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The impact of COVID-19 restrictions and care home strategies on residents with dementia as experienced by family carers in Italy

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Abstract

Objectives

The COVID-19 pandemic and public health measures caused serious consequences for several population cohorts, including people with dementia in care homes and their families. The aim of this study was to explore the impact of COVID-19 on care home residents with dementia as experienced by family carers in Italy. Specifically, strategies implemented to overcome the pandemic's constraints, their influence upon care, and consequences for everyday life of residents with dementia and carers were investigated.

Methods

Semi-structured interviews explored participants' experiences of the pandemic, its restrictions and the services' status during lockdown. Transcripts were analysed via thematic analysis.

Results

26 family carers were interviewed. Three themes emerged: (1) COVID-19 restrictions negatively affected both residents with dementia and family carers, (2) Changing policies in care homes during COVID-19, and (3) Technology use in care homes during COVID-19. COVID-19 restrictions severely affected care home residents with dementia, disrupted their daily living, and accelerated their cognitive decline. Consequently carers' emotional burdens increased. Care home response strategies (safe visiting and digital solutions) were critical, though they were not enough to compensate for the lack of close in-person contacts.

Conclusions

Mixed evidence emerged about the feasibility of care home strategies and their associated benefits. To meet arising needs and possible future pandemic waves, there is a need for updated health strategies. These should prioritise a continuity of therapeutic activities and minimize negative effects on residents' quality of life, whilst incorporating feasible and accessible digital solutions to provide remote communication and psychological support for family carers.

Keywords: COVID-19; dementia; care homes; long-term care; physical distancing; social isolation; technology; caregivers; mental health; public health

Introduction

On March 11, 2020 the World Health Organization declared COVID-19 as a global pandemic (WHO, 2020a). Over one year later, there have been nearly 230 m confirmed cases, and approaching 5 m deaths worldwide (WHO, 2021). Although the pandemic has affected several population cohorts, older people, especially those living with dementia, are one of the most vulnerable groups to the virus (Wynants et al., 2020).

Recent evidence highlights the increasing concern about dementia as a global public health issue (Chirico et al., 2021; Giebel & Hanna, 2021). Regarding the contagion risk, understanding the disease and complying with public health measures such as washing hands, wearing face-masks, and maintaining social distance is difficult for people living with dementia, due to both apraxia (i.e. carrying out purposeful movement) and amnesic deficits (i.e. remembering the public health measures) (Alzheimer Europe, 2020; Giebel et al., 2021c; Mok et al., 2020). Nevertheless, the required physical assistance makes the social distancing often not feasible for people living with dementia and those who take care of them, especially in the more advanced stages of the condition (Alzheimer Europe, 2020; Mok et al., 2020).

A relevant factor in determining the impact of the pandemic on people living with dementia was the context of where they lived: high rates of fatal and severe outcomes emerged from data related to care homes, which have been epicentres of the pandemic (D'Adamo et al., 2020; McMichael et al., 2020; Team et al., 2020; Velayudhan et al., 2020). Among reasons there were: staff-related issues, pinpointed as potential virus carriers (McMichael et al., 2020); an inadequate preparation for a pandemic, a general vulnerability to respiratory disease infection in care homes (Hand et al., 2018; Hwang et al., 2020; Lansbury et al., 2017; McMichael et al., 2020); and a high prevalence of behavioral symptoms among residents, associated with uncontrolled physical contacts and a faster virus spread (Kales et al., 2019; Mok et al., 2020; Wang, 2020).

Moreover, people living with dementia in care homes experienced the harshest consequences of COVID-19, not only due to the virus itself, but also because of the implication of the restrictions adopted to limit the pandemic (Alzheimer Europe, 2020; Low et al., 2021). Governmental restrictions, such as social distancing and blanket visitor bans, have isolated people living with dementia (Giebel et al., 2021b). Pre-existing neuropsychiatric symptoms have been exacerbated (Manca et al., 2020; Numbers & Brodaty, 2021; Vindegaard & Benros, 2020), and the lack of proper cognitive and physical stimulation increased the risk of developing new behavioral changes (Alzheimer Europe, 2020; Wang, 2020). Moreover, traditional strategies to manage the behavioral and psychological symptoms of dementia (BPSD), including recreational activities, were not feasible during the pandemic, as they involved close physical contacts. As a result, the use of drugs increased, as well as the number of isolation measures in emergency rooms (Low et al., 2021; Wang, 2020; WHO, 2020b). The resulting loneliness and social isolation have been associated with poor mental health, depression, and anxiety in people living with dementia as well (Devita et al., 2021; Santini et al., 2020; Velayudhan et al., 2020). However, public health measures have not only impacted residents of care homes, but also their family carers whose levels of stress and anxiety have increased during lockdowns (Cohen et al., 2020), as well as their feelings of guilt and anxiety (Bull et al., 2020; Low et al., 2021).

Over more than one year after the pandemic outbreak, the reported trend highlights a decrease in new cases and death all over the world (WHO, 2021). This evidence is mainly related to the ongoing vaccine campaign, prioritizing people and contexts at high risk of contagion (Italian National Institute of Health, 2021). Simultaneously, several updated strategies to find a balance between physical safety and well-being have been provided, in order to improve the quality of life in care homes during the pandemic (Alzheimer Europe, 2020; British Geriatrics Society, 2020; Bull et al., 2020; Chu et al., 2020; Gordon et al., 2020). Examples of such strategies are: re-introducing safe visiting instead of banning visitors (Low et al., 2021; Verbeek et al., 2020), involving carers in the care process as essential partners (Fallon et al., 2020; Kales et al., 2019; Van der Roest et al., 2020), and maximizing the use of digital communication to connect people living with dementia and their carers (Low et al., 2021; Moon, 2020). Digital tools have been fundamental to compensate for the social distancing during the pandemic, allowing families and residents to keep in contact remotely (He et al., 2021; Pappadà et al.,

2021). In Italy, according to a national survey during the first pandemic wave, more than half of the facilities had adopted technological communication tools, mostly using videocalls, followed by traditional phone calls supplemented by e-mails (Italian National Institute of Health, 2020).

This study is part of a larger international project aimed to explore and compare the impact of COVID-19 and associated public health restrictions on the lives of people living with dementia and family carers across different care settings and between five countries (UK, Australia, India, Italy, Poland). Specifically, the goal of the present study was to analyze the impact of COVID-19 on people living with dementia in care homes as experienced by family carers in Italy. We investigated the strategies implemented to overcome the pandemic's constraints, their role in the process of care, and the consequences on the daily lives of both residents with dementia and carers.

Methods

Participants and recruitment

A convenience sample consisted of adult family carers of people living with dementia in care homes during the COVID-19 pandemic. Participants were recruited through four care homes from four urban areas in three regions of Italy. Recruitment continued until no additional themes emerged during the analysis of three consecutive interviews, considered to represent data saturation (Saunders et al., 2018). As a first step, service managers of the care homes looked for carers willing to contribute by sharing their experiences. Once potential participants were found, researchers contacted them through phone calls, in order to formally inform them about the study and to schedule the interview's appointment. Ethical approval was obtained from the Ethic Committee of the University of Bologna (Italy) [Ref: 41453].

Data collection

All participants completed a written informed consent form via email and were informed by the researchers about the privacy rules, and their right to dropout at any time. Sociodemographic characteristics of family carers were recorded at the start of the interview (i.e. age, gender, nationality, level of education, occupation, retirement status, and relationship with the person living with dementia), as well as details of their family members living with dementia (e.g. years from the diagnosis, type and severity of dementia).

The semi-structured interview covered participants' experiences of, and reactions to, the pandemic; impacts on services delivered during lockdowns; and how this related to the offer and extent of adoption of technology-based communication tools. Topics were chosen based upon the perspective of unpaid carers, a person living with dementia, clinicians, and the social support service providers in the

UK (i.e. team leader of the international project). Then, a process of cultural adaptation and translation in Italian followed. Family carers were also encouraged to describe their thoughts and feelings about main issues and related topics arising. Consistent with the semi-structured interview format, clarification or additional details were asked in case of unclear or peculiar answers.

Interviews were administered remotely through phone calls, to minimize the infection risk, and were collected between December 2020 and April 2021. During this period, Italy was divided into three zones: red for the highest risk, followed by orange and yellow for the lowest one. At the time of data collection, pandemic restrictions were in place in all regions, although with some slightly differences between them.

The interviews were carried out by three researchers adequately trained in qualitative data collection, and the average length of the calls was 45 min (range 30–60 min).

Data analysis

The interviews were audio recorded, transcribed verbatim, and analyzed via inductive thematic analysis (Braun & Clarke, 2006). Two researchers (IC, AP) individually read each interview transcript and employed a bottom-up strategy to identify units of content. Then, codes about the same issue were clustered into themes and sub-themes by each researcher (Table 1 [AQ1](#)). This process was extended and discussed among the remaining study authors until a consensus about consistency was reached, and all discrepancies were resolved (Hickey & Kipping, 1996).

Table 1. List of themes and sub-themes from participants' interviews. 

Themes	Sub-Themes
COVID-19 restrictions negatively affected both residents with dementia and family carers	Faster deterioration and poor well-being among residents Increased emotional distress among carers
Changing policies in care homes during COVID-19	Different approaches to safe visiting after blanket bans Varying degrees of carer satisfaction towards care home policies and procedures
Technology use in care homes during COVID-19	New technological options in care home settings Technology saved relationships Technology did not work for every person and/or any purpose

Results

Background characteristics

Participants were 26 family carers of people living with dementia in care homes. Carers were on

average 56.7 (s.d.=10.6) years old (range30-83). Most carers were female (69.2%) and married (69.2%). The majority of carers were adult children ($n = 21$), followed by partners ($n = 2$) and other relationships ($n = 3$). Most participants finished secondary school (53.8%), some ended their studies after middle school (30.8%), whereas only a few owned an academic degree (15.4%). At the time of the interview, 14 carers (53.9%) were in paid employment.

As for their relatives living with dementia, they were 80.8 (s.d.=8.2) years old (range 64-92) and mostly female (92.3%). The prevalent dementia subtype among them was Alzheimer's disease (77%), followed by vascular dementia (11.5%); others rarer dementia types included fronto-temporal dementia and Lewy Body dementia (11.5%). The mean number of years since diagnosis was 7.2 (s.d. = 4.1; range 1–20) years.

Qualitative findings

Three main themes were identified from the interviews: (1) COVID-19 restrictions negatively affected both residents with dementia and family carers (two subthemes), (2) Changing policies in care homes during COVID-19 (two subthemes), and (3) Technology use in care homes (three subthemes). Each theme and subtheme is described in detail below, and relevant quotes have been reported for each subtheme, with participants' age and gender mentioned.

Theme 1: COVID-19 restrictions negatively affected both residents with dementia and family carers

Faster deterioration and poor well-being among residents

Participants reported that public health measures severely affected people living with dementia in care homes during the COVID-19 pandemic. Social distancing measures and visitor suspension impeded direct physical contact among people living with dementia, their family members, and the residential personnel: they could not touch, hug and kiss each other. Residents were deprived of social interaction and felt abandoned by their carers. Moreover, the reduced social stimulation appeared to negatively impact on residents' cognitive functioning and psychological wellbeing, leading to a lack of motivation and interest in everyday activities and fueling the cycle of cognitive deterioration.

"I'm neither a doctor nor a psychologist, but I think that if you keep being stimulated by those who surround you, then you can somehow still manage to be clear-headed, otherwise not [...] It was a terrible period for her...<It's enough, I don't want to live anymore>, she said. It seemed like she was dead, but not

because of COVID. It was like her heart stopped beating, there was nothing left”.

ID20 - female carer, 65 years, niece

Participants reported that when the virus spread within the care homes those people living with dementia infected were isolated and had to live in separate rooms. Thus, the opportunity for social contacts had been limited further. They felt confused about suddenly being alone in an unknown setting and some started thinking everybody else went home. The isolation procedure was introduced in conjunction with personal protective equipment, which made it challenging for people living with dementia to recognize residential staff wearing face masks. Seeing staff wear personal protective equipment is suggested by carers to have accelerated disease progression and worsened the psychological state of people living with dementia, leading to an increase of depressive symptoms.

“It has been shocking for her to see carers wearing suits and masks; also carers were changed, so she didn’t have any reference left. This change had a great impact on her and her disease progression. Indeed, she poorly speaks now, she has little speech and is a bit shambling [...] ...she doesn’t speak now, she even covers her face with her hands during the meal.”

ID8 - female carer, 64 years, daughter

The effects that these restrictive measures had on people living with dementia was reported to be related to their different levels of awareness of the pandemic situation and their residual cognitive abilities. According to the participants, people living with dementia with limited awareness were less affected by the changes, as they were not able to realize what was happening. On the other hand, people in the earlier stages of the condition, and thus with heightened levels of awareness, were able to notice changes in their daily lives and suffered to a greater extent.

“She ain’t able to understand... there haven’t been many disruptions in her path”.

ID13 - female carer, 30 years, daughter

Increased emotional distress among carers

Participants acknowledged that they had a difficult time during the COVID-19 pandemic. Specifically, they experienced sadness and dejection after the blanket visiting bans were imposed, as they were unable to see their relatives for a long period of time and missed the physical contact. This was augmented by the fact that physical and visual contacts were the main sensory channels they used to communicate. Moreover, carers felt guilty and had second thoughts on the institutionalization of their relatives.

“What I suffered most was not being able to see her, not speaking with her – since there’s no way to interact with her anymore –. What I missed above all was to hug or kiss her”.

ID15 - female carer, 53 years, sister

Participants were worried about the health of their relatives due to the virus infection risk and were afraid of cognitive deterioration through reduced social stimulation, especially that their relatives with dementia might not recognise them anymore as well as leaving them with a sense of being abandoned.

“What concerns me most even now is that the empathy, the relationship, things people with dementia need, have been completely deleted. [...] Time goes on and the disease gets worse, so that is of course the problem with living during a pandemic. In spite of following along, step by step, we saw a sudden worsening of the disease. I’m not sure if, at the end of the pandemic, my mother will still be able to recognize me, since she already struggles now sometimes”.

ID8 - female carer, 64 years, daughter

Theme 2: Changing policies in care homes during COVID-19

Different approaches to safe visiting after blanket bans

Participants reported that, since the onset of the pandemic, visiting care homes was banned by government to prevent the spread of the coronavirus. Most of them were not allowed to see their relatives during the first phase, however some mentioned that they had the chance to see residents through the windows of the facilities, thanks to an agreement with care home staff. Whilst many participants accepted the public health measures despite being upset about these, they recognised their importance to reduce the infection risk. However, some were against the governmental restrictions, expressing disappointment and anger, especially towards the bans on visiting. Furthermore, they felt confused due to a lack of clarity on mobility restrictions, which often made decisions vary across policemen.

“If you call the police, they don’t know what to tell you. Then, if you meet a policeman who’s having a bad day, you are stopped and you get a fine. There’s no clear rule, no solution to visit a relative once a month or once a week”.

ID7 - female carer, 63 years, sister

Afterwards, since national guidelines on visits were updated and limited access from family carers was allowed, different modalities and strategies were reported to be implemented by care home leaderships to allow visits. Participants had to schedule the appointment in advance, though there were no limitations on the number of visits unless the daily schedule was full. Carers reported that visits were carried out in open-air settings, such as gardens, during the summer; on the other hand, during the cooler seasons, innovative strategies were used to ensure indoor visits. Some carers mentioned that visits were available in cleaned and disinfected rooms, where people sat around wide tables to keep a safe distance. Some others told that they sat in front of their relatives, separated by plexiglass transparent barriers, which allowed to reduce the distance between family members. Other carers told that they were able to physically interact with their relatives, even though the contact was protected by plastic cloths, in the so-called “hug-rooms”.

“After the situation improved, visits were allowed [...] It has been created a hug-room, specifically to let people hug through a

towel. I think it's a wonderful idea".

ID22 - female carer, 40 years, daughter

Varying degrees of carer satisfaction towards care home policies and procedures

Most participants were satisfied with the visits' organizations and procedures. However, some carers complained about the low frequency and length of visits, despite the lengthy hygiene practices required to reduce the infection transmission risk.

"They give you settled times you can come. Before entering, they give you the gel and the mask, everything you need; you can stay there half an hour, then you have to go because other people are waiting, and we alternate in a place that can only host four visitors. Twice a week isn't enough".

ID17 - female carer, 61 years, daughter

Few carers highlighted how the adapted visiting procedures were not able to compensate for the lack of physical contact. In particular, the plexiglass barriers were not perceived as adequate, as they could not recreate the tactile sensation due to the huge amount of plastic.

"It doesn't matter whether there's plexiglass, cellophane, or a two-meter distance. Still, I ain't able to touch my mother; I ain't able to hug her. Each of them has its own issues".

ID8 - female carer, 64 years, daughter

Different opinions emerged concerning the presence of the residential staff during the visits. Most carers appreciated their presence as it was helpful to guide the conversation. However, some family members perceived the presence of professionals as an invasion of privacy, as someone was listening

to their conversations and limiting their spontaneity.

“Each member of the family has the right to settle a visit in presence, though it’s not a real presence now. There’s me, my father, and a third person; so, as far as I know, all those people, it still feels like having a guardian nearby who doesn’t allow you to take any step. It’s hard”.

ID5 - female carer, 51 years, daughter

Theme 3: technology use in care homes during COVID-19

New technological options in care home settings

Participants reported that phone calls and sometimes e-mails were used - especially by the head nurses - to update families about residents’ health conditions on a regular and frequent basis. They described video calls as the main means of communication linking family members and people living with dementia: those were delivered through WhatsApp and Skype using devices - smartphones, computers and tablets – that mainly differed by screen size. Participants told that, even though video calls were not immediately introduced as facilities were not ready for the pandemic, scheduled appointments were established after initial adaptation: people could either set a regular daytime slot, or they could arrange a date at the beginning of the week. Nevertheless, few carers mentioned a discontinuity in the video call frequency and a too short length (video calls were usually lasting 10-15 min). As for the video calls settings, different locations were reported by participants: some care homes settled a specific room, in which there was a designated position with a computer; other facilities ran video calls within shared spaces; the last option was bringing tablets or smartphones in residents’ private rooms, that was particularly helpful when there were many COVID-19 cases or the person was isolated. A staff member was always present.

“Once everything was settled, we were given Tuesday and Friday as fixed days (for video calls), always at the same time – 4 pm –, so we knew when they would have called. It was awesome”.

ID7 - female carer, 63 years, sister

Regarding the equipment required for remote communication, several participants mentioned the low quality of the wi-fi connection as well as the insufficient number of devices – often under repair- in the care facilities.

“There were some internet problems, the connection was no good... Moreover, they switched from smartphones to a tablet but they still had problems with it, so they have bought a new one. Now they got two tablets and sometimes one has to be sent to maintenance...”

ID9 - male carer, 66 years, husband

Technology saved relationships

Video calls were appreciated by participants as they could check their relatives’ health status, which was a relief for them. For this reason, they were reported to be preferred over the traditional phone calls.

“For sure, the continuity that has been guaranteed is more complete than a traditional phone call. By using video calls you can see if her head stands right, if she’s sleepy, if she talks, if she interacts, if she’s angry or vigilant”

ID10 - female carer, 46 years, daughter

Participants also discussed the importance of video calls as they enabled the continuity and strengthening of relationships between families and facility staff, which were therefore able to communicate even during the lockdown. Moreover, the video calls implementation was mentioned to bring indirect social benefits too, some families chose to share the experience among relatives: they either gathered in a room to join the video call and see their relative from a single device, or they tried to converge as multiple users in the same online meeting.

“During the video calls you speak with the professional too. She says something, you reply, it’s like all three of us interact together”.

ID11 - male carer, 63 years, son

Participants acknowledged that many people living with dementia seemed to appreciate video calling, and appeared emotionally involved during the remote interactions: even though not everyone was able to verbally answer back, they showed physiological responses (i.e. blushing or raising eyebrows). Nevertheless, video calls represented a useful tool to break routine while providing cognitive and social stimulation for people living with dementia.

“It has been a relief. I even remember that, when she had bad days, we could make these video calls and professionals used to say: ‘Come on, let’s go upstairs where you can video call your brother and she was euphoric”.*

ID7 - female carer, 63 years, sister

Technology did not work for every person and/or any purpose

Based on participants’ reports, the video calling experience was facilitated and brought major benefits when family carers had previous knowledge about technology or a general positive attitude towards digital devices: this eased the learning process. However, when participants lacked the digital skills, they found somehow it difficult to communicate remotely with their relatives. For some respondents, the practical issue of not owning a personal device with internet connectivity (smartphone, tablet, or computer) was the restricting factor.

“There is a weird internet connection here: if I talk from the living room, it doesn’t work; but if I move to the kitchen there are no problems. After we’ve figured it out we used to move there. You slowly learn”.

ID23 - female carer, 64 years, daughter

Participants acknowledged that video calls did not work for those people living with dementia who were more seriously cognitively or sensory limited. Indeed, due to dementia deficits, after a few minutes, they could not focus on the call, and this made them tired and frustrated during the interaction. Participants also mentioned that they could appear disoriented and confused since it was challenging for them to detect the source the voice was coming from, to recognize their carers – due to sensory impairment too -, and to understand what was going on, especially when the device’s screen size was too small.

“They had a smartphone, but my mother sometimes struggled with it, she didn’t know where she was supposed to look... Smartphones don’t really have big screens”.

ID23 - female carer, 64 years, daughter

Overall, video calls were perceived by participants as a partial temporary solution that could not compensate for the need for physical contact. Moreover, some of them did not appreciate the video calling experience when - although their relatives were unable to communicate in any way at that moment - professionals did not interrupt remote interactions, but followed the planned schedule. According to few carers, the activities delivered during the video calls could also become repetitive in the long run. Finally, carers highlighted a functional gap regarding video calls: such remote communication could not provide psychological support for family members, even though it was needed.

“‘Close to the needs’ is a bold statement. I feel relieved when I see her, but my main need would be to go and hug her, bring her in the yard as I used to do before”.

ID25 - female carer, 60 years, daughter

Discussion

The present study investigated the impact of COVID-19 related health measures on care home residents living with dementia and their family carers in Italy, as experienced by the latter. At the beginning of the pandemic Italy was the most affected country in Europe. The virus quickly spread with severe consequences (Cerqua & Di Stefano, 2021). The pandemic impacted particularly negatively on people living with dementia's cognitive functions (Tondo et al., 2021, Rainero et al., 2020). Moreover, an increased carer burden and higher level of emotional distress were found during the period immediately following the lockdown (Rainero et al., 2020; Zucca et al., 2021).

In light of the above-mentioned issues, this study focused on care homes, the epicenters of the virus outbreak. To our knowledge, this is the first study that explores the effects of the strategies implemented in care homes to overcome the pandemic's constraints in Italy, adding to a growing evidence base from other countries (O'Caoimh et al., 2020; Sadler et al., 2021; Wammes et al., 2020). Moreover, this study highlighted the psychological impact of COVID-19 and its related measures to the second pandemic wave on family carers of older care home residents.

The interviews provide evidence on how the implemented restrictions had limited several primary aspects of their relatives' lives, among which the lack of physical contact was prominent. In participants' view, social distancing restrictions and single-room isolation measures imposed by the pandemic significantly reduced the stimulation received by care home residents. This limited in-person social stimulations, consisting of the interactions - between staff, family carers, and other residents - that promote the psychological well-being of people living with dementia (Lee et al., 2017). Furthermore, safe distancing measures limited the provision of those psychosocial interventions that are vital for a good quality of life, as well as for the management of behavioral and psychological symptoms of people living with dementia (Chirico et al., 2021; Keng et al., 2020; Ottoboni et al., 2021). Based on participants' reports, the lack of touch deprived people with limited cognitive abilities and language impairment of those contacts essential for sustaining their mental health (Gleeson & Timmins, 2004; Nicholls et al., 2013; Wu et al., 2017). Thus, environmental stimulation decreased, especially for those residents infected by COVID-19 who moved to unfamiliar settings. As the literature suggests, environmental cues play a key role in facilitating people living with dementia's spatial-temporal orientation and in reducing their behavioral symptoms (Marquardt, 2011). Moreover, the lack of a proper environmental context has been associated with residents' diminished expressions of awareness, in terms of verbal, facial and bodily expressions (Clare et al., 2008; Norberg et al., 2003; O'Shaughnessy et al., 2021).

In line with previous international literature, restrictions implemented against COVID-19 led to an exacerbation of pre-existing cognitive, motor, and behavioral symptoms of dementia, thus accelerating people's cognitive decline, as reported by participants (Alzheimer Europe, 2020; Manca et al., 2020;

Numbers & Brodaty, 2021; Vindegaard & Benros, 2020). Issues noted include depressive symptoms, including abulia, arose or deteriorated among residents, together with increased feelings of loneliness and abandonment, exacerbated as a consequence of isolation procedures (Devita et al., 2021; Santini et al., 2020; Velayudhan et al., 2020).

Beyond people living with dementia, the interviewed carers were also affected by the restrictive measures implemented in care homes. Indeed, they were worried about the health status of their relatives, and how relatives could be impacted by the radical changes occurred in the facilities. As found in previous studies, family carers experienced worries, stress, and anxiety symptoms (Alzheimer Europe, 2020; Cohen et al., 2020; Low et al., 2021). Specifically, their concerns included the general health of their relative, the fear of not being recognised anymore due to the time passing and the progression of dementia, and the abandonment potentially perceived by residents. These findings highlight the urge to update health strategies, so that formalised and continuous psychological support will be provided to family members, including during unexpected and negative circumstances.

Total bans imposed on visits early in the pandemic were gradually replaced by safe visiting measures (Giebel et al., 2021a; Low et al., 2021; Verbeek et al., 2020). However, differences occurred across care homes in relation to the timing of introduction, the adopted modalities, and the guaranteed continuity of visits over the pandemic phases. Furthermore, participants' opinions were mixed about the suitability and effectiveness of the reintroduction of visits. If on the one hand, family members were happy to spend time again with their relatives, they also felt frustrated as they realized how COVID-19 had impacted on residents. Furthermore, even though some solutions were implemented, such as providing hug rooms with plastic-divider cloths, many family carers reported that those measures were not enough to compensate for the lack of physical contact with their relatives.

Using technology to overcome social and geographical distances was found by family carers to be somewhat beneficial. In line with existing literature, the introduction of software to communicate from a remote location during the day was appreciated both by people living with dementia and their relatives (Pappadà et al., 2021; Talbot & Briggs, 2021). In carers' view, benefits associated with scheduled video calls were twofold: they allowed the continuity of contacts among family members and their relatives (Pappadà et al., 2021; Talbot & Briggs, 2021) and, moreover, new connections and bonds between the residential personnel and family carers emerged. Based on participants' reports, as for the emotional benefits, people living with dementia showed happiness during virtual meetings wherever they could recognize their carers and understand, at least partially, the mediated communication process. Also, video calls were sporadically used by the residential personnel as to manage people living with dementia's behavioral and psychological symptoms. Although there is no previous research about the effectiveness of this implementation, positive effects on BPSD have been found using pre-recorded videos by family members for the simulated presence therapies (Hung et al., 2018; Pappadà et al., 2021). Evidence should be similar for video calls considered as an extension of

recorded videos.

Along with benefits, several limitations and barriers associated with the use of technology emerged from carers' interviews. They were mainly related to participants' digital literacy, technical issues, device characteristics - in particular, the small smartphone screen's size - and dementia deficits. Though, it is worth mentioning that some barriers were not only dementia-related, but were based upon the person's characteristics and habits, regardless of the disease. Indeed, in participants' view, many people living with dementia still showed some understanding of the interaction, and few of them even improved in the use of technology over time. In line with recent findings related to the use of digital technologies during the pandemic, people living with mild to moderate dementia were able to learn relevant technological skills. The use of such tools indeed enhanced their wellbeing, boosted their self-actualisation, provided cognitive stimulation, and were an opportunity to strengthen their social connections (Talbot & Briggs, 2021). Therefore, our study shows that, despite carers could more easily adapt to the use of digital tools, people living with dementia could use them as well, depending upon their preserved cognitive skills and psychological state (Lorenz et al., 2019; Pappadà et al., 2021; Talbot & Briggs, 2021).

Limitations and future directions

While this study collected the experience of COVID-19 from the perspective of family carers, what is missing is the perspective of the residents living with dementia. Given pandemic restrictions in care homes, it proved impossible to undertake research interviews with residents adequately. However, future research should explore the psychological impact of the pandemic from the residents' point of view, albeit with the added difficulty that many care home residents live with dementia, particularly in the advanced stages, and are thus likely to experience difficulties in remembering living through the pandemic. Therefore, staff accounts can also prove as a relevant point of view. An important limitation of this study concerns the type of recruitment, i.e. it was a convenience sample rather than a purposive one. Recruitment in future research should involve purposively selected care homes and carers. Moreover, we collected data from three Italian regions, whereas the impact of COVID-19 in the remaining regions is yet to be explored.

Conclusions

This is the first study to highlight the subjective experiences of carers on safe care home visitation during the COVID-19 pandemic in Italy. Findings indicate areas for improvement in health and care strategies within care homes for future pandemic waves as well as future pandemics. In participants' view, new ways to maintain cognitive, physical, and social stimulation in people living with dementia in harsh circumstances are required. Isolation measures should be readjusted to respect residents' dignity and minimize the negative effects on their quality of life. There is a need for strategies able to allow

direct physical contact without increasing infection risk (or at least to simulate the feeling of touch in innovative ways), alongside continuity in safe visiting. Digital solutions should be another avenue to be exploited to stimulate people living with dementia, allow remote communications, and provide continuous psychological support for family carers (Cuffaro et al., 2020; McDermid et al., 2018). To do so, software feasible for people living with dementia should be designed in relation to their cognitive abilities and levels of functioning, as well as training programs both for professionals and family carers should be provided to ease the use of such technologies.

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Conflict of interest

The authors declare no conflicts of interest.

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Authors' contributions

CG led the study and designed the study in the UK with MG and HT, and oversaw the project. IC and AP collected data in Italy, analysed data and wrote drafts of the manuscript. Italian team members IC, AP, GO, MV, RC contributed to data analysis, and all the authors read through drafts of the manuscript and approved the final manuscript.

Data sharing statement

No additional data available.

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3. **Query:** [AQ2] - :Please provide complete details for Team et al. (2020) in the reference list or delete the citation from the text.

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ECDC Public Health Emergency Team, Danis, K., Fonteneau, L., Georges, S., Daniau, C., Bernard-Stoecklin, S., Domegan, L., O'Donnell, J., Hauge, S. H., Dequeker, S., Vandael, E., Van der Heyden, J., Renard, F., Sierra, N. B., Ricchizzi, E., Schweickert, B., Schmidt, N., Abu Sin, M., Eckmanns, T., Paiva, J. A., ... Schneider, E. (2020). High impact of COVID-19 in long-term care facilities, suggestion for monitoring in the EU/EEA, May 2020. Euro surveillance : bulletin Europeen sur les maladies transmissibles = European communicable disease bulletin, 25(22), 2000956. <https://doi.org/10.2807/1560-7917.ES.2020.25.22.2000956>



4. **Query:** [AQ3] - :There is no mention of Danis et al. (2020) in the text. Please insert a citation in the text or delete the reference as appropriate.

Response: [Author - Ilaria Chirico: ilaria.chirico2@unibo.it]: Sorry. Deleted. 


5. **Query:** [AQ4] - :Please provide the volume number and page range.

Response: [Author - Ilaria Chirico: ilaria.chirico2@unibo.it]: The correct reference is:

Cerqua, A., & Di Stefano, R. (2021). When did coronavirus arrive in Europe?. Statistical methods & applications, 1–15. Advance online publication. <https://doi.org/10.1007/s10260-021-00568-4>



6. **Query:** [AQ5] - :The year of publication has been changed as per Crossref details both in the list and in the text for this reference. Please check.

Response: [Author - Ilaria Chirico: ilaria.chirico2@unibo.it]: Ok 

7. **Query:** [AQ6] - :Please provide the page range.

Response: [Author - Ilaria Chirico: ilaria.chirico2@unibo.it]: Page range is:1-7



8. **Query:** [AQ7] - :Please provide the volume number, page range and journal title.

Response: [Author - Ilaria Chirico: ilaria.chirico2@unibo.it]: The correct reference is:

Giebel, C., Hanna, K., Cannon, J., Marlow, P., Tetlow, H., Mason, S., Shenton, J., Rajagopal, M., & Gabbay, M. (2022). Are we allowed to visit now? Concerns and issues surrounding vaccination and infection risks in UK care homes during COVID-19. Age and ageing, 51(1), afab229. <https://doi.org/10.1093/ageing/afab229>




9. **Query:** [AQ8] - :Please provide the volume number and page range.

Response: [Author - Ilaria Chirico: ilaria.chirico2@unibo.it]: The correct reference is:

Giebel, C., Hanna, K., Cannon, J., Shenton, J., Mason, S., Tetlow, H., Marlow, P., Rajagopal, M., & Gabbay, M. (2021). Taking the 'care' out of care homes: The moral dilemma of institutional long-term care provision during COVID-19. Health & social care in the community, 10.1111/hsc.13651. Advance online publication. <https://doi.org/10.1111/hsc.13651>



10. **Query:** [AQ9] - :The year of publication has been changed as per Crossref details in the list and in the text for this reference. Please check.

Response: [Author - *Ilaria Chirico*: *ilaria.chirico2@unibo.it*]: Ok 

11. **Query:** [AQ10] - :Please provide the volume number, page range and journal title.

Response: [Author - *Ilaria Chirico*: *ilaria.chirico2@unibo.it*]: The correct reference is:

Talbot, C. V., & Briggs, P. (2021). The use of digital technologies by people with mild to moderate dementia during the COVID-19 pandemic: A positive technology perspective. *Dementia* (In Press). <https://doi.org/10.31234/osf.io/d4qv8>



12. **Query:** [AQ11] - :Please note that the ORCID section has been created from information supplied with your manuscript submission/CATS. Please correct if this is inaccurate.

Response: [Author - *Ilaria Chirico*: *ilaria.chirico2@unibo.it*]: Please, can you add the ORCID number (Clarissa Giebel) 0000-0002-0746-0566? Thank you. 