people who were important to them; such contact appeared to be enjoyed by recipients:

> *I know she enjoys receiving cards and letters as being able to re-read them helps her to remember things and I also send her photographs of her grandchildren which she loves (C40).*

In contrast to online or phone calls, cards, letters and pictures could go beyond providing 'in the moment' enjoyment, as residents could look at them repeatedly, and they had potential to stimulate discussion with staff; *'they show my cards to staff who go into their bedroom and point to the photo of the two of us on the wall' (C87).*

However, not all residents appeared to connect with post, and some were unable to read letters independently, thus requiring support:

> *Cannot read letters/cards etc. Sometimes gets help with this - sometimes just put onto her table or bed for her to look at (C71).*

Feedback to carers about whether post had been received and resident responses was important, but not always provided. In the absence of feedback, carers did not know how well this method of communication had worked.

Talking to someone else

Carers also kept in touch with their relative/friend indirectly through discussion with CH staff and managers, enabling them to find out how the person was. This could provide reassurance; however, some found that staff were too busy to answer calls or provide sufficient detail; in the context of busy CHs, responses to carer contact could be brief, and did not always meet carer needs:

> *The standard response of 'your mum's fine' over the phone does not really reassure me (C39).*

Speaking with others, while potentially informative, is also qualitatively different to other methods of being in touch, in which the contact is solely with, and dependent upon, staff: *'getting updates from staff just feels like a practical thing, not "keeping in touch" with my sibling - they have no idea I'm asking after them' (C87).*

Carer creativity

Carers demonstrated thoughtfulness and creativity in the ways they maintained contact, seeking out interesting ways of spending time together; sending photos and photo gifts that would stimulate memories; exploring inventive ways to help their relative/friend understand the situation. Table 4 provides examples of such creativity.

Table 4: Creative approaches to staying in touch

Some carers reported that they had not identified or tried alternative methods of contact. This was usually attributed to residents' cognitive impairments/dementia, being non-verbal or becoming distressed, suggesting that some had minimal contact at this time.

Face-to-face contact was essential for many

Many highlighted the importance of face-to-face contact, over and beyond alternative means of contact, which did not permit the close proximity and touch which was important for some:

> *The lack of real contact during lock down is very hard indeed for non-verbal people, as we use touch and close awareness of each other's expressions to communicate when we are together* (*C31)*

In this context, many carers felt that the emphasis on attempting to curb transmission of COVID-19 was at the expense of residents' emotional and social wellbeing, and in violation of their human rights:

> *Many including my Mum are not scared of dying but have been denied their human rights and quality of life because the only metric being looked at is keeping people alive and avoiding Covid transmission. It is existing not living (C59).*

Theme 3 – Staff support was a critical element of staying in touch from a distance

A high proportion of carers reported that their relative/friend required support to maintain contact. Frequently this need was attributed to cognitive impairments and communication difficulties; however, carers also cautioned against overlooking the impact of sensory or physical impairments. Accordingly, staff support was often required to facilitate remote contact. This included assistance to access and use technology; keep devices charged; set up/answer calls; support with reading and writing mail/email; demonstrating how to use technologies and providing encouragement. Support to hold or position devices was also required by some when making online calls.

Staff support could make the difference between successful and unsuccessful approaches to contact. Carer 35 identified that Facetime was the thing that worked best in enabling contact with their relative, yet was also the thing that worked least well '*when not well supported'.*

The requirement for staff support extended beyond the provision of practical assistance. Staff also provided an important bridging role for some, helping link residents and carers, through supporting conversation or talking to them about their families and friends:

> *Staff teams put the phone in my brother's view and we have a conversation which staff team answer for my brother (in a respectful way which supports him to be involved without verbally answering) (C7)*
>
> *Staff have told me they talk to him about the postcards (C23)*

The provision of regular and detailed updates by staff was identified as important, further illustrating the bridging role undertaken by staff. Such updates, where they were sufficiently detailed, provided reassurance, and enabled carers to interact from a distance:

> *Seeing weekly activity plan & posts on a closed social media group about what is happening at the home and in the community…helps me to talk to my brother (C72).*

The availability of support varied; some reported receiving excellent support, others that no or 'patchy' support, had been offered. In some CHs the provision of support depended on which staff were available:

> *Some staff were skilled in supporting people to take part and also told us what he had been doing and how he was coping. Others just left us on the FaceTime without support. (C35).*

These findings point to the need for a whole system approach to contact with friends and families, in which this is not left simply to the goodwill and skills of individual staff, and in which communication and contact are the responsibility of all in the CH. Participant responses indicated some of the ways this could be achieved. They highlighted the importance of ensuring that communication is incorporated into residents' care plans, taking into account individual needs, and that care plans should be followed consistently. Furthermore, participants identified the need for CHs to take a proactive approach to supporting resident contact with family and friends, rather than depending on carers to initiate this. In some services staff helped residents make contact with carers if they could not do so independently, for example, by making, writing and sending birthday cards, and mailing things made in arts and craft sessions. Carers appeared regretful when residents were no longer able to initiate contact, noting 'sadly it's all one way' (C19), and valued support provided:

> *On a couple of occasions my friend has been supported to contact me rather than me always supporting him - that has been wonderful and really makes our relationship feel equal (C15).*

Important elements of a whole system approach were outlined by the following carer:

Don't wait to be asked for help. Make sure families are aware how your staff can help. Is there a laptop or iPad residents can use? Is there a system for booking to use it? When is the best time of day when staff are most likely to be able to help? If residents have their own phone/iPad, etc, do they know they can ask for help making and accepting calls? Do they know they're not being a nuisance if they ask? (C53).

A further area of support, provided both by carers and CHs was the purchase of devices and equipment to facilitate remote communication, such as smart phones and tablets; highlighting the need for financial investment.

Theme 4 – Carers and residents experienced emotional distress as a result of separation

Participants described multiple and painful effects of separation. Carers experienced sadness, distress, guilt and anguish at being unable to see their relative/friend. Further, they worried about the impact of lockdown on their relative, and anxiety about whether they would still be recognised when visits were again possible, and indeed whether they would ever see them again:

> *The last 6 months have been incredibly sad for me. My mum is well cared for but I feel her overall quality of life has been poor as she just doesn't have access to the people who give her pleasure....I wonder if she'll remember who I am when I next get to visit (C40)*
>
> *It has been the worst year of all our lives - knowing mum is deteriorating and not being able to even see her face, to help her feel less sad (C86).*

Participants perceived that their relative/friend's physical, mental and emotional health had been negatively affected by the lack of contact. They believed that residents missed them, were lonely, and did not always understand or remember the reasons for the lack of visits:

> *He still felt very cut off and forgotten a lot of the time. Didn't consistently remember about the lockdown so often thought we'd all forgotten about him (C53).*

Some were concerned that the person they supported had deteriorated during this time; for carers of people with dementia this represented time they knew they would never get back:

> *Mum…..no longer knows who we are, its like we've lost that period of time which is sad (C3).*

Theme 5 – Carers experienced challenges in safeguarding dignity and wellbeing from a distance

While monitoring care quality was an important element of pre-lockdown contact, carers were concerned that CH closures prevented them monitoring their relative/friend's wellbeing and care, in what had effectively become 'closed services':

> *I have not been inside the home since March. I would use my visits to check how staff treated residents you can gauge a lot by interactions both with me and with other residents (C7)*

Some appeared, in their absence, to have been excluded from decision-making processes in which they would have been involved previously:

> *As a deputy of the court of protection very difficult to have a good oversight of the care that is happening.....also things like care plans getting changed without our input (C4).*

The new contact arrangements were worrying for some. The need for staff support to make calls, supervision during socially distanced visits, and lack of access to Wi-Fi in residents' rooms (meaning that calls could not be made in private) were noted to be *unintentional invasions of privacy (C60*), causing concern. Although less frequently mentioned, carers' responses also alluded to potential safeguarding issues associated with remote contact, such as whether meaningful consent to post photos on social media were obtained, and the delicate balance between provision of internet access and online risks to residents:

> *They allowed my brother access to the internet without supervision. We had to accept responsibility as his family- but we trust his keyworker - who says she will let us know if there are any problems (C12)*

Theme 6 – The importance of trust and understanding between carers and care homes was highlighted

Participant responses emphasised the importance of good and trusting relationships with CHs.

> *A lot depends on how much you trust the staff to look after your loved one when you haven't seen them for weeks and to tell you the truth about how they are (C50).*

For some, the relationships they had developed prior to the CH closures helped sustain their contact during the pandemic. However, positive relationships were not always sufficient to ensure that contact was facilitated by the CH. For example, a carer who praised their existing relationship also noted that:

> *We did do some audio video messages for him which were saved to memory stick and left with staff but have had no idea how he has responded to these (14).*

This suggests that the proactivity and active support, previously highlighted as important elements of remote contact, require additional effort over and beyond the building of relationships.

Prior to COVID-19 carers had valued experiencing a sense of welcome when visiting. This remained important when keeping in touch from a distance. While this was maintained for some, others reported feeling that staff were 'impatient' or that they were causing inconvenience when seeking to stay in touch from a distance. Some felt that CHs did not understand or appreciate the difficulties of separation for carers and residents, or recognise the importance of carers and of supporting contact, and concluded that CHs did not always perceive this as part of their role. The support provided by carers' during pre-COVID visits may not have been visible, so that the full extent of their roles may not always have been recognised:

> *In general, if there are regular visitors, they are probably doing/facilitating a lot the home may not be aware of - including keeping in touch with others and with the outside world (C71)*

Discussion

The COVID-19 pandemic, and the closure of CHs to families and friends meant that all carers, regardless of location, became, in effect, 'distance carers'. During this time the importance of ongoing relationships with carers was underscored by the many accounts of carer and resident distress reported as a consequence of separation, both within this UK study and elsewhere (Van der Roest et al, 2020; Verbeek et al, 2020; Wammes et al, 2020; Low et al., 2021). These difficult circumstances required carers, residents and CHs to try new ways of maintaining contact. This study explored and highlighted the diverse ways which were employed to stay in touch. These included familiar and new ways of connecting, and carers reported using creative ways to maintain contact; similarly creative approaches to facilitating resident/family contact have been reported among CH staff (Hockley et al., 2021; Gieblel et al., 2022).

During the pandemic, there has been a strong focus on the potential of technologies to help CH residents connect with families and friends. This study found that technologies provided enjoyable and meaningful interaction and contact for some, while being inaccessible and distressing for others; further, Talbot and Briggs (2022) have highlighted the cognitive demands and fatigue associated with online calls for people living with dementia. However, our study also found that other, non-technological methods of communication were valued, and that each of the methods of connecting residents and families identified were successful for some, while being challenging or inappropriate for others. The individual resident responses to the different methods of remote contact highlights the need for carers and care staff to explore different methods with each resident to find the best fit, and the need for a personalised approach to supporting residents to maintain contact with family and friends from a distance, in which the method of communication and the support provided are tailored to individual needs, skills and preferences. The findings also highlight the different benefits of these varied approaches to communication. Online technologies and phone calls provide real-time, immediate and multi-sensory connections to the person; letters and gifts do not deliver an 'in the moment' connection, but can be looked at time and time again, and provide a tangible and ongoing reminder for residents of their families and friends, and a topic of conversation with care staff.

The importance of staff support to assist residents in maintaining contact with families and friends was highlighted by participants, and was required by many CH residents. Remote contact requires staff to undertake a range of activities. These include providing practical assistance, such as setting up and managing calls, reading/writing cards and letters, and the need for staff who are digitally skilled and confident was evident. However, remote contact is not solely about practical arrangements, or the use of technologies, and for some includes the need for support with making connections and conversation. These findings point to a need for staff to have time to try out different communication methods with residents, and to be skilled in facilitating communication and interaction using a variety of different means.

The findings indicate that, while the skills and attributes of individual staff are significant, the wider CH culture is also important. Organisational cultures may facilitate, or militate against, contact between carers and residents, both during visits and remotely. Our findings suggest that CH cultures which promote positive contact include relational elements in which staff appreciate the value of residents' families and friends, welcome their contact and involvement, and develop positive, mutually supportive relationships, in which carers feel they are part of the care team or co-workers alongside paid staff. This appears to be facilitated by effective leadership (Brown-Wilson, 2009). A stable CH workforce with low staff turnover also appears to facilitate contact, enabling consistency, and meaning that 'the sometimes complicated process of building trust' does not have to be continually re-navigated (Hoek et al, 2021, 1642). Remote contact requires an organisational culture in which staff are available and able to support contact, the CH provides meaningful feedback and updates, communication plans are made and followed, and a proactive approach to initiating contact is taken, rather than relying solely on carer or resident effort. Further, access to sufficient resources, such as Wi-Fi, tablets, computers and adapted phones, is required. In contrast, a lack of infrastructure to support remote contact, including insufficient devices, poor connectivity, and a lack of staff abilities, confidence and availability have been identified in some CHs (Fearn et al, 2021; Chu et al., 2022), indicating a need for funding to develop technology facilitated contact. However, 'parachuting in of digital technologies is not enough' (Gallistl et al, 2021); instead support to use technologies is required, as well as access to training to enable staff to develop digital skills and the skills to facilitate contact and conversation between carers and residents respectfully and meaningfully, using a range of communication methods, within a culture which is welcoming of carer contact.

A positive culture in respect of distance contact is one in which carers can:

> *Ring as often as you wish to check that your loved one is still receiving quality care….If they are a good team you won't have to ask because they will want to share with you what your loved one has been doing (C14).*

Supporting remote contact does however place significant demands on CH staff in terms of the additional time, support and skills required, in comparison to supporting visits. Carers' roles and contributions to the health and wellbeing of residents may be less obvious to staff when carers are physically outside the CH. Moreover, the role and support needs of distance carers may not be well understood. Staff may make judgements and assumptions about the importance and commitment of family members who are not in frequent contact (Tozer et al., 2013), although many distance carers are in fact in regular contact. In this study there were examples of CHs which had welcomed carer visits, but had not provided equivalent support for remote contact. This may indicate that not all CHs appreciate and value the importance of contact from distance carers or have the willingness, time or skills to facilitate this; in addition, it may be easier to welcome visitors (who may during their visits relieve staff of the need to provide some support) than it is to enable contact from a distance. Hockley et al (2021) identified that communication from a distance, as experienced during COVID-19, meant that, at a time when staff faced unprecedented demands and significant personal risk, they were required to be more proactive in communicating with families, in contrast to the more opportunistic contact experienced during visits. Furthermore, more direct communication with families was necessitated due to the requirement to set up and conduct calls. Whether and how these changes impact on the staff/carer relationship and the experience of these changed dynamics are worthy of further research.

Care homes were under pressure prior to the pandemic, ’woefully under-resourced’ with high workloads, time pressures and an undervalued workforce (Kupeli et al, 2018, Devi et al, 2020, Towers et al, 2020; 156). These pressures have been exacerbated during the pandemic with CHs experiencing high levels of staff absence, death and illness of staff and residents, staff anxious to protect residents and their own families from infection, and worried about risks to their own health, while adapting to new challenges for which they were equipped with scant guidance, and required to step into roles usually fulfilled by carers/professionals (Devi et al., 2020; Embreghts et al, 2021; Giebel et al, 2021; Marshall et al, 2021). At this time CHs had to undertake difficult decisions which ‘required daily emotional, moral and logistical energy’ (Marshall et al., 2021, 4). Within this context, supporting remote contact may have been ‘one more ask, and task’ for stressed and under-resourced staff (Towers et al, 2020; 156). Nevertheless, many CHs have worked to provide exemplary support for resident contact, with staff using a range of methods to connect with families and keep them informed (Hockley et al, 2021). There is a need for further research to identify what enables and supports good practice and cultures of remote contact, beyond the strictures and constraints of the pandemic, taking into account the ongoing challenges within CHs.

Although less widely reported by participants, this study, in common with recent findings from the UK and the Netherlands (Giebel et al 2022) highlighted potential concerns associated with remote contact. The need for staff support to enable residents to use phones and digital technologies, and to support conversation, meant that contact did not always take place privately; this may inhibit open discussion, questioning and exploration of issues of concern, important in enabling carers to monitor wellbeing and safety from a distance. Further, while digital technologies enabled some residents to adopt new and enjoyable means of contact, these were not risk free, and required individuals and their supporters to navigate a complex balance between online freedoms and protection. Some CH residents have expressed concerns regarding online privacy, and highlighted a lack of privacy when communicating via technologies in communal areas (Moyle et al, 2020; Neves et al, 2021), which are sometimes the only spaces with access to WiFi. This indicates a need to explore individual views and anxieties, as well as the resources available to support privacy. Care staff have also echoed these anxieties about the safety and privacy of online technologies (Clifford Simplican et al, 2018). There is a need for further research to explore best practice in managing risks associated with remote contact without restricting opportunities, including exploring staff awareness of risks and strategies to reduce these, and any training needs and gaps. This is a critical area for further exploration as the population, and by extension the future CH population, becomes more digitally connected, and has increasing expectations of using online technologies for contact with family and friends.

This study has highlighted the importance of support to enable families, friends and CH residents to stay in touch and maintain these important relationships. However, the needs of residents who do not have families and friends should not be ignored, although these have been little studied to date (Chamberlain et al, 2020). While this group fell outside the parameters of the research, exploration of the best ways of helping link residents without family and friends to sources of support and friendship within the wider community is necessary. Volunteers may play valuable roles in CHs, both in delivering activities and through volunteer befriending, and may therefore be an additional resource for CHs (Fearn et al., 2021; Handley et al., 2022). During COVID-19 volunteers have also been unable to visit CHs, although some have worked to sustain contact remotely; however managing, training and supporting volunteers also requires input and resources from CHs, further illustrating how efforts to connect residents to those outside the CH can be simultaneously beneficial and demanding of staff time and effort (Fearn et al., 2021; Handley et al., 2022).

Recommendations

The findings highlight a number of recommendations to support remote contact:

- There is no optimal way of staying in touch - a personalised approach is required, ensuring that the best methods are identified for each individual.
- Different methods of communication provide different benefits and the value of different modes of communication should be recognised. Some (online and phone calls) provide valuable 'in the moment' connections, while others (post, photos, videos) can be returned to over time, and promote conversation with CH staff. Therefore, a blended approach to communication is advised.
- Remote contact requires a sense of welcome to be communicated to carers. However, it also demands different skills and roles for staff which need to be recognised. These include managing the practical aspects of remote communication (such as setting up and supporting calls, reading and writing post), supporting interaction and conversation between carers and residents from a distance, and discussing family and friends with residents during periods of absence. Staff may need training and support as they take on new roles.
- Issues of privacy, safety and safeguarding when undertaking remote communication should be considered by CHs, commissioners and policy makers, with further research required to explore issues and solutions, enabling a balance between safety and restrictions to be achieved and best practice identified.
- The importance of communication and connections from a distance should be recognised as a significant issue, with ongoing relevance beyond the COVID-19 pandemic, in which the continued role of distance carers is acknowledged.

Strengths and limitations

The survey was publicised and completed online; other more diverse methods of publicity and participation were limited, due to the lockdown restrictions and social distancing in place for much of the research. This therefore excluded those without access to digital technologies, skills or confidence (Braun et al, 2021); their perspectives need to be explored in future research.

A strength of the study is the diversity among participants in respect of the different relationships and CH residents represented. This extends the focus beyond those caring for ageing parents, who have been the main focus in much CH research both during and before the pandemic, so that the paper is representative of the wider CH and carer population. However, in common with previous research focussing on care home visits and maintaining carer/resident contact there was little diversity in respect of ethnic origin and gender, with the perspectives of those from non-White British backgrounds and male carers unrepresented (Watts and Cavaye, 2018; O'Caoimh et al, 2020; Author's Own, 2020a; Hoek et al, 2021; Chu et al, 2022); further work is required to explore their perspectives. Spousal carers were also under-represented. This is an important group who could be expected to be among the most frequent, often daily, visitors to care homes. While the diversity of internet use among older people should be acknowledged (White et al., 2020b), older people appear to be among those especially at risk of digital exclusion (Nguyen et al, 2021; Seifert et al, 2021), and may therefore experience particular difficulties in adopting online communication and staying in touch if unable to visit. However, they may also need to be able to maintain contact remotely at times, for example, during periods of ill health or if transport is unavailable. The needs and experiences of all such carers should therefore be included in future research.

Conclusion

This study explored carer experiences of staying in touch with CH residents during an exceptional time. However, remote contact is an ongoing need for some residents and their carers, for whom it represents a long-term element of their continued relationships. The findings highlighted the diverse and creative ways carers employed to keep in touch and the need for personalised approaches, which recognise individual needs and preferences, the value of different modes of contact, and underscored the importance of staff support. Care home cultures were identified as significant in facilitating remote contact, with CHs requiring access to equipment and technologies, staff being trained, skilled and provided with time to enable them to provide competent and confident assistance using diverse approaches, and ensuring that they welcomed carer contact from a distance as well as in person, all identified as important.

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Conflict of interest statement

The Authors declare that there is no conflict of interest

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References

1. Baumbusch, J. and Phinney, A. (2014) Invisible hands: the role of highly involved families in long-term residential care*, Journal of Family Nursing,* 20(1): 73–97 DOI: 10.1177/1074840713507777
2. Beadle-Brown, J., Mansell, J., Whelton, B., Hutchinson, A., and Skidmore, C. (2006) Too far to go: out of area placements for people with intellectual disabilities, *Tizard Learning Disability Review,* 11(1): 24–34. https://doi.org/10.1108/1359547420 0600005
3. Bigby, C., Webber, R. and Bowers, B. (2015) Sibling roles in the lives of older group home residents with intellectual disability: working with staff to safeguard wellbeing, *Australian Social Work,* 68(4): 453-468. https://doi.org/10.1080/0312407X.2014.950678
4. Braun, V., and V. Clarke. (2006) Using thematic analysis in psychology, *Qualitative Research in Psychology,* 3(2): 77-101. https://doi.org/10.1191/1478088706qp063oa
5. Braun, V., Clarke, V., Boulton, E., Davey, L. and McEvoy, C. (2021) The online survey as a qualitative research tool, *International Journal of Social Research Methodology*, 24(6): 641-654. DOI: 10.1080/13645579.2020.1805550
6. Brown Wilson, C. (2009) Developing community in care homes through a relationship-centred approach, *Health and Social Care in the Community*, 17(2): 177–186. https://doi.org/10.1111/j.1365-2524.2008.00815.x
7. Chamberlain, S. A., Duggleby, W., Teaster, P. B., Fast, J. and Estabrooks, C. A. (2020) Challenges in caring for unbefriended residents in longterm care homes: a qualitative study, *Journals of Gerontology: Social Sciences* 75(9): 2050-2061. https://doi.org/10.1093/geronb/gbaa079
8. Chu, C. H., Yee, A. and Stamatopoulos, V. (2022) Poor and lost connections: essential family caregivers' experiences using technology with family living in long-term care homes during COVID-19, *Journal of Applied Geronology,* 0(0): 1 – 10. https://doi.org/10.1177%2F07334648221081850
9. Clifford Simplican, S., Shivers, C., Chen, J. and Leader, G. (2018) "With a touch of a button": staff perceptions on integrating technology in an Irish service provider for people with intellectual disabilities, *Journal of Applied Research in Intellectual Disabilities*, 31: e130-139. DOI: 10.1111/jar.12350
10. Dewar, B. and MacBride, T. (2017) Developing caring conversations in care homes: an appreciative inquiry, *Health and Social Care in the Community*, 25(4): 1375–1386. https://doi.org/10.1111/hsc.12436
11. Devi, R., Hinsliffe-Smith, K., Goodman, C. and Gordon, A. L. (2020) The COVID-19 pandemic in UK care homes – revealing the cracks in the system, *The Journal of Nursing Home Research Sciences,* 6: 58-60.http://dx.doi.org/10.14283/jnhrs.2020.17
12. de Vries, D., Pols, J., M'charek, A. and van Weert, J. (2022) The impact of physical distancing on socially vulnerable people needing care during the COVID-19 pandemic in the Netherlands, *International Journal of Care and Caring,* 1-16. https://doi.org/10.1332/239788221X16216113385146
13. Embreghts, P. J. C. M., Tournier, T., and Frielink, N. (2021) Experiences and needs of direct support staff working with people with intellectual disabilities during the COVID-19 pandemic: a thematic analysis*, Journal of Applied Research in Intellectual Disabilities*, 34(2): 480-490. https://doi.org/10.1111/jar.12812
14. Fearn, M., Harper, R., Major, G., Bhar, S., Bryant, C., Dow, B., Dunt, D., Mnatzaganian, G., O'Connor, D., Ratcliffe, J., Samuel, S., Bagnall, A. M. and Doyle, C. (2021) Befriending older

adults in nursing homes: volunteer perceptions of switching to remote befriending in the COVID-19 era, *Clinical Gerontologist*, 44:4, 430-438, DOI: 10.1080/07317115.2020.1868646

15. Gallistl, V., Seifert, A. and Kolland, F. (2021) COVID-19 as a “digital push?” Research experiences from long-term care and recommendations for the post-pandemic era. *Frontiers in Public Health* 9, Article 660064. https://doi.org/10.3389/fpubh.2021.660064
16. Giebel, C., Hanna, K., Cannon, J., Shenton, J., Mason, S., Tetlow, H., Marlow, P., Rajagopal, M. and Gabbay, M. (2021) Working in a care home during the COVID-19 pandemic: how has the pandemic changed working practices? Medrxiv
17. Giebel, C., de Boer, B. Gabbay, M., Marlow, P., Stoop, A., Gerritsen, D. and Verbeek, H. (2022) “Because if I don’t hold his hand then I might as well not be there”: experiences of Dutch and UK care home visiting during the COVID-19 pandemic, *International Journal of Psychogeriatrics https://doi.org/10.1017/S1041610221002799*
18. Handley, M., Bunn, F., Dunn, V., Hill, C., and Goodman, C. (2022) Effectiveness and sustainability of volunteering with older people living in care homes: a mixed methods systematic review. *Health and Social Care in the Community*, 30(3): 836–855. https://doi.org/10.1111/hsc.13576
19. Hockley, J, Hafford-Letchfield, T, Swift, S, Mason, B, Iversholt, R, Palattiyil, G, Sidhva, D, Quinn, N, Jamieson, L, Musselbrook, K, Jain, S, McKie, L & Tolson, D 2021, COVID, communication and care homes: a staffs’ perspective of supporting the emotional needs of families, *Journal of Long-Term Care*, 167-176. http://doi.org/10.31389/jltc.74.
20. Hoek, L. J. M., van Haastreght, J. C. M., de Vries, E., Backhaus, R., Hamers, J. P. H. and Verbeek, H. (2021) Partnerships in nursing homes: how do family caregivers of residents with dementia perceive collaboration with staff? *Dementia*, 20(5): 1631-1648. DOI: 10.1177/1471301220962235
21. House of Commons/House of Lords/Joint Committee on Human Rights (2021) Care homes: visiting restrictions during the covid-19 pandemic. https://committees.parliament.uk/publications/5747/documents/65438/default/
22. Hughes, S. E., Woods, B., Algar-Skaife, K., Jelley, H. and Jones, C.H. (2019) A collaborative approach: care staff and families working together to safeguard the quality of life of residents living with advanced dementia*, Journal of Central Nervous System Disease,* 11: 1-9. https://doi.org/10.1177%2F1179573519843872
23. Inns, T., Keenan, A., Huyton, R., Harris, J., Iturriza-Gomara, M., O’Brien, S. J. and Vivanos, R. (2018) How timely closure can reduce outbreak duration: gastroenteritis in care homes in North West England, 2012–2016, *BMC Public Health*, 18:488. https://doi.org/10.1186/s12889-018-5413-x
24. Kemp, C. L. (2021) #MoreThanAVisitor: families as “essential” care partners during COVID-19, *The Gerontologist,* 61(2): 145-151. https://doi.org/10.1093/geront/gnaa161
25. Kupeli. N., Leavey, G., Harrington, J., Lord, K., King, M., Nazareth, I., Moore, K., Sampson, E. L. and Jones, L. (2018) What are the barriers to care integration for those at the advanced stages of dementia living in care homes in the UK? Health care professional perspective, *Dementia*, 17(2):164-179. https://doi.org/10.1177%2F1471301216636302
26. Lao, S. S. W., Low, L. P. L. and Wong, K. K. Y. (2019) Older residents’ perceptions of family involvement in residential care, *International Journal of Qualitative Studies on Health and Well-being,* 14(1): 1611298, https://doi.org/10.1080/17482631.2019.1611298
27. Low, L-F., Hinsliff-Smith, K., Sinha, S., Verbeek, H., Siette, J., Dow, B., Backhaus, R., Devi, R., Spilsbury, K., Brown, J., Griffiths, A. and Comas-Herrera, A. (2021) Safe visiting at care homes during COVID-19: a review of international guidelines and emerging practices during

the COVID-19 pandemic. https://ltccovid.org/wp-content/uploads/2021/01/Care-home-visiting-policies-international-report-19-January-2021-4.pdf

28. Marshall, F., Gordon, A., Gladman, J. R. F. and Bishop, S. (2021) Care homes, their communities, and resilience in the face of the COVID-19 pandemic: interim findings from a qualitative study, *BMC Geriatrics*, 21:102. https://doi.org/10.1186/s12877-021-02053-9
29. McCleary, L., Munro, M., Jackson, L. and Mendelsohn, L. (2006) Impact of SARS visiting restrictions on relatives of long-term care residents, *Journal of Social Work in Long-Term Care*, 3(3-4): 3-20. https://doi.org/10.1300/J181v03n03_02
30. Miller, V. J. (2019) Investigating barriers to family visitation of nursing home residents: a systematic review, *Journal of Gerontological Social Work*, 62(3): 261-278, DOI: 10.1080/01634372.2018.1544957
31. Miller, V. J. (2020) The experience of transportation to visit a nursing home resident: a case study, *Social Work in Health Care*, 59(5): 300-321. DOI: 10.1080/00981389.2020.1756556
32. Milte, R., Shulver, W., Killington, M., Bradley, C., Ratcliffe, J. and Crotty, M. (2016) Quality in residential care from the perspective of people living with dementia: the importance of personhood, *Archives of Gerontology and Geriatrics,* 63: 9–17. http://dx.doi.org/10.1016/j.archger.2015.11.007
33. Moyle, W., Jones, C., Murfield, J. and Liu, F. (2020) ‘For me at 90, it’s going to be difficult’: feasibility of using iPad video-conferencing with older adults in long-term aged care, *Aging and Mental Health*, 24(2), 349-352. https://doi.org/10.1080/13607863.2018.1525605
34. Mullin, J., Simpson, J. and Froggatt, K. (2011) Experiences of spouses of people with dementia in long-term care, *Dementia*, 12(2): 177-191. https://doi.org/10.1177%2F1471301211418096
35. Neves, B. B., Waycott, J. and Maddox, A. (2021) When technologies are not enough: the challenges of digital interventions to address loneliness in later life, *Sociological Research Online,* 0(0): 1-21. https://doi.org/10.1177%2F13607804211029298
36. Nguyen, M. H., Hargittai, E. and Marler, W. (2021) Digital inequality in communication during a time of physical distancing: the case of COVID-19, *Computers in Human Behavior,* 120: 106717. https://doi.org/10.1016/j.chb.2021.106717
37. O’Caoimh, R., O’Donovan, M. R., Monahan, M. P., Dalton O’Connor, C. D., Buckley, C., Kilty, C., Fitzgerald, S., Hartigan, I. and Cornally, N. (2020) Psychosocial impact of COVID-19 nursing home restrictions on visitors of residents with cognitive impairment: a cross-sectional study as part of the engaging remotely in care (ERiC) project, *Frontiers in Psychology*, 11, Article 585373, 1-9. https://doi.org/10.3389/fpsyt.2020.585373
38. Pasque, K., Bastiaens, H., Van Bogaert, P. and Dilles, T.(2018) Living in a nursing home: a phenomenological study exploring residents’ loneliness and other feelings, *Scandinavian Journal of Caring Sciences,* 32(4): 1477-1484. https://doi.org/10.1111/scs.12599
39. Prieto-Flores, M-F., Forjaz, M. J., Fernandez-Mayoralas, G., Rojo-Perez, F., and Martinez-Martin, P. (2011) Factors associated with loneliness of noninstitutionalized and institutionalized older adults, *Journal of Aging and Health*, 23(1): 177–194. https://doi.org/10.1177%2F0898264310382658
40. Richardson, S. J., Carroll, C. B., Cose, J., Gordon, A. L., O’Brien, J., Quinn, T. J., Rochester, L., Sayer, A. A., Shenkin, S. D., van der Velde, N., Woo, J. and Witham, M. D. (2020) Research with older people in a world with COVID-19: identification of current and future priorities, challenges and opportunities, *Age and Ageing*, 49(6): 901 – 906. https://doi.org/10.1093/ageing/afaa149

41. Seifert, A., Cotton, S. R. and Xie, B. (2021) A double burden of exclusion? digital and social exclusion of older adults in times of COVID-19, *Journals of Gerontology*, 76(3): e99–e103. https://doi.org/10.1093/geronb/gbaa098

42. Sims, S., Harris, R., Hussain, S., Rafferty, A. M., Desia, A., Palmer, S., Brearley, S., Adams, R., Rees, L. and Fitzpatrick, J. M. (2022) Social distancing and isolation strategies to prevent and control the transmission of COVID-19 and other infectious diseases in care homes for older people: an international review, *International Journal of Environmental Research and Public Health,* 19(6):3450. https://doi.org/10.3390/ijerph19063450

43. Talbot, C. V. and Briggs, P. (2022) The use of digital technologies by people with mild-to-moderate dementia during the COVID-19 pandemic: a positive technology perspective, *Dementia,* 0(0), 1-18. https://doi.org/10.1177%2F14713012221079477

44. Towers, A-M., Killett, A., Handley, M, Almack, K., Backhouse, T., Bunn, D., Dunn, F., Dickinson, A., Mathie, E., Maryhof, A., Mikelyte, R. and Goodman, C. (2020) Producing 'top tips' for care home staff during the COVID-19 pandemic in England: rapid reviews inform evidence-based practice but reveal major gaps, *Journal of Long-Term Care*, 151 – 166. DOI: 10.1111/jar.12350

45. Tozer, R., Atkin, K. and Wenham, A. (2013) Continuity, commitment and context: adult siblings of people with autism plus learning disability, *Health and Social Care in the Community,* 21(5): 480-88. doi: 10.1111/hsc.12034

46. Van der Roest, H. G., Prins, M., van der Verden, C., Steinmetz, S., Stolte, E., van Tilburg, T. G. and de Vries, D.H. (2020) The impact of COVID-19 measures on well-being of older long-term care facility residents in the Netherlands, *Journal of the American Medical Directors Association,* 21(211):1569-1570. http://doi.org/10.1016/j.jamda.2020.09.007

47. Vereijken, F. R., Giesbers, S. A. H., Jahoda, A. and Embreghts, P. J. C. M. (2022) Homeward bound: exploring the motives of mothers who brought their offspring with intellectual disabilities home from residential settings during the COVID-19 pandemic, *Journal of Applied Research in Intellectual Disabilities*, 35(1): 150-159. https://doi.org/10.1111/jar.12930

48. Verbeek, H., Gerritsen, D. L., Backhais, R., de Boer, B. S., Koopmans, R. T. C. M. and Hamers, J. P. H. (2020) Allowing visitors back in the nursing home during the COVID-19 crisis: a Dutch national study into first experiences and impact on well-being, *JAMDA,* 900-904. https://doi.org/10.1016/j.jamda.2020.06.020

49. Wammes, J. D., Kolk, D., van der Bresselaar, J. H., McNeil-Vroomen, J. L., Buurman-van, B. M. and van Rijn, M. (2020) Evaluating perspectives of relatives of nursing home residents on the nursing home visiting restrictions during the COVID-19 crisis: a Dutch Cross-Sectional Survey Study, *JAMDA,* 21: 938-942. https://doi.org/10.1016/j.jamda.2020.09.031

50. Watts, J. H. and Cavaye, J. (2018) Being a former carer: impacts on health and well-being, *Illness, Crisis and Loss,* 26(4), 330–345. DOI: 10.1177/1054137316679992

51. White, C., Wray, J. and Whitfield, C. (2020a) 'A fifty mile round trip to change a lightbulb': an exploratory study of carers' experiences of providing help, care and support to families and friends from a distance, *Health and Social Care in the Community,* 28(5): 1632-1642. https://doi.org/10.1111/hsc.12988

52. White, C., Wolverson, E., Dunn, R. and Zafeiridi, E. (2020b) The views of carers, people living with dementia and healthcare practitioners about the value of online information and peer support, *International Journal of Care and Caring,* 4(4): 549-571. https://doi.org/10.1332/239788220X15934528490504

Tables

Table 1 – Participant characteristics

Characteristic	% (n)
Gender	
Male	7.86 (7)
Female	91.1 (82)
Prefer not to say	1.1 (1)
Ethnicity	
White British	93.3 (84)
Other White background	3.3 (3)
Asian/Asian British	1.1 (1)
Prefer not to say	1.1 (1)
Other ethnic background	1.1 (1)
Age	
25 – 34	3.3 (3)
35 – 44	7.8 (7)
45 – 54	26.7 (24)
55 – 64	42.2 (38)
65 – 74	15.6 (14)
75 or over	4.4 (4)
Geographic location	
England	91 (81)
Scotland	5.6 (5)
Wales	2.2 (2)
Northern Ireland	1.1 (1)
Distance from CH; travel time required when visiting (each way)	
Less than half an hour	42.5 (37)
30 – 60 minutes	20.7 (18)
1 – 2 hours	12.6 (11)
2 – 3 hours	8 (7)
3 – 4 hours	6.9 (6)
4 – 5 hours	5.7 (5)
5 hours of more	3.4 (3)
10 hours or more	1.1 (1)
Frequency of visits pre-pandemic	
Daily	11.2 (10)
More than once a week	31.1 (28)
Once a week	26.6 (24)
One a fortnight	7.7 (7)
Once a month	11.2 (10)
Less than once a month	7.7 (7)
Did not usually visit in person	3.4 (3)
Other	1.1 (1)
Employment status prior to pandemic	
Employed	57.2 (41)
Retired	28.1 (25)
Student/training	4.5 (4)
Unemployed/not in paid work	5.6 (5)

Other	4.5 (4)
Relationship of CH resident to carer	
Parent	50.5 (46)
Adult Daughter/Son	19. 8 (18)
Sibling	10.9 (10)
Other family member	6.6(6)
Spouse/partner	5.5 (5)
Friend	4.4 (4)
Grandparent	2.2 (2)

Table 2 – Characteristics of CH residents

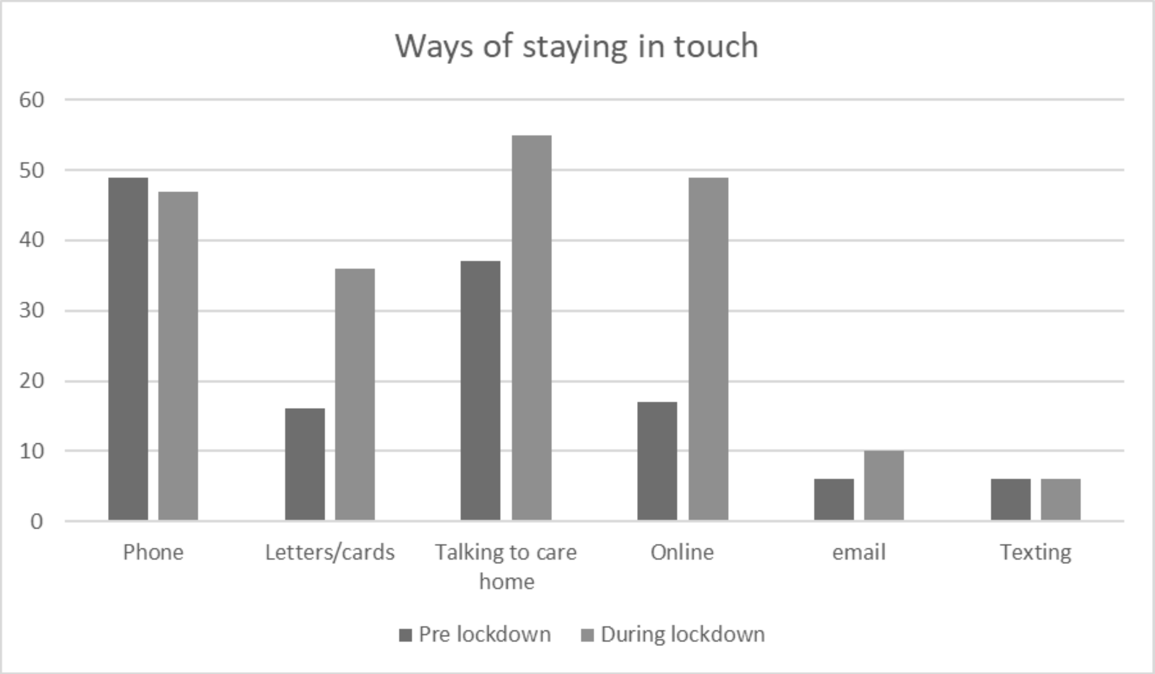
Characteristic	% (n)
Gender	
Male	40 (36)
Female	61.1 (55)
Ethnicity	
White British	93.3 (84)
Other White Background	4.4 (4)
Asian/Asian British	1.1 (1)
Prefer not to say	1.1 (1)
Age	
18 – 24	3.3 (3)
25 – 34	8.9 (8)
35 – 44	5.6 (5)
45 – 54	11.1 (10)
55 – 64	5.6 (5)
65 – 74	12.2 (11)
75 years and over	53.3 (48)
Geographic location	
England	87.8 (79)
Scotland	5.6 (5)
Wales	5.6 (5)
Northern Ireland	1.1 (1)
Description of resident (multiple answers could be selected)	
Older person	32.2 (29)
Person living with dementia/memory loss	47.8 (43)
Person with learning disabilities	31.1 (28)
Person with Autism	13.3 (12)
Person with mental health needs	10 (9)
Physically disabled person	35.6 (32)
Person with long term health condition/illness	33.3 (30)
Person with sensory disability	16.7 (15)
‘Other’	2.2 (2)
Residence	
Care Home	54.9 (50)
Nursing Home	31.9 (29)
Independent supported living	7.8 (7)
Residential community	4.4 (4)

Not sure	1 (1)

Table 4: Creative approaches to staying in touch

Spending time together	I started reading stories on Skype which she is really enjoying. I made social stories to try and explain the current situation. We sing songs (C17) Find out what motivates your loved one and use this to communicate with them (in our case football quizzes) (C35)
Using photos	I also had a cushion printed with family photos which I am told my relative connected with (C75) I send him a photo post card every week. The postcard has a photo of family members, and at least every other week a photo of me and him. With a message (C23) Send big photos they can put up and look at between calls - it gives them something new to think about and to talk to carers about. Or get a photo book made for them to keep nearby (C52)
Explaining the pandemic	I produce regular large print 'Covid newsletters' for her to read with her video magnifier as she can't hear the news (C60)
Sending personalised gifts and treats	All things mum knows are coming from me the things I would do when there….Lucozade for afternoon. Tissues as shes never without one. Treats for staff from mum all the things she know are coming from a loved one although she's not 100% sure if where I fit in she knows & has maintained that familiar connection with me (C58)
Using video	I sent a video message and the home filmed my mum watching it (C41)

Figure one – Ways of staying in touch before and during lockdown



Alt text:

Graph showing how people stayed in touch before and during lockdown. Highlights increases in use of sending letters, talking to someone, online calls and email.