Palliative Care and Social Practice
2026, Vol. 20: 1–11
DOI: 10.1177/26323524251413623
journals.sagepub.com/home/pcr

The impact of the COVID-19 pandemic on end-of-life care in LTCFs in England: A qualitative study of LTCF staff experiences

Natalie Cotterell[1] **and Danni Collingridge Moore**[1]

Abstract

Background: The COVID-19 pandemic significantly increased the number of deaths within long-term care facilities (LTCFs) globally. Restrictions around visitation and social distancing were common; however, research conducted during the pandemic demonstrates that these policies impacted the ways in which end-of-life care was delivered in LTCFs.

Aim: This paper aims to explore the experiences of LTCF staff members in England in providing end-of-life care in the context of policies issued by the government at the time.

Methods: Secondary analysis of data collected from qualitative, semi-structured interviews conducted with 24 LTCF staff working across eight LTCFs in the north-west of England were analysed. Interviews were conducted with LTCF staff members, exploring their experiences of working in adult social care during the COVID-19 pandemic. Themes related to providing end-of-life care during this time were identified and analysed using thematic analysis.

Findings: Thematic analysis identified four key themes including: discrepancies in following COVID-19 UK government guidelines including visitation at end of life as an exception; the influence of staffing on delivering end-of-life care; utilising technology to substitute physical presence at end-of-life visits; and the emotional impact of delivering end-of-life care under COVID-19 restrictions.

Conclusion: The findings demonstrate the numerous challenges LTCF staff experienced when delivering end-of-life care during the COVID-19 pandemic in terms of the practicalities of managing resident deaths, facilitating visitation, and the associated impact on emotional well-being. Ensuring that all LTCF staff are trained to recognise end-of-life care, in the event of a future pandemic, will better equip LTCFs in providing high-quality care. It is paramount that guidance on managing family contact at end of life is consistent, while considering the impact of implementing such guidance on the mental and emotional well-being of LTCF staff members.

Keywords
coronavirus, COVID-19, long-term care facilities, LTCFs, nursing homes, health policy, public health, palliative care, end of life

Received: 3 March 2025; accepted: 18 December 2025

Introduction

The COVID-19 pandemic had a substantial impact on older adults living in long-term care facilities (LTCFs). During the course of the pandemic, the number of deaths occurring in LTCFs across the world significantly increased.[1] In England, between March 2020 and January 2022, COVID-19 was mentioned on 16.6% of LTCF resident death certificates.[2] LTCF residents were frequently deemed unsuitable for hospital admission due to pressures on bed occupancy, regardless of COVID-19 status, which contributed to end-of-life care increasingly taking place within LTCFs.[3] Unsurprisingly, the COVID-19 pandemic had widespread implications for the delivery of end-of-life

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[1]Division of Health Research, Lancaster University, UK

Corresponding author:
Danni Collingridge Moore, Division of Health Research, Lancaster University, Lancaster LA1 4YG, UK.
Email: d.collingridgemoore@lancaster.ac.uk

care in LTCFs, both for residents infected with COVID-19 and those who died from other causes.

The terms 'palliative' or 'end-of-life care' are often used interchangeably in Europe[4]; in this paper, the term 'end-of-life care' will be used to refer to the care that individuals receive when they are likely to die within the next 12 months, with the aim of relieving suffering and improving quality of life for patients and families dealing with any type of life-threatening illness.[5] Prior to the pandemic, the UK National End-of-Life Care Strategy recognised the need for high-quality end-of-life care in LTCFs; however, delivering such care in these settings can be difficult.[6] Barriers to implementing end-of-life care interventions include limited recognition of the need for end-of-life care, lack of support from management or wider stakeholders, and difficulties adopting end-of-life care into routine practice.[7] These are additional challenges to the wider issues encountered in providing end-of-life care to older adults and those with dementia, both of which are common characteristics of the LTCF population in the United Kingdom and in Europe.

The impact of COVID-19 on end-of-life care in LTCFs is only now, in retrospect, being fully understood. During the pandemic, LTCFs were expected to follow the COVID-19 restrictions relating to infection prevention and control, social distancing, and visitation, further limiting LTCF staff time and resources to deliver end-of-life care.[8] Despite the increased demand on staff time, there was relatively little guidance on delivering end-of-life care during pandemics in LTCFs.[9] One online national survey of LTCFs in England highlighted variation in the provision of palliative and end-of-life care, with 18% of LTCFs reporting that they did not allow visitors for residents approaching end of life.[10] Although technology was used to support remote communication at end of life, qualitative studies have found this to be time-consuming and difficult for residents to engage with, especially those living with dementia.[11,12] Furthermore, a mixed-methods systematic review demonstrated the negative impact of the pandemic on end-of-life care in LTCFs.[13] On reviewing nine studies, the authors found that end-of-life care, especially advance care planning, had been disrupted during the COVID-19 pandemic in the United Kingdom, Ireland, Italy, Spain, Sweden, Peru, Mexico, and the United States. Four themes were identified: the importance of advance care planning; increased responsibilities and expectations; emotional trauma and fear among staff; and professional pride and resilience, concluding that the pandemic reduced advance care planning, while increasing care staff responsibilities and exposure to death, which contributed to the heightened emotional trauma experienced by staff. These findings are consistent with wider research that has demonstrated the overall emotional toll that residents' deaths during the pandemic had on LTCF staff.[14,15] Initiatives to provide online learning on end-of-life care during the pandemic resulted in increased awareness and understanding of advance care planning, increased confidence for advance care planning, and increased willingness to talk about advance care planning; however, staff engagement was limited by a lack of time to complete the training.[16]

The current paper draws upon data collected as part of a wider study, which aimed to explore the implementation of COVID-19 restrictions in LTCFs in north-west England, examining the extent to which policies issued by the government were effective in their implementation, from the perspective of LTCF staff. An analysis of data collected during semi-structured, qualitative interviews with LTCF staff members, which focuses on exploring the experiences of LTCF staff members in providing end-of-life care, is presented in this paper.

Methods

Research design

The findings presented in this paper are based on the secondary analysis of data from semi-structured, qualitative interviews with LTCF staff that were undertaken as part of a larger mixed-methods case study, conducted by the authors. The study aimed to explore the implementation of government issued policies in LTCFs during the COVID-19 pandemic, related to six broad themes: infection prevention and control, hospital discharge, testing and vaccination, staffing, visitation, and continuing routine care, including palliative and end-of-life care. Three sources of data were collected for each facility; COVID-19-related deaths reported to the Care Quality Commission (CQC), a self-completion survey on the awareness, effectiveness, and difficulty of implementing COVID-19 guidance, and qualitative semi-structured interviews with LTCF staff. Further reporting of the methodological approach used has been reported elsewhere.[17])

Recruitment and sampling

Data collection took place in eight LTCFs in north-west England, within six local authorities. In the area, LTCFs were eligible to take part if they were registered with the CQC to provide residential or nursing care to older adults aged 65 and over and the facility was active during the COVID-19 pandemic. In England, LTCFs are registered with the CQC, which is the independent regulator of health and adult social care services; however, it is not part of the National Health Service (NHS). The NHS is a publicly funded healthcare system, but it is not responsible for the regulation or general funding of LTCFs or the CQC. LTCFs were notified of the study between October 2023 and March 2024 through the Enabling Research in Care Homes Network with the sample size limited to eight LTCFs.[18] Convenience sampling was used; all LTCFs that met the inclusion criteria and contacted with research team were accepted to take part in the study.

In each facility, between two and four staff were identified by the facility manager to be approached by the research team with information packs about taking part in qualitative interviews. Inclusion criteria included being able to participate in the interview in English, being aged 18 years or older, willing to provide written informed consent and previous experience working in the facility during the COVID-19 pandemic. Purposive sampling of participants in terms of job role was applied to capture a range of perspectives, reducing the risk of over-representing a single viewpoint. Participants were informed of the purpose of the research being conducted, including information on funding sources, ethical review, and sources of further support, if required. Each interviewee received a £25 gift voucher as a thank you gesture.

Written informed consent was obtained by N.C., who conducted the qualitative interviews. Informed consent was provided by the LTCF manager and the participant. Written informed consent included the publication of quotes in subsequent publications and reports, and ethical approval was obtained from Lancaster University FHM Research Ethics Committee (reference: FHM-2023-3368-RECR-3).

Data collection

The qualitative component of the study adopted a descriptive design, which is an appropriate approach for exploring participants' experiences, perceptions, and meanings in depth. Descriptive designs aim to provide a comprehensive summary of specific events or phenomena as experienced by individuals.[19,20] This approach allowed for a rich, detailed understanding of the experiences of LTCF staff during the COVID-19 pandemic, by capturing their narratives in their own words.

Semi-structured interviews were conducted either online using Microsoft Teams or in person (in a private meeting space within the LTCF). Interviews ranged from 40 to 60 min and were carried out at a convenient time during each staff members working shift. Interviews were conducted by N.C., a female researcher with a PhD and 5 years' experience conducting qualitative research. Each interview was limited to the researcher and participant, with D.C.M. observing a subset of the interviews.

The topic guide used in the interviews focused on the experience of LTCF staff members in implementing the key policy recommendations issued by the UK government during the COVID-19 pandemic. Prompts included the participants role in the LTCF when the COVID-19 pandemic started, whether they were aware of the recommendations related to continuing routine care, how well they thought their facility put these measures into place, how easy these guidelines were to put in place, the challenges encountered, what putting these guidelines into place achieved, and whether they were effective at reducing the spread of COVID-19.

Researcher bias was addressed by each member of the research team keeping a reflexive journal and reflective debriefing discussions held after each interview. In addition, each researcher acknowledged their personal perspectives on the research area and discussed approaches to mitigate their influence on data collection and analysis.

All interview data were anonymised upon transcription, and participants were given unique identification codes. In this paper, facility identifiers have been removed from quotations to ensure individuals cannot be identified from the data reported. Data from all eight cases in the primary dataset were included in the analysis. Participants were not asked to provide feedback on the transcripts or findings, and no repeat interviews were conducted.

Thematic analysis

All interviews were audio recorded and transcribed verbatim using Microsoft Teams and managed using Atlas.ti software.[21] Transcripts were checked for accuracy by N.C. and D.C.M. The data collected were analysed using thematic analysis.[22] In the first step, data familiarisation, the transcripts were read and re-read by the research team to allow for familiarisation. Second, initial codes were generated, and third, emerging themes were derived from the data through discussion within the research team, which were revised iteratively. During the development of codes, the research team documented initial codes, iterations, and rationales for adjustments. Similarly, the identification of themes was tracked through analytic memos that recorded how themes were refined. Fourth, these themes were reviewed and finally the remaining themes were defined and named. Any disagreements were resolved through discussion with a third researcher external to the study. Data saturation was achieved after coding 20 interviews. The COREQ checklist for the comprehensive reporting of qualitative studies was used to guide the reporting of this analysis (Supplemental Information 1).[23]

Results

Sample characteristics

Twenty-four LTCF staff members participated in the semi-structured interviews. Twenty-one participants were female, and 21 participants identified as White British (of the remaining 3, 2 identified as Indian or British Indian, and 1 identified as Portuguese). Twenty-two reported English as their first language, and the average age was 46 years, ranging from 23 to 68 years. Participants had spent 5–46 years working in direct patient care (average 21 years) and 5–46 years working in LTCFs (average

Table 1. Demographic and occupational characteristics of participants.

Characteristic	Mean	Range	*n*	%
Age	45.9	28–68		
Gender – female			21	87.5
Ethnicity – White British			21	87.5
English as a first language			22	91.7
Working in direct patient care (years)	21.3	5–46		
Working in LTCFs (years)	18.2	5–46		
Working full time			19	79.2
Current position or role				
Manager			5	20.8
Deputy manager			2	8.3
Head of operations			1	4.2
Manager – clinical			3	12.5
Care assistant – senior			6	25.0
Care assistant			3	12.5
Activity co-ordinator			1	4.2
Housekeepers			3	12.5
Number of residents being provided direct care*	39.9	12–118		
Highest level of education completed				
Tertiary level			10	41.7
Higher-secondary level			6	25.0
Lower-secondary			8	33.3

*The mean number of residents each interview participant provided care to daily.

18 years). Participation was open to any staff role, providing the other inclusion criteria were met, and the sample included a range of managers, care assistants, and other roles (Table 1).

Findings

All eight of the LTCFs included in the study had experience of providing end-of-life care both prior to and during the pandemic. One LTCF experienced no deaths from COVID-19 and provided end-of-life care for only one resident, who did not test positive for COVID-19, when the restrictions related to the pandemic had eased. In total, four core themes were conceptualised: discrepancies in following COVID-19 UK government guidelines; the influence of staffing on delivering end-of-life care; utilising technology to substitute physical presence at end-of-life visits; and the emotional impact of delivering end-of-life care under COVID-19 restrictions.

Discrepancies in adhering to COVID-19 government guidelines

The first theme identified referred to staff making exceptions and actively choosing to partially or fully not adhere to government guidance, based on perceived risks and personal judgement. Participants reflected on the belief that these decisions were the ‘right thing to do’, applying their own values and imagining what they would want in similar circumstances. This sometimes involved creatively using the building to facilitate visits or physical contact with residents and relatives during end of life, especially when strong relationships had been built. While these actions reflected deeply held personal and professional values regarding the role of LTCF staff in providing care and comfort at end of life, they created challenges over time, making it difficult to maintain uniformity in practice.

Visitation as an exception. Participants in the majority of the eight LTCFs included in the study reported allowing visitation at end of life, which at times was viewed by some participants as breaching the public guidance issued by the government. Some managers in particular considered end of life to be an exceptional circumstance, claiming it was ‘different’, and viewed the risk of COVID-19 transmission as smaller than not providing appropriate end-of-life care.

One manager explained that they thought the risks of allowing visitation with personal protective equipment (PPE) did not outweigh the benefits of visiting a loved one at the end of their life; thus, the facility bent the rules and allowed visitation at the end of life as an exception:

> Yeah, of course we did [allow visitation at the end of life]. I mean, you can’t . . . I don’t know how any sane person could say, oh, you’re not coming in in case you bring COVID to someone who’s already dying. You know, what difference is that going to make? Some of the things we did in our LTCF, we probably shouldn’t have done, but in hindsight now I think that a lot of other LTCFs wish they’d done it that way because, you know, you’d think of yourself in that situation and you know, what are the risks really? P014

Other staff members spoke of how the organisation of the LTCF building helped them to allow visitation as an exception. One member of staff remembered how they moved residents who were at the end of their life to ground floor rooms that were more easily accessible, so they could ‘bend the rules’ and allow visitation under the exceptional circumstance of death being anticipated. In another LTCF, staff provided end-of-life care for two residents during the pandemic, both of whom were already living in conveniently placed rooms: one on the top floor by a fire escape and one on the ground floor next to the fire door. This enabled the LTCF to allow visitation as an exception at end of life with relative ease:

> It was really quite funny because the two people who died were at the end of the building. One was on the top floor, so the family used to come up the fire escape and come in. They’d walk up and then they come in that door, and then the other lady was on the ground floor in the room below, and there was a fire door right next to her, so she’d just come. She’d ring the front doorbell, and then she’d go round to

> where she needed to. She used to go just straight in the room with her face mask and the gloves and stuff and then just literally go back out again. She didn't . . . they didn't mingle, we said if you need anything or you're worried about your mum or whatever, just press the bell and somebody will come. P002

However, staff in other LTCFs followed the guidance more strictly and did not allow visitation even when a resident was viewed as nearing the end of their life. Staff reported finding it difficult seeing relatives watching their loved one die from outside the facility, that is, through a window; one member of staff revealed that they breached the guidance and hugged a grieving relative, claiming standing there and not providing comfort was 'not a human thing to do':

> There's one person that sticks in my head. It was a lady, she was in a bedroom here, on end of life and her family couldn't come in, and they were stood at the window with the priest watching her die. And we were in the room, trying to hold it together. We couldn't. We couldn't hold it together. You wanted to hug the relatives, and say sorry, but you can't. I'm not gonna lie though, there was one woman who I was very close to, and I'm very close to the family and she died, and I said I can't stand here and watch you break down on your own, and I did hug her because I can't watch somebody physically breakdown and just stand there, it's not a human thing to do. You can give me guidance but I'm going to support that person. P013

In another LTCF, a senior carer spoke about finding the rapidly changing guidance difficult to deal with in terms of allowing visitation at end of life, with one relative unable to say goodbye to their husband, and another being allowed to visit their husband at end of life just a 2 weeks later:

> Yeah, we had this one guy, and he was dying, and they wouldn't let his wife come and see him, so she had to stand at his bedroom window. And then there was, like, two weeks later, another guy was dying, but then the rules had changed, his wife was allowed in, and they were friends, so then she was really upset. P007

In the same LTCF, the housekeeper described how a relative had to watch her husband die through a window 'in the freezing cold' and how 'she should not have had to do that', further demonstrating the conflict staff felt about the government guidance related to end of life.

The influence of staffing on providing end-of-life care

The second theme identified related to the significant influence of staffing on providing end-of-life care, with experience of death and familiarity with the routine and procedures of each individual facility playing a crucial role. Staff often held the care they provided at end of life to a high standard and valued the experience and knowledge that their role involved. The ability to recognise end-of-life needs, for example, allowed timely arrangements, despite pressures and limited external support. However, challenges included the need for time to teach newly recruited or agency staff and upskilling less experienced staff members. This theme also included the relationship of LTCF staff with wider health services, specifically addressing poor practices around advance care planning and managing restricted access to specialist input and equipment.

The recruitment of staff inexperienced in end of life. All LTCFs who took part in the interviews reported that the pandemic caused staff shortages at some point in their LTCFs. At the height of the pandemic, the government guidance advised care staff to isolate for up to 2 weeks if they developed symptoms of COVID-19 or if they or someone in their household tested positive for COVID-19.[8] In addition, some managers reported losing members of staff after the government had announced that COVID-19 vaccinations were to be made mandatory for those working in LTCFs. This meant that some LTCFs relied on agency staff or rapidly recruited new starters, which had implications for end-of-life care within the facility.

Across numerous interviews, experiences of conflict between permanent LTCF staff and agency staff were reported. Several interviewees explained how agency staff did not know the building, residents, or routines well and how this impacted the quality of end-of-life care provided. Participant 001 described themself as '*a bit of a snob when it comes to end-of-life care*' as they carried out specific rituals when caring for individuals who had died. They lamented that the agency staff did not know the existing end-of-life routines within the LTCF, which made providing quality end-of-life care challenging:

> Like I said about the girl who had never seen a death. She'd never washed them. I've always been taught with my training as well, and what I like to do is I open the door to let the spirit out. I like to give them a wash, wear their favourite clothes and that's how I've always been, and it's like you're doing one nearly every shift, and some of these people have never seen one before, because you come into here and you don't necessarily die straight away. P001

Another care worker reported that the LTCF they worked in had rapidly recruited individuals who had no prior experience or training in providing social care – the majority of whom came from the hospitality sector as many employees were out of work due to the closure of hospitality establishments.

> This is the only sector which was running – the health sector. [. . .] But whoever hasn't worked in care before, they only know to feed people maybe, even with washing, they

> struggled. [. . .] It's always difficult when there is a new starter, we always need to teach them. But at that time, I was working like we were working with four staff for 35-36 residents, four staff and most of them (residents) were bedbound. [. . .] I had no time to teach them . . . but the company couldn't find staff. P009

Some participants felt these staff were more of a hindrance than a help as a significant amount of time was needed to show them what to do when workload was already overwhelming. In particular, end-of-life care was found to be a challenge for inexperienced staff who had not dealt with death before.

The role of wider health services. The relationship between LTCFs and wider health services varied greatly, especially in relation to the role of wider health services when delivering end-of-life care. Several LTCFs reported reduced support from wider services, forcing staff to take on more responsibilities around end of life. For example, staff reported having to increase their knowledge of end-of-life protocols and procedures, some of whom were asked to pronounce residents as dead with a physician or general practitioner present on the phone, at times when medical professionals avoided entering LTCFs.

Several staff reported areas of potential bad practice from colleagues within the wider health service related to residents at end of life. One example was the use of blanket 'Do Not Resuscitate (DNR)' orders which were issued through the post to all residents in one LTCF without any prior discussion with the facility manager. The same interviewee recalled overhearing a conversation with a hospital doctor explaining to a resident that a DNR meant that they did not need to go into hospital if they tested positive for COVID-19:

> I'll never forget this . . . they explained to a lady, who had dementia . . . well, she had memory loss, and he said to her, 'so we need to speak to you about do not resuscitate', and she said, 'what does that mean?' He said 'that you don't have to go to hospital, that's what that means', and she agreed to that, to not being resuscitated, so they lied, the doctors lied about what a DNR actually meant. They told her it just means you don't go to hospital if you get COVID. P013

One participant reported that the restrictions on the resources LTCFs could have compared to wider health services meant that essentials such as oxygen were not available. They suggested that negative societal attitudes towards older people prevented residents from receiving appropriate healthcare, demonstrating the lack of support LTCFs received from wider services.

> I had to try and comfort people at the time who were dying. We couldn't have oxygen. We were not allowed to. We were not allowed to have oxygen. They weren't considered suitable to go to hospital because hospital was full, and we were told that they were old, and they had to stay here. [. . .] What was the heartbreaking thing was one resident got refused hospital and oxygen. Nobody should be refused oxygen. Nobody. P006

Recognising end of life. Several LTCF staff discussed the speed and variability of decline of individuals dying with COVID-19, reportedly making it difficult to recognise when a resident was about to die. This was a challenge as staff needed to recognise when someone was 'really at the end of life' so that they could consider informing family members, allowing and organising visitation. Participant 011 spoke about the difficulty of 'getting there on time' when individuals were COVID-19 positive, as the decline was often quick and there were minimal staff to facilitate visiting:

> We tried to get there, you know, we did try to get there. I mean, the last thing you want is for somebody to die on their own. That's the very last thing you want. We do try to get there, but like I said, we were running on minimal staff, and I'll be honest, I don't know how we did it. P011

Participants explained how COVID-19 more commonly infected those who were already nearing the end of their life, reflecting on how they could recognise that an individual was going to die from COVID-19. Others reported the importance of developing skills to recognise the presentation of the stages of end of life that older adults commonly experience. Staff needed to recognise when individuals were in the last days of dying in order to allow visitation, explaining how many of their residents could be seen as at the end of their life and so it was a skill to recognise when visitation was necessary.

Utilising technology to substitute physical presence at end-of-life visits

The third theme related to staff efforts to utilise technology to support end-of-life care, often as a substitute for physical presence. While digital tools were introduced to maintain connections, they often proved inadequate for residents with dementia and those who valued physical contact, providing justification for staff to bend rules round visitation. These attempts were underpinned by a commitment to person-centred care and respect for residents. Virtual approaches required creative management and sometimes fostered stronger relationships with families, but they underscored the challenges of delivering compassionate end-of-life care within restrictive guidelines.

Digital contact 'not the same' as physical visits. All LTCFs used digital technology as a substitute for physical visitation during lockdowns, though only some used technology to aid communication for those residents at end of life. Those who did not utilise technology instead facilitated face-to-face visitation when practically possible. In the LTCFs who did not offer visitation as an exception at end of life, digital technology was used to assist communication between the resident and their loved ones. Most LTCFs received dedicated iPads to assist with communication; however, in others where iPads were not purchased, staff were forced to use their personal phones.

Several staff, however, commented on how they felt it was inappropriate to substitute physical visitation with digital communication at the end of life, particularly as residents at the end of life often could not look at the screen or comprehend the nature of the communication, let alone understand how to use the technology effectively. Participant 010 felt communication through technology was 'totally different' to having a physical presence:

> How far the video call and virtual would support an end of life person rather than if somebody had been in and touched their hand is totally different to someone saying hi over the phone or a video call. P010

Other staff members echoed this point; Participant 018 spoke of the difference between physical and online communication between end-of-life residents and their loved ones, highlighting that their LTCF 'safely' breached public guidance and prioritised face-to-face visiting for those at end of life:

> Obviously we tried to facilitate things like Zoom, but you know when you're nonverbal and you know . . . there's nothing like that contact really, so we really stretched the special circumstances kind of thing and used it to our advantage really, but also was kept safe in doing that, but making sure that people got that family time. P018

The presence of physical contact at the end of life was highlighted as important by all interviewees. Participant 001 described the heartbreak they felt when assisting video calls with dying residents, reporting how they grew closer with the residents' families through empathising with their situation:

> Not even ones that were dying were allowed to have any visitors, which was heartbreaking. It was just heartbreaking and watching them, like seeing their parents or grandparents dying on a phone like it's 'I'm really sorry, but no it's not gonna be the night', kind of thing. It's 'do you want me to video call you?' It's how to reassure someone that's dying on a video call and you not being able to be there and that's where we got close with all the families. P001

Emotional impact of delivering end-of-life care under COVID-19 restrictions

The final theme related to the emotional impact of providing end-of-life care during the pandemic. Staff often felt helpless, as the high number of cases and rapid decline left little time for meaningful interventions. These experiences raised concerns about long-term psychological effects, compounded by limited availability of emotional support.

Trauma and helplessness. Staff who had provided end-of-life care during the pandemic or were present for a large number of deaths reported feeling traumatised by the experience, and there was a strong sense of helplessness amongst staff. Participant 012 echoed this, while others reported that this sense of helplessness was also felt by the residents and relatives:

> It was tough because you've got so many and it's like an impossible task because you just got so many just dropping in front of you. [. . .] I felt helpless. P012

Participant 001 described how traumatising they found some of the COVID-19-related deaths, mentioning that they had a younger member of staff who had started the job just weeks before the pandemic began and had no experience of seeing death:

> The amount of residents that we lost, there's always one that'll stick in my mind because it was traumatising, and that's the girl I worked with who had never witnessed a death before. She'd never even done care before. Oh, it was awful. [. . .]. P001

One interviewee had received counselling after dealing with a significant number of deaths in a matter of weeks; others explained that they were still coming to terms with feeling helpless and not being able to prevent the deaths as Participant 013 echoed here:

> People's lives were lost and there was nothing we could do about it. I still have nightmares to this day. There's one that's a recurrent one where I come into work, and all the residents are there that died. I see them all sat there, and they turn around and say 'you let us die', and I know I didn't let them die, but that's how it feels that we didn't get the help. We didn't get the help to help these residents and all we could do was just sit there with them while they died. P013

Participant 021 described how they were 'left', which further contributed to the challenges of providing appropriate end-of-life care:

> There was no support for us at all, there was nothing for any of the staff or certainly the people managing the situation. We were completely and utterly left on our own to it P021

Overall, however, there was a lack of formal support for those who had provided end-of-life care during the pandemic, both in an emotional and practical sense.

Discussion

The findings of this paper further expand the current knowledge base on the impact the COVID-19 pandemic had on providing end-of-life care in LTCFs, identifying four core themes that centre around: discrepancies following COVID-19 restrictions across LTCFs; the influence of staffing on the delivery of end-of-life care; the role of technology at end of life; and the emotional impact of delivering end-of-life care during the pandemic amongst care staff.

The themes identified align with previous research indicating that service provision varied considerably across LTCFs, directly affecting staff capacity to deliver end-of-life care.[3] Staff shortages led some facilities to depend on agency workers and/or newly recruited, often inexperienced personnel, exacerbating the workload of existing staff. Broader health services were perceived as failing to support LTCFs in providing appropriate end-of-life care, and instances of poor practice were observed – most notably, the use of blanket advance care planning orders, which had been flagged as a concern early in the pandemic.[24] Staff working in LTCFs during this time also reported challenges in accessing essential healthcare resources such as oxygen and PPE, further hindering their ability to deliver adequate care. At times, reduced engagement with external health services during the pandemic increased the burden on LTCF staff, who were required to take on expanded responsibilities in providing end-of-life care. Notably, the ability of staff to promptly and confidently recognise when a resident was nearing death emerged as critical, particularly for enabling timely decisions around visitation. This was especially pertinent for residents with COVID-19, whose symptoms were often atypical and whose condition could deteriorate rapidly compared to those without the virus.

Each LTCF differed in the way staff implemented the COVID-19 government guidelines; consistent with previous surveys, the majority of LTCFs allowed visitation as an exception at end of life, consequently breaching public guidance.[10] The current research expands on this knowledge, demonstrating that this occurred in LTCFs with suitable building infrastructures which supported 'safe visiting', for example, where rooms were able to be accessed via fire escapes. The management of other LTCFs did not make any exceptions, meaning that residents died alone, which staff reported as emotionally challenging, with conflicted feelings about their role within this approach. Expanding on this, staff further reported that relatives of residents found it difficult to see LTCFs implement different approaches to visitation at end of life, highlighting issues around equity.

The findings also demonstrate the importance of technology for end-of-life residents during the pandemic. Some LTCFs substituted all visits with digital technology, and although staff explained how technology was less preferable to having a physical presence for dying residents, it was generally considered to be better than having no communication at all with loved ones before death. The adverse emotional impact of providing end-of-life care under COVID-19 restrictions was apparent across all staff members including long-term trauma due to experiencing feelings of helplessness. Supportive of previous research, staff were either not offered or could not access adequate emotional support.[25] Some staff mentioned that a lack of formal support, both emotional and practical, made it more challenging to deliver appropriate end-of-life care. This heightened responsibility was particularly felt by managers who had emotionally vulnerable staff increasingly relying on them for emotional support. Previous research found that LTCF managers in the United Kingdom reported experiencing the highest levels of stress and anxiety during the pandemic compared to other European countries, increased responsibility, and an overwhelming workload while dealing with a high number of resident deaths may be a potential contribution.[26]

There are several implications of these findings, the majority of which in some form reflect changes that would benefit from being priority areas to address before the next pandemic. First, the findings highlight the importance of having clear and consistent guidance on how LTCFs should operate during a pandemic, particularly addressing the delivery of end-of-life care. Much of the responsibility during the COVID-19 pandemic lay with the individual LTCF managers, meaning that the implementation of guidance varied significantly, unintentionally creating inequities amongst residents, staff, and relatives. Within this guidance, the potential emotional impact of implementation must be considered, emphasising the need for stakeholder involvement at all stages of policy development. In addition, any policy developed should be applicable in the context of end of life or have in built flexibility in its implementation when a resident is approaching end of life. These 'caveats' should be included within all aspects of protecting adult social care, including infection prevention and control measures, testing, and visitation restrictions.

Second, there is a clear need for LTCF staff to be trained on end-of-life care, with a specific focus on identifying end of life in older adults. It is vital that LTCF staff can deliver appropriate end-of-life care, meaning that all staff should receive some form of training on how best to provide end-of-life care, including in the context of when resources such as staffing or access to wider health services are limited. Training could also include clear guidance on what the responsibilities of LTCF staff are, and where these responsibilities end, specifically in terms of the legalities of advance care planning. Staff time is often a barrier to undertaking training; therefore, it is vital that LTCF staff are consulted in the development of education resources and that any training is co-designed to increase the feasibility of implementing training within an LTCF.[27]

Third, it is important that LTCFs encourage residents to create informed advance care plans so that their wishes and goals of care, in the event of another pandemic, can be met. The importance of advance care planning has been highlighted in previous research and may help to avoid unethical and inappropriate blanket policies, as discussed in this paper.[28] There is also further potential for strategies and approaches that target and track advance care planning discussions for residents who may potentially be at a greater risk of contracting COVID-19, which have yet to be fully explored in England.[29] The experiences of the COVID-19 pandemic also highlight the potential for discussing what to expect at end of life with residents and relatives, and how this could be handled by LTCF staff, including if there were visitation restrictions in place, or if the resident deteriorated unexpectedly or at speed. Initiatives to support LTCF staff in communicating likely trajectories of decline at admission could support this.[30]

Finally, there is an urgent need for emotional support for LTCF staff who continue to provide end-of-life care for residents. Long-term and unprocessed trauma was common amongst interviewees, with many stating that numerous colleagues had left the care sector completely either during or after the pandemic. The sector is characterised by a low-paid and often under-recognised workforce who deliver care to individuals with multiple and complex needs; yet the emotional demands of this work are too often forgotten.[31] It is recommended that care staff are offered appropriate emotional and bereavement support in order to process their experiences during the COVID-19 pandemic, and to build resilience and coping skills in the event of another pandemic.

Strengths and limitations

This research is one of the first qualitative studies to be completed in LTCFs in England which considers the full timeline of COVID-19 restrictions implemented by the UK government, and its impact on the delivery of end-of-life care. In addition, data were collected in the context of interviews discussing wider policy recommendations, allowing the relative importance of how different policies during the pandemic to be directed and discussed by interview participants.

This study has several limitations related to the identification and recruitment of the participant sample. First, the study did not include LTCFs that are no longer operational, which may affect the applicability of the findings to current settings. Second, the research was conducted within a single geographic region in England, potentially limiting the generalisability of the results to other areas. Third, participation was restricted to individuals who could communicate in English, which may have excluded valuable perspectives from non-English speaking staff. The authors were also not able to interview individuals who resigned during the pandemic about their experiences of providing end-of-life care, meaning that the views of those who potentially left the long-term care sector are not reflected in the findings. Finally, the use of convenience sampling to recruit LTCFs may have resulted in facilities who were willing to share their experiences taking part, with the experience of less willing facilities absent from these findings. All LTCFs that took part were most recently rated ‘good’ or ‘outstanding’ by the CQC, limiting the conclusions which can be drawn. Participants were initially identified and approached by the facility manager; therefore, it is unclear how many participants refused to participate.

An additional limitation of this study relates to the origin of the data. In the initial research, participants were invited to share their experiences of working in a facility during the COVID-19 pandemic, with a focus on reflecting on key policies implemented during that time. One area of reflection was end-of-life care, which formed the basis of the data analysed in this paper. While this open-ended approach allowed participants to highlight the experiences most meaningful to them, it may have limited the depth of insight into any single aspect of COVID-19 policy. The data also did not capture the level of staff knowledge or practices related to end-of-life care within each facility prior to the pandemic at a baseline; however, the extent to which this devalues the experiences shared by staff members is limited.

Conclusion

These findings have further explored how the COVID-19 pandemic impacted the delivery of end-of-life care by LTCF staff in England. LTCF staff were required to provide end-of-life care within the context of visitation restrictions, staff shortages, and limited guidance. There are clear recommendations on how end of life could be managed better in future pandemics; however, many of these require further training, investment, and support to be put in place now, in advance of its need. The emotional trauma staff endured during the pandemic while delivering end-of-life care is clear. In the future, it is imperative that research explores how best to support care workers, while amplifying the voices of adult social care workers is central to developing effective national responses to pandemics.

Acknowledgements

The authors would like to acknowledge and thank the Enabling Research in Care Homes Network for supporting the recruitment for the study from which these data were collected. The authors would also like to thank the LTCFs and staff members who took part in this research for their valued contribution.

ORCID iDs

Natalie Cotterell https://orcid.org/0009-0009-5434-4718
Danni Collingridge Moore https://orcid.org/0000-0002-5861-8706

Ethical considerations

Research Ethics Committee approval was obtained from the Lancaster University Faculty of Health and Medicine Research Ethics Committee (reference: FHM-2023-3368-RECR-3).

Consent to participate

Written informed consent was provided by the LTCF manager and the interview participants.

Consent for publication

Written informed consent was collected from both the manager of the LTCFs recruited to the study and the LTCF staff member participating in the interview. Written informed consent included the publication of quotes in subsequent publications and reports.

Author contributions

Natalie Cotterell: Data curation; Formal analysis; Writing – original draft; Writing – review & editing.
Danni Collingridge Moore: Conceptualisation; Data curation; Formal analysis; Funding acquisition; Supervision.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The research was funded by the Dowager Countess Eleanor Peel Trust, as part of the Sir Robert Boyd Fellowship. The views expressed are those of the authors and not necessarily those of the Dowager Countess Eleanor Peel Trust.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Data availability statement

Data are available from the authors upon reasonable request.

Supplemental material

Supplemental material for this article is available online.

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