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‘We went from understanding, to disappointment, resentment and often grief all in the space of 6 months’ A qualitative study of the stories of family carers of care home residents during COVID-19 pandemic in 2020.

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ABSTRACT

When the WHO announced a global pandemic in response to COVID-19, individual countries reacted in a similar way with care homes closing their doors to visits, including visits from family members. The UK was no different, initially they closed to protect care home residents during a period of uncertainty, particularly as many were frail, with complex health needs and classed as vulnerable to the virus. This did however, create a sustained period of uncertainty for family members as well as the wider UK care home community. During 2020, 13 family carers in the UK shared their experiences through this period of COVID related enforced lockdowns, in total 27 interviews were conducted.

Our findings and three themes narrate to time points when we were conducting interviews and were often linked to key changes in policy, often in the wider society but not conveyed into care home practices or visiting policies. Three overarching themes are described: Understanding and Acceptance, Disappointment and Resentment, Grief and Sense of Loss

KEYWORDS

Family carers, visiting, care home practice, communication, residents and families, COVID-19 pandemic

BACKGROUND

Like in the majority of countries the global COVID-19 pandemic resulted in some drastic unprecedented actions required for the care of all populations including the vulnerable, frail and elderly (1). Providing care for an older population is an international concern with many countries facing an ageing demographic. Care is often provided in a number of ways including residential care, often referred to as care homes, residential or aged care facility. For the purposes of reporting, we are using the international definition of nursing home which is suggested by Sanford et al., 2015 (2).

In the UK there are over 19,000 independently owned care homes. Care home managers, deputies, clinical staff, health and domestic assistants all care for and interact with residents to provide the care to meet individual resident need. Evidence suggests that quality of care is dependent on the quality of interactions including having contact with family and friends (3, 4). We know human interactions can aid the fostering of greater understanding about an individual, provide connections and deliver an improved experience for recipient and carer (3).

On the 23rd March 2020 the Prime Minister Johnson announced a UK wide lockdown. This followed an earlier announcement about protecting the National Health Service (NHS) by discharging patients who may be medically well but held up by administrative or lack of rehabilitation (post-acute care) or other problems. This related to 115,000 acute beds currently occupied by patients awaiting discharge or with lengths of stay over 21 days. Many of these beds were occupied by older frail patients, who may have dementia (5). Many of these patient groups were subsequently discharged into care homes, often without testing for Covid-19 and without care homes being adequately prepared such as having limited or no access to Protective Personal Equipment (PPE) (6).



Stories of family carers of care home residents during COVID-19

The 1st UK lockdown was initially planned for a 3-week period with a review on the 16th April, 2020 which resulted in a further lockdown until relaxing of restrictions in May 2020, although lockdown remained in place for care home visiting.

To provide some context to the issues for UK care homes, despite daily announcements of deaths from COVID-19 in the UK media these did not include any care home deaths which could be attributed to the virus. It was not until June 2020 that it was recognised that there was a high proportion of deaths of care home residents over and above what would be normal occurrence, reported as excess deaths (7). In England and Wales, 29,393 excess deaths were reported for the care home sector between 28th December 2019 and 12th June 2020 (8). 19,394 deaths were directly attributable to COVID-19 (8). As of 12th June 2020, care home deaths caused by COVID-19 comprised 47% of all deaths attributable to COVID-19 in England and Wales, illustrating the significance of care home settings and the vulnerabilities of residents to the virus (9).

Meanwhile, family carers who had a relative living in a care home were advised that they were closed to visits of any kind, although during this time care continued to be provided by NHS staff and agency staff. In the main, from March 2020, care homes in the UK were closed to family visits in any capacity.

Whilst there was a general consensus that protecting people who could be susceptible to the virus including those living in care homes was essential. However, during the 1st national lockdown there was a lack of preparation and clear comprehensive guidance for such restricted visiting practices. It soon became apparent that whilst some guidance was starting to be developed often it was left to individual care homes to interpret (3, 10).

In addition, during this period of UK lockdown, key stakeholders; care homes, family and residents were becoming frustrated as to the lack of clarity over granting access to resume visits. This led to some forming pressure groups on social media and coveting national press attention (11, 12).



AIMS

This study was initiated by a research team who witnessed the continuing impact to stakeholders involved in the care of older people living in care homes during the pandemic and enforced UK lockdown. This study explored the experiences of one group of stakeholders, that of family carers. In particular family carers who could be classed as 'regular visitors' who visited their relatives at least 3 times per month. We took the view that these 'regular visitors' would be more likely to feel the greatest impact on restrictions and therefore provide the most illuminating perspectives. We were also aware of work in the sector which gave voice to other key stakeholders, care home managers (13) and distant carers (14, 15).

Therefore, the aim of this study was to conduct qualitative interviews with family carers who considered themselves to be a 'regular visitor' to a relative living in a care home. We aimed to repeat interviews over time to explore how their experiences changed during the pandemic lockdown. In the UK two nationwide lockdowns occurred during 2020, this study was conducted during the 1st lockdown, March 2020 onwards.

METHODOLOGY

This was a qualitative study using interviews with participants as the data collection method using the principles of grounded theory (16). Due to the pandemic University ethical approval was granted (April 2020) to conduct online interviews using online platforms (Zoom or Microsoft Teams). This did enable recruitment and participation across England whilst no travelling was permitted. Scotland, Wales and Northern Ireland adopted slightly different policies for their lockdown and restrictions for care homes so were excluded from our recruitment strategy. Interviews were considered the most appropriate method of data collection as it would enable a richness of data and provide the participants voice to the phenomena of interest, that of visits to care homes during a pandemic.

Use of social media (Facebook and Twitter) and a dedicated web page were utilised for the recruitment of participants. In total, 20 family carers sought information about the study and 13 participants were eligible and agreed to be involved, drawn from diverse care homes located in different geographic areas of England. Each participant confirming their relative was over 65 years of



Stories of family carers of care home residents during COVID-19

age, was already a care home resident (residential or nursing home) before the 1st UK lockdown in March 2020. This criterion was used so that we could capture their experiences prior to and during the visiting restrictions. We use the term family carer meaning a person who has a relative for example, partner, spouse, parent or uncle/aunt, brother/sister.

It was intended that a series of interviews would be conducted, to a maximum of 5 which would cover key milestones and was envisaged to complete at the end of the 1st UK lockdown, initially considered as a 3-week lockdown and then extended to 8 weeks (17). The key milestones were initially considered to be times during the 1st lockdown and as these lockdown restrictions were lifted. However, due to the extension of the UK 1st lockdown the study team extended the data collection period over a longer time frame - June to October 2020. All interviews were concluded prior to the announcement of a 2nd UK wide lockdown (5/11/2020) or during a 3rd lockdown (December 2021) (17).

ETHICS

As with any research that is conducted around a potentially sensitive topic, only experienced researchers conducted the interviews (the authors). Participants were provided with written and verbal information about the study and were assured of the confidentiality of their identities, as well as those of their relatives and the care home. All participants provided verbally recorded consent for each interview as well as completing a consent form which was returned by secure email.

METHODS

All 13 eligible participants who consented to take part in the study were interviewed at least once, and overall, a total of 27 online interviews were conducted (see Table 1 and Appendix 1). The research team (KHS, SG, JB, KDV) maintained contact with the same participants throughout to provide continuity and build a trusting relationship. All participants were female and were looking after a parent (n=9) or a spouse (n=4). Table 1 illustrates the different relationships between the relatives and residents, age profiles and number of interviews per participant.



Stories of family carers of care home residents during COVID-19

Table 1 – Demographic of participant and relative, dementia diagnosis of relative and number of interviews conducted

| Participant identification | Sex | Relationship | Age of participant | Age of relative | Relative has dementia? | Interviews conducted |
|----------------------------|-----|---|--------------------|-----------------|------------------------|----------------------|
| 001 | F | Daughter (participant)- Mother (relative) | 57 | 76 | Yes | 4 |
| 002 | F | Daughter (participant)- Mother (relative) | 54 | 92 | No | 3 |
| 004 | F | Daughter (participant)- Mother (resident) | 56 | 86 | Yes | 2 |
| 007 | F | Daughter (participant)- Father (relative) | 93 | Not recorded | Yes | 1 |
| 008 | F | Wife (participant) – Husband (resident) | 72 | 72 | Yes | 4 |
| 009 | F | Daughter (participant)- Mother (resident) | 56 | 95 | Yes | 2 |
| 010 | F | Daughter (participant)- Mother (relative) | 65 | 93 | No | 1 |
| 011 | F | Daughter (participant) - Father (resident) | 63 | 96 | No | 1 |
| 013 | F | Daughter (participant)- Mother (relative) | 62 | 96 | No | 2 |
| 014 | F | Wife (participant) – Husband (resident) | 71 | 71 | Yes | 2 |
| 015 | F | Wife (participant) – Husband (resident) | 67 | 70 | Yes | 3 |
| 017 | F | Daughter (participant) – Father (resident) | Not recorded | 89 | no | 1 |
| 019 | F | Wife (participant) – Husband (resident) | 66 | 81 | yes | 1 |

The average age of residents was 78 and 60 for the study participants with the majority as daughters of the resident. Not all 13 participants engaged in the maximum number of planned interviews. During the study period four residents died and therefore we ceased to conduct follow up interviews

Stories of family carers of care home residents during COVID-19

with relatives. Compassionate online conversations or emails to pass on our condolences were sent. In total 27 interviews were conducted with 8 taking part in at least 2 interviews (see Table 1).

During the first interview, we asked participants if their relative had received a formal diagnosis of dementia or had a cognitive impairment. Of the 13 residents, eight had a formally recorded diagnosis (61%) and five had no formal diagnosis, although two residents had shown some confusion and an indication of a cognitive decline (see Table 1). Two of the 8 residents had received an early onset diagnosis: one participant's spouse at the age of 64 and one participant's mother at the age of 63. This data on dementia status was not a direct focus for this study but is indicative of the UK profile of care home residents (18) and we were keen to show that our sample mirrored the national picture of dementia status. Work has been conducted elsewhere about the impact of the pandemic for those with a dementia diagnosis (19, 20).



Stories of family carers of care home residents during COVID-19

Interviews were recorded and stored on a password protected shared drive by the research team. An initial cross section of first interviews were transcribed verbatim allowing the team to look for patterns and similarities as well as shape future interview direction. Whilst an interview topic guide was devised at the outset, this was amended by each researcher to reflect any events or incidents that their participant had discussed at the previous interview, such as birthdays, family occasions or anticipated changes in visiting restrictions, for example guidance changes on testing when visiting or the nature of visits. Our interviews became iterative and a living record of the participants experiences at the time, allowing a narrative history of events which threaded throughout each participant's lived experiences.

Data analysis was conducted using qualitative content analysis methods described by Graneheim and Lundman (21). Based on inductive reasoning (22, 23), the authors adopted an open-minded analysis approach to identify meaningful subjects and extend an interpretive level of understanding concerning the family carers' experiences. The aim of this content analysis was to produce a condensed description to understand the phenomenon (24).

The first round of interviews was conducted in June and July 2020, when visiting restrictions were still in place despite some lifting of restrictions for the wider UK population earlier in May, 2020. Interviews then continued into October 2020, providing 27 interviews from across the 13 participants in total.

FINDINGS

Our findings and three themes narrate to time points when we were conducting interviews and were often linked to key changes in policy, often in the wider society but not conveyed into care home practices or visiting policies in addition to any other identified milestones by the participants. Three overarching themes are described: Understanding and Acceptance, Disappointment and Resentment, Grief and Sense of Loss

Theme: Understanding and Acceptance

This theme relates to the period when interviews were conducted with all 13 participants during June into July 2020, some 8+ weeks after the UK lockdown began and when visits were not



Stories of family carers of care home residents during COVID-19

permitted into any UK care home or clinical setting. To provide some context to the participants in this study, it was not unusual that they visited their loved ones on a daily basis or at least 4 - 5 times a week, they came and went as they pleased prior to March 2020. All that changed once the lockdown was announced.

Whilst a nationwide lockdown was anticipated by the UK public and agencies (25), the speed of imposed restrictions on visiting care homes prior to the announcement was described:

“The receptionist I know very well. I hadn’t gone on the Friday.... she called me she said we’re going to close down and so I dashed there to mum I mean there’d kind of been murmurings that we will be closing down” PT13

“They said towards the end of the week this was the Monday they were going to make the decision so I was aware you know but not that it was going to happen that day” PT8

“Email, it was email but because I know most of the staff there as well, they were keeping in touch with phone calls and when I went in, they were telling me as well” PT10

Whilst there was an acceptance that shutting for visits was in the best interests of the resident, some spoke about a desire to have made more meaning from their last visit:

“If I’d known about it, I would have, you know, stayed a bit longer and sorted something out. I would have been in my head being prepared. When it came up, I was just devastated and then of course your head starts playing tricks when will I get to see him you know. I found that really difficult” PT8

During this initial time period of the lockdown there was an overriding acceptance that this was the most appropriate approach to protect loved ones from the COVID infection and that not being able to visit was a “small price to pay” (P2). In addition, all participants were themselves conforming to the mandatory UK requirements, this included staying at home except for limited purposes, any interactions in public to no more than two people and certain businesses to be closed (26). The measures taken by UK care homes in restricting access was no different from other countries (see 10) or in Taiwan, (27) or the Netherlands (28,29). All the participants agreed that the best cause of

Stories of family carers of care home residents during COVID-19

action at the time of the 1st interview (8 weeks into the care home closures) was to stop any relative visits.

Theme: Disappointment and Resentment

A further eight follow-up second interviews were conducted during July and August, 2020. All participants were invited but at this stage, four residents had unfortunately died and one participant declined to respond. In July 2020, the nationwide restrictions were lifted in England. Except this was not the case for permitting relative visits to care homes who remained closed to such visits. During these second follow up interviews, participants shared how they were feeling about the continual restricted practices when the wider society appeared to be returning to normality. This included permission to resume visits to restaurants, meeting with family and friends, as well as shops and beauty facilities were encouraged to reopen. Participants shared how unfair this seemed when they all were still experienced restricted visiting policies:

“it’s like Russian roulette, whilst we have opened up airports and we’ve opened up you know gymnasiums and nail bars. Then I’m going to get my hair done tomorrow I’ll be there for four hours I’ll be sitting but I still can’t go and see my mam” PT10

“These new guidelines [1st June] they are only guidelines but then everything we’ve all been doing is guidelines nothing is actually the law and again it’s open to them [care homes] not necessarily having to follow the guidelines so it’s a really difficult situation” PT2

Levels of disappointment, resentment and moral distress of wanting to do the best for their relative but still wanting and seeking access to comfort and see relatives was evident:

“Upsetting really, you know the fact that he was so close and I couldn’t touch him. We’ve had video calls throughout you know the lockdown but it’s really difficult again because he really doesn’t understand what’s going on obviously, he sees my face on the screen and it’s just like sort of you know it’s been tough. It’s better to see him in the flesh” PT8

In their interview’s they shared openly that prior to the lockdown they felt part of their relatives’ care home community. They felt valued for their contributions, often providing day to day care,

Stories of family carers of care home residents during COVID-19

mental stimulation through activities they did with their relative, even taking part in regularly organised activities by the care home:

I read to him, I play music, I tell him about the children and things like that... although this can be physically and emotionally exhausting but I would stay for a reasonable piece of time” P19

The participants were heavily invested in supporting the care home, often visiting at least 4 - 5 times a week if not every day prior to the imposed visiting restrictions.

The good will and understanding from the participants in our study and seen in the previous theme, started to diminish over the course of their follow up interviews. It was even more acute when it was clear that care home visiting restrictions were not going to be lifted but further restrictive practices were imposed, such as only offering booked appointments, having only one designated family member to visit and limiting access at certain times. Various examples of managed visits were shared including visits that mainly consisted of a short duration (between 30 minutes to one hour maximum per week). Alternative visiting arrangements such as window visits (seeing a relative from outside usually through a window), open garden visits (bookable visits to be held outside), use of a purpose-built room/or space, or with use of technology:

“As far as contact with my mother I have been able to speak to her on the mobile phone, the conversations are short and it depends upon what carer she is with as to how they handle the call with her because she needs to be directed in holding the phone” PT2

Any visits had to be in-line with PPE requirements which in turn caused their own issues, especially for those residents with dementia as our participants grappled with:

“Mum’s trying to touch my face, you know. And she can hear me but obviously everybody’s wearing masks” PT13

There was an overall sense that despite the virus still in the general population but with the development of the vaccine and more general freedom of movements for the majority, care homes were still not widely open to visits. This was despite the majority if not all residents and staff being vaccinated. There was a sense from our participants of indignation that this was no longer fair. They

Stories of family carers of care home residents during COVID-19

missed their regular interactions with their relatives and for those with a resident with dementia they had a sense of resident decline (30).

Theme: Grief and Sense of Loss

Following our first interview and in arranging the second interview we were advised of four deaths amongst residents, these participants then had to deal with the death and loss of their relative, often having not had any physically contact with their relative for some considerable time due to the restricted visiting. We felt it was not appropriate at this time to continue to conduct interviews with these family carers or collect any further data unless they specifically requested to reflect on their experiences. This was mainly due to the nature of our interview questioning which revolved around the experiences of visiting.

All of our participants did indicate that they felt assured that despite the overall restricted visiting policies in their care home they would be allowed access if it was felt there was imminent risk of end of life or deterioration:

“I am afraid; if anything happens to him will I be allowed to go in, will it be the last time I see him. Will I have the chance to, you know, prepare myself for it. They did say I’d be able to go in but whether I would if anything happened, I don’t know”PT8

“They did say that if the medical condition changed, they would facilitate very controlled visiting, if at all possible” P19

For the remaining contributors some 6 months after the UK wide lockdown in March 2020 family had not returned to visiting their relatives in the manner that they had pre-lockdown:

“We don’t visit with the closure but we do have phone calls, emails and a weekly newsletter now, which is very nice and they continued to put his care notes online, password protected, so I could see them” P19

A further four participants continued with their interviews, but also began to express their sense of loss and connection with their relative, including physically not seeing their relative during this

Stories of family carers of care home residents during COVID-19

protracted period of isolation and not returning to the pre-pandemic lockdown visits they had enjoyed:

“It feels a bit like I don’t know whether he takes it in or not you know it’s pretty difficult you know he sleeps quite a lot now so sometimes they’ll phone up and he’ll seem to take a dive [health deteriorating] and the next minute he’s asleep” PT8

Often relating to a physical deterioration in the resident:

“So, I had to put a mask on. I went in. It was very, it was really upsetting. I got to her room and she was sitting in her chair. It was literally, it was absolutely I can honestly say I felt that it was so heart-breaking. I saw her sitting there and I’ve never seen her looking[?]. I have seen her before but she just looked so drained. She looked so frail because she is so physically helpless” PT2

“I was so concerned for mum, and then, you know we’ve heard that she’s anaemic, 6 stone 2, not eating not drinking you know. I’m pushing to say can we come and visit” PT13

DISCUSSION

What is clear from our findings is that whilst initially willingly complying with the lockdown restrictions imposed in the UK, relatives later felt frustrated and dis-empowered when trying to regain access to their loved ones. After a protracted period of time, they wished to return to the pre-lockdown period prior to March 2020 and the freedoms of visiting a care home at a time and place to suit them and the resident and indeed to continue the positive relationship they had previously with the care home.

Our findings, from this qualitative study, illustrates the experiences of 13 relatives during the lockdown who actually experienced a much longer and sustained period of restricted access to their relatives who lived in a care home than the restrictions imposed on the UK wider society.

The relatives’ experiences shared in this study have some similarities to other relatives during COVID-19 restrictions, either with care homes for older people (31) or different types of residential

Stories of family carers of care home residents during COVID-19

living (14). However, there were differences in the nature of the restricted access, for example with our European neighbours. During the UK extended period of care home visiting restrictions, some other European care homes took a different view to permitting access, allowing access and a more nuanced view on the risks to residents versus their wellbeing (10). In some cases, they devised different policies and practices to resume family visits despite instances of the virus in the wider community, particularly at this time when there was no evidence of higher risk from allowing visitors into the care home (10). These included examples in the Netherlands who opened all care homes to visitors in order to improve well-being for residents (28), in line with the WHO interim directive (32) and in consideration of the rights of residents to maintain contacts with relatives in the USA (33). This was not the case in the UK which experienced a much longer period of restrictions not helped with three national lockdowns.

Whilst there was acceptance that this was the 'right thing to do' at the start of the lockdown, it did create moral distress for family as the restrictions continued. They wanted to visit and see their family but likewise did not want to pass on the virus, particularly at this time when a COVID vaccination was still under development. This moral distress and lack of transparency for family was apparent when the rest of the UK was seen to be returning to some form of normal activity, such as visiting friends and family, shopping and entertaining and celebrating family occasions. For the majority of our participants, they were still restricted by having to book and agree time slots and make visitor appointments, make use of technology (if a new outbreak occurred in the home), wear PPE and follow the care home or localised guidance. In some cases, participants had to deal with the death of a loved one, someone they might not have seen for many months or only at the very end of life.

An accepted limitation of this study is that we only explored the experiences of a small group of self-identified 'regular visitors' over a 6-month time period during the 1st UK lockdown. Although this has provided a useful barometer for the overall impacts for some relatives during this time, we accept that in this study we did not recruit relatives who may not be classed as 'regular' visitors but may care from a distance or visit less frequently. Some work has been conducted in this arena across a wider range of residential, long term care settings across different resident age profiles (14).



Stories of family carers of care home residents during COVID-19

Furthermore, the research team accept that we are only reporting one side of a very complex and unprecedented situation not just for the UK but globally (34). Therefore, these findings need to be understood in the context of the situation and seek the views of others such as care home managers and staff (13, 35), health and social care policy makers (10, 36, 37) and where possible care home residents (3, 4, 38).

Whilst there was mounting pressure from UK media outlets and family pressure groups, it was some 14 months after the 1st UK lockdown that family could resume visits with the newly defined status of a formalised title 'essential care giver' (ECG) (39). This newly defined status was due in part because of more accurate and rapid COVID-19 surveillance methods as well as the development and widespread immunisation programme in the UK. In addition, there was some acknowledgement of the value of, and effect on mental health and wellbeing on residents and carers with denial of access (4, 30, 40, 41).

Since 2022 no visiting restrictions are in force for UK care homes despite continuing concerns about new variants of C-19 (42). This is similar to other approaches to visitor interactions as seen in Holland (28) and what was advocated for in the USA (33) and in Hong Kong (31).

Indeed, we believe that our study and subsequent findings offers a unique perspective from those that previously considered themselves part of the fabric of a care home, visiting relatives. Their overall experiences over the timeline of the UK lockdowns (43) illustrates the ongoing frustrations for recognition of the value of family and friends visits to those in a care home. The effects of the pandemic on the care home community and all stakeholders have also and rather sharply brought in to focus an important societal question; how do we continue to meet the health and social care needs for residents in long term care (44) whilst ensuring a continuity of care, dignity and rights of residents? This builds on further discussions about the issues that the pandemic has presented, namely the long-term planning for care home responses for future pandemics and visitor restrictions (6). Whilst this study was conducted in England there are many similarities to other international studies (10) that explored the complexity of issues for all those stakeholders involved in providing care in this setting. Together with work conducted in this sphere this adds a collective value and debate as to future implementation for models of care for our aged populations.

Stories of family carers of care home residents during COVID-19

It can safely be stated that the imposed and lengthy restrictions on all parties, including care home staff (13, 46) has had a detrimental impact on the relationships between all stakeholders (3, 29). In some cases, this all comes too late for many who have lost a loved one during this period. This study has collected data in relation to other aspects such as end of life provision, communication approaches and use of technology of which some has been reported separately (46, 47).

CONCLUSION

Overall, it is clear that this pandemic was unprecedented and aspects of guidance and policy setting had to be reactive and constantly reviewed, not just in the UK but across all countries (3, 10, 31, 48). It is noted that major errors were made in the UK with a condemnatory report “*Coronavirus: lessons learned to date*” (49) outlining failings directly impacting those living and working in the UK care home sector. Care homes already have policies in place for temporary closures, for infection control purposes for example, so we should now be morally invested to ensure that future policies and protocols are in place which are proactive and nimble enough to protect and serve our care home populations in the future. This should not be at the cost of relatives continuing their valued interactions with their relatives. Now is the time to consider different approaches which could meet the ongoing needs of relatives who might be ‘regular visitors’ as well as care homes and how they might manage different approaches aside from an in person visit to maintain regular contact with care home residents. We acknowledge that we are not able to offer one solution to the complex issues that this study presents but instead hope that this raises the perspectives of a population that to date is neglected from the literature, that of regular family visitors. Indeed, DHSC guidance is now very clear that there are “no nationally set direct restrictions on visiting in care homes” (42). Therefore, we propose that care home visiting protocols are now reviewed in conjunction with all stakeholders, care homes, relatives and residents.

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Stories of family carers of care home residents during COVID-19

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Appendix 1 Interviews conducted in each phase

| Interviews conducted | Number of participants |
|--------------------------------------|------------------------|
| 1 st interview | 13 |
| 2 nd interview | 8 |
| 3 rd interview | 4 |
| 4 th interview | 2 |
| Total number of interviews conducted | 27 |