

# Exploring the Challenges Faced by Health Care Professionals Working with People Living with Dementia Amid COVID-19 Pandemic in the English West Midlands Region



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RESEARCH

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## ABSTRACT

**Context:** The challenges faced by health care professionals working with people living with dementia amid the COVID-19 pandemic in the English West Midlands region.

**Objective:** This study explored the challenges faced by health care professionals working with people living with dementia amid the COVID-19 pandemic.

**Methods:** This study utilised an in-depth qualitative study guided by a phenomenological approach. The participants included 30 ( $n = 30$ ) health and social care professionals who were working in care homes with people living with dementia. In-depth interviews were used to collect data through online platforms, including Zoom, WhatsApp, and Microsoft Teams. A thematic approach was used to analyse the data.

**Findings:** The study found that challenges such as enforcing social distancing, communication, increased anxiety and restlessness, safeguarding dilemmas, safe staffing, and emotional labour affected health care professionals during the COVID-19 pandemic.

**Limitations:** This research was only carried out in the Midlands. Research encompassing other regions in the UK will be ideal to enable comparisons of different regions.

**Implications for practice:** In the future, there is a need to monitor all admissions coming into the care home to make sure that they are not infected by the virus, as this will safeguard vulnerable residents in the care home. Also, the provision of adequate staffing in dementia care homes to manage and enforce all safeguarding protocols and regulations to make sure that the vulnerable people they look after are adequately protected is crucial in the future. Support and guidance that is relevant to people living with dementia should be made available, especially during a pandemic.

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## INTRODUCTION

COVID-19 has claimed a substantial number of lives since its outbreak in China in December 2019 (Lin et al., 2020). On 30 January 2020, the World Health Organization (WHO) declared the novel virus outbreak of COVID-19 to be a public health emergency of international concern that posed a high risk to countries with vulnerable health systems (Ekpenyong et al., 2020; Sohrabi et al., 2020). More than 5,907,177 cases had been reported across the six continents of the world at the time of writing this article (Hanley et al., 2020). The WHO probably reflects only a fraction of the actual number of infections, as most countries only conduct tests on people with serious symptoms (Mizumoto et al., 2020). Prior to the COVID-19 pandemic, the care of people living with dementia has not been easy. COVID-19 has posed more challenges to health and social care professionals working with people living with dementia, especially when trying to prevent the infection from spreading. As of 29 May 2020, a total of 272,826 tests for COVID-19 had been conducted across the UK (Datta, 2020).

Caring itself poses many challenges for families, but providing care for someone with dementia can be especially difficult. Dementia is one of the major public health challenges of the 21st century (Giebel et al., 2021). Czapka and Sagbakken (2020) noted that dementia affects mental processes, behaviour, and the ability to perform everyday tasks. Further, a Pinquart and Sorensen (2003) study found differences between carers and non-carers and concluded that caring for people with dementia is associated with a higher stress level than caring for people with physical impairments. The challenges of dementia, according to Czapka and Sagbakken (2020), are often assumed to be so heavy that carers are often referred to as 'the invisible second patients'.

The COVID-19 outbreak had a huge impact on everyone, particularly on people living with dementia and their carers. The outbreak of COVID-19 caused additional challenges for nurses and health and social care workers caring for people living with dementia and for them as individuals, thereby making daily life much harder (Mohammed, 2017). COVID-19 seems to have amplified difficulties for people living with dementia to access and utilise vital care and generally live well with the condition (Giebel et al., 2022). People living with dementia have difficulty with keeping accurate information regarding COVID-19 social distancing and self-quarantine measures and, as such, are in more danger and are exposed to higher chances of contracting the virus (Wang et al., 2020). Furthermore, people living with dementia can find it difficult to understand what is happening regarding the pandemic. The inability of some people living with dementia to keep accurate information provided makes

it a challenge for their carers when trying to help them in exercising social distancing (Hung & Chaudhury, 2011).

Evidence shows that two-thirds of people living with dementia live within the community, whilst the rest tend to reside in care homes (Thambidurai, 2012). Care home residents with dementia are reported to make up around 70% of the care home population (Turner, 2020). A critical challenge at this point is that people living with dementia often do not seek help because they may not realise they need it or they may forget what help and measures are available, especially if it is outside the usual range of support (Rochford-Brennan & Keogh, 2020). The effects of social distancing and self-quarantine measures on people living with dementia and their caregivers have huge implications on their mental, physical, psychological, and emotional well-being (Samanyika, 2015).

Backhouse et al. (2021) found that care homes were equally affected by the pandemic in several ways, such as care homes being shut down in some places for a year for outside visits, apart from occasional window visits between family members and residents, or digital visits via telephone call or Microsoft Teams. Emerging research highlights that along with the disruption to formal dementia services, restrictions have led to a further loss of support from family and friends for people with dementia and family carers (Hughes & Tabet, 2021). According to research, dementia was one of the most common comorbidities (11.9%) recorded among COVID-19-positive deceased patients (Cipriani & Di Fiorino, 2020). This may be because people living with dementia have little to no ability to keep accurate information and maintain self-isolation. Developing research has suggested how social support services have been closed or operated on a minimum level during the early stages of the pandemic (Giebel et al., 2021).

In light of this, it becomes important to explore the challenges affecting those working in dementia frontline health and social care in the midst of COVID-19 pandemic and deduce implications for professionals by sharing lessons learned through the first-hand experiences of those working in this challenging environment. It is hoped that this study will provide new and useful data that contributes to the emerging evidence about how to handle this type of challenge in the future.

## METHODOLOGY

### RESEARCH DESIGN

This study utilised an explorative qualitative approach (Hjeltnes et al., 2015). An explorative study is usually used to understand the problem rather than provide a conclusive solution to the problem (Pietkiewicz et al., 2014). The research team included experienced qualitative researchers from public health and nursing.

## RECRUITMENT AND PARTICIPANTS

The inclusion criteria for participation were that the professionals were working in care homes catering to people living with dementia. They should have worked in care homes for not less than 12 months, and the care homes should be in the English Midlands region in the UK.

Ethical approval was granted by the Nottingham Trent University ethics committee. The researchers approached managers of care homes with an informational leaflet inviting their workers to take part in the study. Those who were interested in taking part were given detailed information about the study and the role of the participants. Written consent was obtained before the study commenced. Only the details of those participants who had agreed to take part in the research had their names and details passed to the researchers.

## DATA COLLECTION

The in-depth interviews took place over a period of two months. All the interviews were conducted via online platforms, including Zoom, WhatsApp, and Microsoft Teams, at a mutually convenient prearranged time. Only the researchers and the research participants were at the interview. A total of three care homes located in the English West Midlands took part in the study. A semi-structured flexible interview guide was used for the interviews. The research participants were first asked about the work they did in general and the type of people they cared for and the associated challenges during the COVID-19 pandemic. The interview guide included questions on experiences of working with people living with dementia in a pandemic situation like COVID-19, preparations for a pandemic, and the impact of social distancing, including the lockdown, on the care and management of individuals living with dementia.

To ensure the credibility of the data, probing questions, such as 'As you mentioned ...' and 'Let us talk a little more about ...,' were used. The interviews lasted between 45 minutes and one hour, guided by the research participants' desire to talk. The research participants were given time to revisit their experiences and reflect before the interviews and were assured that anything they contributed would be respected and valued. All the interviews were audiorecorded with permission from the research participants. The researchers also took notes during the interviews as a way of recording some critical non-verbal communication pertinent to the study. The final sample size was based on data saturation when no new information was forthcoming.

Data collection for this study was carried out in December 2020.

## ANALYTICAL APPROACH

All the audiorecorded interviews were transcribed verbatim. Each transcript was about 20 pages long

on average and contained rich and informative data. Following the preliminary analysis of the transcripts, the researchers invited the research participants to confirm the data in the transcripts. This was meant to ensure the credibility of the data collected. Following the coding of texts, the data analysis was guided by Pietkiewicz and Smith (2014). The Pietkiewicz and Smith (2014) method was adopted because it offered a clear and systematic approach to provide a concise but comprehensive description of the issues being studied with opportunities for research participant validation (Chan, Fung & Chien, 2013). The initial stage of analysis involved repeated reading of transcripts and extraction of significant statements by the three researchers. Coding was independently done by the three researchers. The initial codes were formed after identifying features such as words and phrases that were relevant to the research aim. Afterwards, we examined coexisting codes and codes with high usage counts to identify emerging patterns, which composed our themes. The emerging themes were reviewed to ensure they were relevant to the research question and objectives. We later defined themes, looked for supporting and conflicting examples, and revised themes as necessary until we agreed that the themes were compelling and unique.

The analysis was done manually. The researchers met regularly to review codes to agree on themes identified and to check for accuracy and consistency. The themes formed the final output of the findings in this study and are supported by extractions from the interview scripts.

## RESULTS

A total of 30 participants were recruited, including nurses ( $n = 15$ ), support workers ( $n = 10$ ), and care managers ( $n = 5$ ). The ages ranged between 20 and 60 years. The average year of working experience with people living with dementia was between 1 to 3 years, and they included managers, nurses, and care and support workers. See [Tables 1](#) for the research participants' profiles.

Our analysis identified six themes: enforcing social distancing, communication, increased anxiety and restlessness, safeguarding dilemmas, safe staffing, and emotional labour. Each theme is described and supported by captions from research participants.

### ENFORCING SOCIAL DISTANCING

Participants reported that it was impossible to maintain social distancing whilst supporting people living with dementia. Their need for personal care and intimate support meant that sometimes two or more staff were working in close proximity.

|  | OCCUPATION |                 |               |                           |
|--|------------|-----------------|---------------|---------------------------|
|  | NURSES     | SUPPORT WORKERS | CARE MANAGERS | TOTAL NO. OF PARTICIPANTS |
| Male   | 6          | 6               | 1             | 13                        |
| Female   | 9          | 4               | 4             | 16                        |
| <b>Totals</b>  | <b>15</b>  | <b>10</b>       | <b>5</b>      | <b>30</b>                 |
| <b>Age</b>   |            |                 |               |                           |
| 20–30 years  | 3          | 3               | 1             | 7                         |
| 31–40 years  | 4          | 1               | 2             | 7                         |
| 41–50 years  | 4          | 4               | 1             | 9                         |
| 51+ years  | 4          | 2               | 1             | 7                         |
| <b>Totals</b>  | <b>15</b>  | <b>10</b>       | <b>5</b>      | <b>30</b>                 |
| <b>Occupations of the participants and years of experience</b> |            |                 |               |                           |
| 1–3 years  | 4          | 2               | 1             | 7                         |
| 4–6 years  | 2          | 4               | 3             | 9                         |
| 7–9 years  | 6          | 2               | 0             | 8                         |
| 10–12 years  | 1          | 2               | 1             | 4                         |
| 13+ years  | 2          | 0               | 0             | 2                         |
| <b>Totals</b>  | <b>15</b>  | <b>10</b>       | <b>5</b>      | <b>30</b>                 |

**Table 1** Participants' characteristics.

You tell me, how do you maintain social distance when you are providing personal care? Sometimes two or three staff are needed for one client.

Social distancing and self-isolation [are] just a joke. The person has dementia. You ask them to stay in their room, but the next thing you know they are in John's room.

I can wear personal protection equipment (PPE), but of what use is it if the resident has been to everybody's room?

## COMMUNICATION

Communication became a challenge, as staff wore PPE, which made it difficult for people living with dementia to recognise faces and understand what was being said, including using body language and touch when communicating.

We have one client who keeps asking who we are when we go in with the PPE masks and all.

We have clients who cannot communicate verbally, but you can tell from their faces, because we know them well, that they are afraid and confused when we are attending to them wearing PPE.

They want to hold hands, hug, and touch because that is what they are used to. It's very difficult for them to understand.

## INCREASED ANXIETY AND RESTLESSNESS

Participants noted that there was an increase in anxiety, restlessness, and low mood amongst the residents. Deterioration in mood and behaviour amongst residents made it difficult for health and social care professionals to support people living with dementia.

Some service users began to create false alarms, repeatedly stating that they had symptoms when they did not.

Our clients already have high levels of anxiety, and this situation has only made it worse.

We do not have the usual entertainment and activities, so people's behaviour is obviously getting worse. ... We like to be person-centred in these things, but it's very difficult right now.

## SAFEGUARDING DILEMMAS

Participants spoke of the dilemmas involved in safeguarding people living with dementia within the parameters of the law, balancing the least restrictive practices with the rights of the individuals.

[T]he unit has been rearranged, and the lounge has been shut off; so they can't go in there. They are already confined, and this makes it worse. But what can we do?

There was a lot of pressure, but we had to refuse to take hospital discharges without testing.

It is so difficult to tell if someone with dementia has COVID-19 symptoms because they might present differently. We need priority testing for all of us in the care homes.

### SAFE STAFFING

Participants reported that there was a shortage of staff brought on by the COVID-19 pandemic. Greater and yet unsustainable staffing levels were required to maintain 1:1 support for people living with dementia. Additional staff was also needed to support those who had additional physical needs arising from accidents and staff sickness absences.

Residents with dementia who tested positive have no ability to self-isolate. They needed 1:1 support, so it's impossible to properly self-isolate.

Because of dementia, some can easily fall. When an elderly person falls, they have to go to hospital, and there's more danger of exposure to COVID-19. So we isolate them, and this needs 1:1.

We lost a lot of staff. We had staff who were off sick with symptoms, others were shielding, and one was pregnant and opted to stay off work without pay due to the anxiety and fear.

### EMOTIONAL LABOUR

Participants described feeling drained by the amount of emotional labour involved in reassuring residents, relatives, and other professionals who were getting in touch at all times of the day by telephone, as they could not visit the care home. They also experienced worry and distress about the pandemic but continued to undertake their duties regardless of the emotional toll on them.

Some families have provided their loved ones in the home with phones and tablets to stay in touch. They are calling daily, nonstop, for updates. We have to reassure them all no matter what. At the end of the day, you are just drained.

I worry about what will happen after the pandemic when relatives go back to normal and not keeping in touch daily. We will be left picking up the pieces. It's our job, but it's heart-breaking.

For some, close relationships with family or spouses have been eroded by social shielding. Now we are trying to reassure the residents and their relatives who have anxiety going through the roof. We are really worried about them all, but we stay professional.

## DISCUSSION

This study explored the challenges faced by health care professionals working with people living with dementia amid the COVID-19 pandemic in the English West Midlands region. Overall, we found that social distancing, also known as physical distancing, is a non-pharmaceutical intervention or measure intended to prevent the spread of a contagious disease by maintaining a physical distance between people and reducing the number of times people come into close contact with each other (Fong et al., 2020). The method requires due diligence to uphold it and can be challenging to enforce when working with people living with dementia or learning disabilities (Allcott et al., 2020). The research participants reported difficulties in enforcing social distance whilst working with people living with dementia during the COVID-19 pandemic. The need to perform personal care and intimate support on people living with dementia meant that sometimes two or more staff were working in close proximity with each other and the individuals they were looking after. Such a scenario in the absence of PPE made it easy for COVID-19 to spread from one person to another (Nyashanu, Pfende & Ekpenyong, 2020; Rowan & Laffey, 2020). It is therefore important to consider increasing physical space in care homes looking after people living with dementia. This can be achieved by reducing the number of residents in a care home to create more space and enhance social distancing. This is because people living with dementia require a high level of support, especially during outbreaks, so there is a need to make sure that COVID-19-infected individuals have adequate 1:1 support to make sure that social distancing can be maintained. Where the number of patients is more than the number of staff, it becomes difficult for staff to provide them with the needed support, thereby facilitating the spread of the virus. With regards to the difficulties experienced by people living with dementia in maintaining social distancing during a pandemic, there is a need to make sure that there is adequate PPE for carers in care homes.

Communication is one of the most important aspects when looking after people with different needs like dementia (Olsson et al., 2012). Failure to have clear and effective communication in place can lead to an array of challenges, especially in pandemic periods like COVID-19, where infection can easily spread amongst individuals and health professionals. There must be clear and effective lines of communication aligned to the Health



and Social Care Standards during the decision-making process, which should be underpinned by information already known about the person. All decisions taken must be clearly documented within the care and support plan.

The research participants reported communication challenges because the PPE worn by health care staff made it difficult for people living with dementia to recognise faces and to understand what was being said by the staff. To improve communication between staff and the residents, touch was used to make communication effective. Such challenges meant that there was a possibility of COVID-19 infection transfer if any of the individuals were affected by COVID-19. There is a need to constantly monitor the communication abilities of people living with dementia to make sure that the staff keeps abreast of the individuals' changing communication needs and updates to their care plans (Haq et al., 2013). Training staff to improve their communication capabilities when working with people living with dementia is also important.

Rapid changes in the environment can impact the mood and behaviour of people living with dementia (Khan & Curtice, 2011). Such change can come with increased anxiety and restlessness. The research participants reported an increase in anxiety, restlessness, and low mood amongst the residents following rapid changes in the environment to manage the spread of COVID-19. This subsequent deterioration in mood and behaviour posed challenges for health and social care professionals looking after people living with dementia, including potential threats of COVID-19 spreading in the care home. There is a need for the government to move all people living with dementia affected by COVID-19 from care homes into hospitals until they recover. This is important in reducing pressure on the workforce in nursing homes, which also experience problems in acquiring PPE (Nyashanu, Pfende & Ekpenyong, 2022; Horwath & Morrison, 2011). All new admissions from hospitals into the care homes for people living with dementia need to be tested for COVID-19 before they are admitted to make sure that people living with dementia in care homes are shielded.

For a smooth transition, nursing leadership is crucial to safeguard the quality of care, and nursing staff must work collaboratively within a multidisciplinary care team to initiate advance care planning talks in a timely way, review and document advance care plans, and adapt goals of care, as they may change because of the COVID-19 pandemic.

'Safeguarding' refers to the process of protecting vulnerable people and providing safe and effective care. This includes all procedures designed to prevent harm to individuals (Kelly & Innes, 2013). It is important that when safeguarding vulnerable people, their rights are observed and respected in line with the 1998 Human Rights Act (Kelly & Innes, 2013). The research participants reported dilemmas with safeguarding people living with

dementia within the parameters of the law, balancing the least restrictive practices with the rights of the individuals. This made it difficult for the health and social care professionals to keep potentially COVID-19-infected individuals apart from each other, as they could not confine them in restrictive spaces like their bedrooms, which may be viewed as an infringement on their basic rights pertaining to freedom of movement (Deguara, 2018). There is a need for the government to investigate the issues around the restriction of movement among vulnerable individuals in care homes during pandemic periods like COVID-19 and to provide clear legal direction to health and social care professionals pertaining to their powers when enforcing social distancing. This legal definition of powers in enforcing social distancing is important for the protection of both health and social care professionals and people living with dementia.

Staffing levels when working with people living with dementia are important to ensure the facilitation of social distancing during pandemics like COVID-19 (Wallace et al., 2020). Owing to the high level of support needed by people living with dementia during a pandemic, there is a need to make sure that COVID-19-infected individuals have adequate 1:1 support to make sure that social distancing can be maintained (World Health Organization, 2020). The research participants reported a severe shortage of staff in care homes during the COVID-19 pandemic. The shortage was due to staff sickness absences and self-isolation for some following coming into contact with infected individuals. There is a need for the government to support rapid testing and quick turnaround in obtaining results in times of pandemics in care homes for both health and social care professionals and people living with dementia. This will ensure a quick return of staff on self-isolation rather than waiting for 7–14 days to elapse (Visser, 2020). More importantly, quarantine will be implemented before many people can get infected.

'Emotional labour' refers to the work involved in regulating emotional displays in accordance with occupational norms, which can involve 'surface acting', a superficial display of desired emotions, and 'deep acting', genuinely deeply felt and expressed emotions (Hochschild, 2012). During a pandemic such as COVID-19, health and social care professionals found the amount of work involved in maintaining the required 'sunny' and comforting disposition exhausting. A balance was difficult to achieve between emotional engagement due to the severity of the health risks and the volume of support output required of them. There is a need to establish onsite supportive services for health professionals (Winefield, Coventry & Lambert, 2004). This will help in reducing pressure on the staff whilst getting opportunities for debriefing to alleviate the impact of COVID-19. More importantly, there is a need to improve the working conditions, including remunerations of health care professionals.

## IMPLICATIONS FOR PROFESSIONALS WORKING WITH PEOPLE LIVING WITH DEMENTIA

Findings from this study can help to inform future strategies. As an outcome of this study, we recommend the following:

- In the future, there is a need to have adequate staff in dementia care homes who are aware and can manage and enforce all safeguarding protocols and regulations to make sure that the vulnerable people they look after are adequately protected.
- Guidance that is relevant to people living with dementia is crucial.
- All health and social care professionals working with people living with dementia need to have access to fast testing to make sure they are diagnosed before COVID-19 spreads to other health and social care workers and people living with dementia.
- Support preparedness should be made available for future pandemics.

## LIMITATIONS OF THE STUDY

This research was only carried out in the Midlands. Research encompassing other regions in the UK will be ideal to enable comparisons of different regions. The study utilised a qualitative approach only; qualitative study does not require a large sample size, but rather a saturation level must be reached. Even though a saturation level was reached in the current study, its findings are not representative and as such cannot be generalised. Hence, in the future, it might be important for the study to include a mixed method.

A mixed methods study will allow the exploration of the different issues from different approaches. Interviews conducted in this study only represent one point in time, between the first and second waves of the pandemic, and do not provide any insight into the new concerns and needs that have developed and changed as the pandemic spread into the second year.

## CONCLUSIONS

Adequate staff levels are important when working with people living with dementia during a pandemic like COVID-19. There is a need to monitor all admissions coming into the care home to make sure that they are not infected by COVID-19, as this will safeguard vulnerable residents in the care home. It is also important that fast tests for COVID-19 are readily available for both residents and health and social care professionals in the care home to enable a fast and robust response to any COVID-19 infection before it spreads.

## ETHICS AND CONSENT

Ethical approval was granted by the Nottingham Trent University ethics committee. Consent was obtained from participants before the commencement of the study.

## COMPETING INTERESTS

The authors have no competing interests to declare.


## AUTHOR CONTRIBUTIONS

The corresponding author attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted. All authors contributed to the drafting of the manuscript and approved the final draft.

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