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Living in a care home during COVID-19: A case study of one person living with dementia

Abstract

Purpose – The paper aims to understand the lived experience of a person living with dementia in a care home during the COVID-19 pandemic. It responds to the absence in research of the voices of people with dementia living in care homes during the pandemic.

Design/methodology/approach – The paper adopts a single case study design applied thematic analysis to semi-structured interview data to discover the experiences of one person living with dementia in a care home during a period of lockdown.

Findings – Five themes reveal how the participant responded to the practical and emotional challenges of the pandemic: (1) autonomy; (2) fears; (3) keeping connected; (4) keeping safe and (5) other people living with dementia. These themes highlight the participant's ability to adapt, accept and dispute lockdown restrictions, revealing considerable insight into their situation.

Research limitations/implications – The pandemic has restricted access to care homes, which informed the single case study design. This approach to the research may restrict the generalisability of the findings. Other researchers are encouraged to include the voices of people with dementia living in care homes in further studies.

Practical implications – Implications for practice, presented in this paper, promote quality psychosocial approaches when healthcare workers engage with people living with dementia during periods of restricted activity.

Originality/value – Unlike other studies about the impact of the pandemic on care homes, this paper explores the experience of the pandemic in care homes from the perspective of a person living with dementia.

Keywords: Dementia, Lived experience, COVID-19, Care homes, Case Study, Thematic Analysis

Article Type: Research paper

Background

Lockdown and social distancing measures during the COVID-19 crisis apply to all members of the UK population. Older people living in care homes may experience isolation if they are unable to maintain contact with family members (Zamir et al., 2018) whilst embargos on visitors have reduced the availability of activities for care home residents leading to further isolation (Wang et al., 2020). Organisations in the UK, including John's Campaign, Dementia UK and the Alzheimer's Society have united as 'One Dementia Voice', to advocate the recognition of family caregivers as key workers, to access safe regular COVID-19 testing and allow care home visits (Alzheimer's Society, 2020).

The general population of older people is at greater risk of contracting the virus, compared to their younger counterparts, with 80% of people with severe symptoms over the age of 50 (Intensive Care National Audit and Research Centre, 2020). Mortality figures in UK hospitals also confirm the greater risk to the older population, with 89% of deaths related to COVID-19 attributed to people in these older age ranges. This figure is consistent with data from the European Union, with 86% of hospital based, COVID-19 related deaths being reported in older populations. There is also evidence of greater mortality in people with comorbidities including hypertension, diabetes, chronic respiratory disease and cardiovascular health issues (Jordan, Adab & Cheng, 2020). In care homes, where large numbers of people living with dementia reside, the risk is amplified further as physical comorbidities are often the catalyst for placement in these environments (Toot et al., 2017).

Guidelines and recommendations to inform the delivery of services in care homes have been produced in response to the current crisis nationally (British Geriatrics Society, 2020; Public Health England, 2020) and internationally (Alzheimer's Disease International, 2020; Alzheimer Europe, 2020). The response to the COVID-19 crisis recognises that the operation

of care homes has altered, with care workers adjusting to new working practices in an attempt to balance the adverse effects of isolation whilst striving to reduce the risk to exposure /infection. Narratives in the UK have understandably focused on the high proportion of deaths (Oliver, 2020) or the dangerous lack of available personal protective equipment in care home settings (Lacobucci, 2020).

The efforts of caregivers to protect this population against COVID-19 is regarded as potentially curbed as people with dementia are positioned as unable to understand personal protection information and are therefore, unable to comply with lockdown regulations (Brown et al., 2020; Velayudhan, Aarsland & Ballard, 2020). Equally, there are concerns that people living with dementia in care homes are frightened by caregivers who wear personal protection equipment (Velayudhan, Aarsland & Ballard, 2020) and therefore, may withdraw from care interventions or from the limited social interactions, provided by these staff members.

Listening to care home residents with dementia

The voices of people living with dementia in these care settings are noticeably absent during the COVID-19 crisis. It should not be assumed that all people with dementia living in care homes lack insight into the current need for quarantine or the capacity to regulate their behaviour in response to the guidelines. Although narratives of people living with dementia in care homes are included in research, (Nwe Winn Thein, D'Souza & Sheehan, 2011; Goodman et al., 2013; Tak et al., 2015; Mjørud et al., 2017), these narratives are scarce, considering the sizeable population of this societal group. People living with dementia in care homes should be encouraged to share their experiences of living with and adjusting to social distancing measures and their reaction to the threat of COVID-19.

Methods

Study design

The study adopts a qualitative single-case study approach (Yin, 1998). The person represents a critical case study, who was identified through purposive sampling, informed by their position as a person living with dementia, their residence in a care home setting with other people living with dementia and their capacity to understand and consent to the study (Farrugia, 2019). A single case study was chosen as the pandemic negated the opportunities to identify further participants in care homes due to visiting restrictions and the importance of sharing this narrative in a timely manner. The authors are active dementia researchers and educators, with backgrounds in nursing and clinical psychology.

The participant

The case study is built on the experiences of one female (pseudonym used - Patti) living in a residential care home for people living with dementia in Wales, UK. Patti was 71 years of age and diagnosed with fronto-temporal dementia. Whilst many people living with dementia move into care homes when their needs can no longer be met at home, Patti had moved into the residential care home 18 months before the interview initially for respite when her husband was ill and remained there as a permanent resident following the death of her husband. Her continued acknowledgement of this decision reflected her mild dementia symptoms at the time of the interview. The interviewer was familiar with Patti who had acted as a speaker for a dementia education programme, led by the authors. The participant had previously agreed to share her experience of living in a care home prior to the lockdown and was therefore, already in contact with the researchers.

Ethical approval

Ethical approval for the study was granted by the University Health and Medical Sciences Academic Ethics Committee. Patti stated she did not wish to receive written information and preferred to discuss the study verbally. A full verbal description of the study was provided with opportunity to ask questions. The interviewer assessed Patti's capacity through her understanding of the study prior to the interview and she was able to provide valid and informed consent.

Data collection

The interview was conducted using a semi-structured design. Eighteen questions were developed from the pandemic literature, concerning isolation, resilience, well-being and threat. The semi-structured approach was adopted to allow the interview to move away from any potential bias within the questions, to support Patti to describe her own experiences and perspectives without thematic confines. This approach to the interview granted in-depth access to experiences and feelings, acknowledging sensitive issues which could be addressed through follow-up comments and questions (DeJonckheere & Vaughn, 2019). The interview was offered using video call software but based on the preference of Patti was conducted over the telephone (14/7/20) with the interview taking place over 59 minutes. An additional device was attached to the interviewer's telephone to record Patti providing verbal consent and the details of the interview.

Data analysis

The interview was transcribed verbatim and then uploaded to the qualitative data analysis software, ATLAS.ti (ATLAS.ti Version 8 Software, 2020).

Transcription codes were included to highlight areas of emphasis within the interview. The final transcript included 29 pages of complex discourse, which was profoundly personal,

covering Patti's responses to the formally developed questions in the interview set and her open, informal experiences and feelings.

The interview team listened to the interview recording and read through the transcript several times. Thematic analysis was used to enable an in-depth exploration of the narrative, reporting on the more nuanced elements of the data, whilst also allowing the descriptive honesty of the personal narrative to be presented, unencumbered by analytical manipulation (Braun & Clarke, 2006, 2014).

The three authors independently reflected on the data and proposed potential themes, which were used by the lead author to evaluate the formal coding and analysis. Interview data and coding was discussed between the authors through an on-going dialogue using email and on-line meetings. Codes were narrowed into 34 areas, which were subject to thematic analysis, revealing 5 distinct and repeating themes concerning the experience and feelings of living in a care home during the COVID 19 pandemic: (1) autonomy (2) fears (3) keeping connected (4) keeping safe and (5) other people living with dementia. These themes will now be presented in detail.

Findings

Autonomy

Patti reported that whilst she accepted a loss of self-governance initiated by the introduction of lockdown measures, a lack of certainty regarding the long-term situation inspired her to have thoughts of taking greater control of her destiny. She suggested that her position as a care home resident meant that she lacked the privileges of other members of society who could risk contracting the infection through potentially unsafe actions such as visiting family members or having family members visit her:

I mean we, we haven't been able to decide whether we want to risk going to see our families, we're just forbidden to go out.

Patti's determination to retain governance over her future also led her to consider whether she could leave the home:

I even went through a little stage where I was thinking, is there another way to live where I don't have to come back in.

Whilst Patti preferred to determine her own behaviour against lockdown restrictions, her recognition of her own requirements for 24 hour support outweighed her desire for greater autonomy. The rationale that leaving the care home would cause an imposition on her children's life also illustrated her self-governance, informed by her enduring personal insight.

The threat of a continuing lockdown found Patti contemplating her only, allowed, avenues of leaving the home, which she identified as deterioration or death. Whilst Patti identified these as the likely causes of leaving the home even before the pandemic, the perception of her current life in the home, lacking stimulation and familial contact, suggested that people were not living a fulfilled life, but only waiting for one of the options to occur. For Patti, this was unacceptable:

..we're here until, unless we go worse and we go in a home, a, a nursing home, we're here until death" and I, I said "One way or the other, are we going to be deprived living until we die".

Patti was still able to find ways to promote her autonomy and decision-making. During the onset of the lockdown, a prescription of medication was offered to Patti to treat anxiety caused by the new restrictions. Patti argued that her anxiety was not physiological, but social and environmental. The acceptance of Patti's self-determination was regarded as a victory: *we got that one sorted out. We fought that one.*

Fears

Although Patti described the continued updates on the virus as interesting, she also shared her concerns about what would happen if the pandemic reached the home. Patti considered the arrival of the virus as a threat to all residents at the home, acknowledging that their age and underlying health needs heightened their vulnerability. Patti spoke positively about how care staff had reduced the possibility of the virus entering the home but also shared her anxiety that one person's actions could cause the death of many residents:

I suppose just the fact that it could just go right through the place, and everybody could drop like flies...you don't really expect to come through the other side of Covid.

Patti did not dwell upon the fear of death, with the potential threat of a continued lockdown and the effect on her social and spiritual opportunities representing a greater fear. She reported a difficulty in finding a local church, which met her spiritual needs, prior to lockdown and feared that finding a suitable location for worship may never happen. Patti had joined a virtual choir group but found it stressful as it bore little resemblance to the previous face-to-face activity.

Patti described the barriers to her family as the social restrictions most keenly felt. Whilst, Patti was still able to have some contact with family members, the risk of continued restrictions prompted fears of losing typical familial interactions and events during the summer:

..to think that winter's coming on, so I thought, "Am I going to be able to go out this summer at all?". "Can I go and sit in my daughter's garden and be looked after?"

The twin fears of lockdown and the risks associated with COVID-19, were borne through Patti's understanding of daily news updates regarding the virus, indicating her ongoing rationality to conform her beliefs, and her fears, through empirical evidence.

Keeping connected

Although there had been occasions since the lockdown that she had physically met family members (sitting with one family member in the courtyard) she described the lack of close contact as the most damaging aspect of lockdown on her overall quality of life. Prior to the pandemic, Patti had never attempted to use video technology and was reluctant to use this means of communication, but now celebrated the opportunity to see, as well as speak to, her family. Patti reported that staff at the care home recognised the value of this technology and actively supported the residents who lacked the ability to make these calls independently.

Patti also discussed the absence of friends who she was unable to see due to their own need to isolate and their inability to use the technology. Similarly, Patti expressed frustration at the mail service, as staff would inform her that she had received mail but would have to wait another three days to receive it, due to quarantine measures.

A further aspect of the theme was a continued effort to remain connected to the wider world. Patti reported that she had attempted to watch all the daily bulletins regarding the government's response to the pandemic. Keeping connected with the ongoing situation also granted her with knowledge, which often people outside the care home did not appear privy to:

I've even phoned the children and told them new things that they didn't know, because they weren't watching the news.

Patti did express frustration that her connection to the pandemic response was based on her observations of the English response on national television news. The Welsh Assembly leads health in Wales, whilst the UK Parliament informs England's health services. This has resulted in differences regarding how Wales and England have responded to the pandemic.

Patti was frustrated that the Welsh government updates were inaccessible to her, as they clashed with lunchtime at the care home.

Keeping safe

Patti reported that there had been no cases of the virus in the home and praised the staff for their preventative actions. She also considered that the lack of restrictions on resident's behaviour (*there hasn't been any, any discouragement to, erm, to wander*) indicated how staff had tried to support the continuation of daily activities in the home:

The staff have been marvellous, and we've also had very great care and the staff have been extremely careful.....to make sure that we're safe.

Patti also described her own vigilance regarding potential threats including challenging the status and purpose of a visitor. The person revealed that they were a visiting doctor but the incident provided proof for Patti of the requirement to challenge any unusual activity and not rely entirely on care staff alone to protect her from the virus. Whilst no residents were allowed out of the building, a number of people (including care staff, health and social professionals) continued to access the building. Patti recognised the requirement for residents to access these services but felt that her ability to maintain her own safety was compromised by the actions of these professionals:

..just what bothers me is the fact that if somebody brings it in, we've got no choice as to whether we want to risk it or not, have we? It's not our choice then is it? If I choose to go out, but I know that if I chose to go out, I wouldn't be able to come back in.

Whilst Patti felt protected by care staff from the virus, she also discerned that a degree of secrecy was present in the care home staff's communications with her. Patti adjudged information relating to the care home's response to the pandemic as her business and that she should have access to any decision making process.

Other people living with dementia

Patti reported that her relationship with other residents had not altered although the behaviour of some residents was more difficult to accept due to the risks presented by the virus:

I don't like people coming in my room, especially when they're at the stage where they, they're fiddling and messing with everything and I certainly don't like that since Covid.

Patti had observed residents asking to vacate the building with the refusal to open the door explained as a consequence of lockdown by staff. Patti considered that the behaviour of the residents was not driven by the current restrictions but was a continuation of their previous behaviour. Patti reported changes in the demeanour of residents, who were more agitated and paranoid particularly at meal times. She considered the change to be directly related to people in the communal areas spending hours in each other's company.

Patti described the requirement to repeatedly explain the pandemic as *wearing*, with many residents unable to retain the information. Nevertheless, Patti advocated for the need to keep residents informed about the pandemic and to not make assumptions that residents cannot understand what is happening. When challenging the visiting doctor, Patti considered the doctor's absence of an introduction was symptomatic of a general belief that it is not necessary to explain anything to care home residents with dementia as they will not understand:

They might get all confused but in their brain they still understand a lot and should be told.

Whilst Patti felt that her own ability to retain and consider information was greater than many other residents, she had observed how the underlying beliefs of others could be potentially disempowering for herself and other residents.

Discussion

In this article, we sought to address the absence of the voices of people living with dementia in care homes during the COVID-19 pandemic in the literature. This case study suggests that the concerns of a person living with dementia with continuing insight are commensurate with current public health events but also reveal the practical and emotional challenges during lockdown in a care setting with other residents living with dementia. The inclusion of people living with dementia in decisions about how care homes achieve lockdown could be particularly consequential for the well-being of residents who express insight into the home's pandemic response. These findings are supported by telephone interviews with cognitively impaired older adults living alone, which illustrated that people may understand the need to take precautions (e.g. wearing a mask) even if they do not fully understand the situation (Portacolone et al., 2021).

Patti's experience of being offered medication to reduce anxiety suggested her reaction to the restrictions was potentially abnormal and required chemical intervention. Patti's insight allowed her to decline the medication as incommensurable with the social and environmental causes of her anxiety. This discourse illustrated that care staff accepted Patti's capacity to make decisions regarding her own care and treatment although Patti felt excluded in decisions made about the care home's overall pandemic response.

The impact of continued uncertainty was evident in Patti's experience with visiting relatives. Patti described relatives who had to stand outside when one member of their household was allowed to visit inside the home, which appeared to be inconsistent with the guidance at the time. Equally, families of people living in care homes may be frustrated by the uncertainty regarding care home visiting guidelines, particularly as there exists a lack of consistency between care providers and across different areas of the UK.

The behaviours of residents observed by Patti were consistent with their pre-lockdown behaviour and whilst the behaviour would typically lead to the same practical conclusion the reasons provided for these decisions were now attributed to the lockdown restrictions. The use of deception or therapeutic lying is an established intervention for caregivers working with people with dementia to promote their best interests (Culley et al., 2013; Seaman & Stone, 2017). Staff employ therapeutic lying when the person may attempt a behaviour, which results in potential risks to health or well-being. The pandemic has provided explanations to dissuade people living with dementia to engage in certain behaviours without the requirement of a therapeutic lie. Truth telling has been suggested as a mechanism to maintain greater autonomy in people living with dementia, as lying disrespects the person's self-determination and governance (Tuckett, 2012). However, as the behavioural outcome is unchanged, the verbal explanation may have a limited impact on the person themselves, although care staff may feel less conflicted as they are not required to consider the ethical dilemmas of deception.

In *Autonomy* Patti discarded the idea of leaving the home due to the potential burden this could cause her children. Correlates between family members experiences of burden and having a dependent relative with dementia have been the subject of historical and more recent research (Samuelsson et al., 2001; Lilly et al., 2012; Abreu et al., 2020; Krutter et al., 2020). The perception of burden from the perspective of the person with dementia is generally absent from the literature although similarities can be observed between Patti and older people in Cahill et al's (2009) study who also expressed a reluctance to burden their family members. The empathy exhibited by Patti is inconsistent with studies into the phenomenon and people with frontotemporal dementia (Lough et al., 2006; Eslinger et al., 2011), although Patti's continued empathy is also indicative of the mild stage of dementia she was experiencing at the time of the interview.

The theme of *Fears* represented the vulnerabilities perceived by Patti regarding the physical effects of the virus and ongoing social restrictions. The fear of the virus is commensurate with the statistics concerning the susceptibility of people with dementia within care homes to COVID-19. However, descriptions of care homes as chaotic, where simply surviving could be sometimes regarded as a success (Cowan, 2020) are not reflected in Patti's overall experience of her care home.

Social restrictions included an inability to attend to her religious needs in a church setting. Religion may play a vital role in the identity of the person and will often be a source of comfort during periods of crisis (Bentzen, 2020). Whilst suggestions have been published to protect religious practices for older adults during the pandemic (Dein et al., 2020), the impact of these suggestions on care home practices has not been investigated. Older adults with cognitive impairment have previously identified religion and religious services as coping strategies during the pandemic and have spoken positively about online provision (Portacolone et al., 2021). However, this study suggests virtual activities may not be as beneficial to the mental health of some participants compared to physically attending a service.

Some residents using video call technology required more assistance than others. This is consistent with previous suggestions that residents can benefit from video call applications but will have various support needs and responses to the technology based on prior experience (Siette, Wuthrich & Low, 2020). Patti's positivity regarding the technology is reflected in previous research where a person living with dementia in a care home during the pandemic was observed to experience less anxiety and agitation following video calls with their daughter (Padala, Jendro & Orr, 2020).

The care home had not experienced any cases of the virus and Patti shared her belief that staff were instrumental in maintaining the safety of residents. The theme of keeping safe encapsulated Patti's own efforts to maintain safety as well as the efforts of staff. Patti's continued belief in her own power to maintain a degree of safety is inconsistent with the voices of people living in care homes in Chee's (2020) qualitative study, where older people described feeling powerless and unable to protect themselves from the risks of Covid-19.

Across the five themes, Patti had adapted to lockdown restrictions despite her frustration with the lack of certainty about the future. The case study suggests that a person living with dementia can retain an ability to resiliently adapt to their current situation, even in a global health crisis.

Implications for practice

Care homes must ensure that residents are involved in decisions about their residence, with the offer of inclusion matching the insight, ability and interest of the individual. Whilst some aspects remained such as, declining medication, the exclusion from other decisions for example, having information about lockdown responses withheld created a sense of disempowerment and considerations to leave the home. Patti should have been empowered to follow a person-centred routine, providing her with the opportunity to watch the Welsh national news and have her lunch at a suitable time.

Whilst the COVID-19 virus is a source of anxiety, everyday fears tend to be driven by the psychosocial losses caused by restrictions. The loss of religious support may be a cause of increased anxiety and care staff should support any practical rituals, which may negate these losses whilst physical attendance at places of worship is not possible. Whilst Patti's rejection of the virtual choir may not reflect the experience of all people using virtual tools to engage

with community activities, care staff should be aware that residents denied their usual rituals might experience discomfort through their absence.

The value of video calling was emphasised by Patti's ability to adapt and use the technology. Whilst research about the use of video call technology in care homes with people living with dementia is in its infancy, the observations shared by Patti would support previous recommendations for innovations and improvements to make video call technology easier to use for older adults (Chu, Donato-Woodger & Dainton, 2020).

Patti was complimentary regarding the actions of staff to keep the residents safe and instigated her own checks on visitors who had not explained their presence in the home. This feeling of safety was crucial to Patti's feelings of well-being and care staff should ensure that they endeavour to ask residents about their feelings of safety, rather than assume that safety measures alone would fulfil this need.

Patti described incidents of increased agitation due to residents living together without respite. Health providers should be vigilant that changes in behaviour in people living with dementia are investigated thoroughly to prevent any unnecessary medical interventions or relocations from the facility due to social, psychological or environmental causes.

Strengths and limitations

The semi-structured interview was a strength of the study. We wanted to capture the unique experience of Patti and providing open-ended questions promotes responses, which reflect a genuine human narrative through their ambiguity and complexity (Thomson et al., 2020).

Using data from one interview with one participant limits the generalisability of the study.

Whilst this lack of generalisability could be regarded as a limitation of the study, Patti's unique voice is integral to our understanding of her experience during the pandemic and it is

not the authors' intention to suggest that this represents the experience of all people with dementia living in a care home.

Suggestions for future research

Collecting additional narratives of people living with dementia in care homes would begin to address the absence of this population's voices in the current literature. This work should be addressed as a matter of urgency if we are to understand the actual lived experience of a global pandemic in care home settings.

Conclusion

In this article, the unique experiences of one person living in a care home with dementia were presented. As the first attempt to thematically capture the care home experience of the pandemic for people with dementia, it should be of interest to people working in the care home sector and could be used as a foundation for further studies relating to this subject area. This case study indicates that a person living with dementia in a care home may still retain a high level of insight into restrictions related to the COVID-19 pandemic and care providers should promote their inclusion in decision making activities regarding care home adaptations in response to the pandemic.

Whilst we hope this article encourages discussion within research and practice fields regarding the importance of hearing these voices, we also hope that this study does not remain an isolated narrative.

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