



Experiences of elderly people with dementia during COVID- 19 pandemic in UK

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Introduction

The global population is aging, and people are living longer lives than before. It is now common for people to expect to live beyond their 60s. In fact, the number of older people in the world is increasing, and they make up a larger percentage of the population in every country. One of the six persons alive in 2030 will reportedly be in their sixties. By 2050, the number of persons over 60 will double globally (2100 million). Between 2020 and 2050, the number of people 80 and older is projected to treble, reaching 426 million (WHO, 2022).

Dementia strikes one person globally every three seconds. In 2020, there will be more than 55 million dementia sufferers in the world. Its population is anticipated to double every 20 years, rising to 78 million in 2030 and 139 million in 2050. The majority of these increases will occur in nations on the Development route. By 2050, 71% of dementia patients would reside in low- and middle-income nations, up from the current 60%. Increasing numbers of old people are living in places like China, India, South Asia, and the Western Pacific (Alzheimer's Disease International, 2020).

Governments have been urged to take action to stop the COVID-19 pandemic's spread by limiting travel and stopping companies, upsetting lives and routines, as a result of the global crisis that resulted from its emergence towards the end of 2019. of all of its population, particularly those in vulnerable positions like elderly people with dementia (Tam, Dosso and Robillard, 2021). The emerging coronavirus disease (COVID-19), which spread quickly, prompted the adoption of extensive restrictions such as quarantine and physical/social isolation measures. According to the Office for National Statistics (ONS), people with dementia accounted for 50% of COVID-19-related deaths in care facilities in the United Kingdom (Alzheimer's Society, 2020). In England, there are an estimated 675,000 dementia sufferers, the majority of them older than 65 and have additional medical conditions that make them more susceptible to experiencing severe symptoms and disease effects (Burns et al., 2021).

The aim of this study is analyse the experiences of elderly people with dementia during COVID-19 living in UK, Through of following objectives: 1. Conduct a comprehensive and thorough systematic literature review to gain a deep understanding of the experiences of elderly people with dementia during the COVID-19 pandemic while living in the UK. 2. Analyze and interpret different statistics and policies related to the experiences of elderly people with dementia during the COVID-19 pandemic in the UK to gain a broader perspective of the situation.

3. Synthesize and compare the research findings from the systematic literature review to identify commonalities and differences, and provide insights on how they contribute to the current knowledge base.

4. Develop clear and coherent themes based on the research findings to gain a more nuanced understanding of the experiences of elderly people with dementia during the COVID-19 pandemic in the UK. 5. Provide meaningful and actionable recommendations for future research that can further advance our understanding of the experiences of elderly people with dementia during the COVID-19 pandemic in the UK.

Background

At the genetic level, ageing is caused by the buildup of numerous types of cellular and molecular harm that occur gradually. As a result, both mental and physical abilities gradually deteriorate, disease risk increases, and eventually, mortality results. These changes are not continuous or constant, and they only tangentially correspond to an individual's age expressed in years. It is not accidental that older age groups exhibit more diversity. Aside from biological changes, ageing is frequently linked to other life transitions, including retirement, moving to a more suitable home, and losing friends and relationships (WHO, 2022).

Dementia is a general term used to describe a variety of degenerative disorders that damage the brain, impair high-level cognitive abilities including memory, language, and thinking, and are followed by a decline in daily functioning or social functioning. Many non-cognitive symptoms, including delusions, sadness, anxiety, apathy, sleeping problems, and irritability, may be present in people with dementia and may be influenced by biological, psychological, environmental, social, and/or unsatisfied demands (Social Care Wales, n.d.). As advancing age, dementia rates rise. Alzheimer's disease death rates have been increasing while coronary heart disease death rates have now been declining. The number of people with dementia may increase globally from 47 million in 2015 to 131 million in 2050. In 2015, it was estimated that dementia cost the globe \$818 billion, and by 2030, that figure is predicted to reach \$2 trillion. Despite the fact that drugs for dementia are only modestly effective, dementia screening may still have some clinical benefits. Dementia affects many older persons, many of whom may be living or driving dangerously or have unmet requirements (Jaul and Barron, 2017).

In everyday life, those who have Alzheimer's disease and similar dementias are among the most vulnerable members of society, depending on family members or paid carers to get by. Due of the morbidity and death caused by COVID-19 as well as the indirect impacts of the pandemic on their reliance on social support and the healthcare system, this pandemic further exacerbates their susceptibility (Brown et al., 2020).

Government restrictions were created to stop the spread of the virus as a result of the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) showing up in the first few months of 2020. On March 23, 2020, the government of the United Kingdom (UK) imposed a nationwide lockdown that lasted for more than nine months. High-risk individuals were urged not to leave their houses, while seniors, 70 and older, who were classified as moderate-risk, were encouraged to maintain tight social isolation. Although the majority of those with dementia fell into the age-related risk category, dementia itself was not at the time considered to be a greater risk factor for COVID-19 (Tuijt et al., 2021).

There are laws and guidance in place in the UK that specifically relate to elderly people with dementia and the COVID-19 pandemic including: Coronavirus Act 2020 includes provisions related to social care, including changes to the way in which care is delivered and changes to assessments and funding for care. The Act also provides for temporary modifications to the Mental Health Act 1983, which may affect the care and treatment of people with dementia (Legislation.gov.uk, 2020). The National Institute for Health and Care Excellence (NICE) has also published guidelines for care homes and home care providers on how to manage COVID-19 in people with dementia, including recommendations for infection control, staff training, and communication with families (NICE, 2021).

The significance of conducting this study is to provide voice to those who are living with dementia at COVID-19, hear about their experiences, and collect data that will help support future research.

Methods

Search strategy / Data collection

The aim of conducting a literature review is to establish a comprehensive knowledge base for research purposes. By gathering and analyzing relevant publications, academic articles, and primary research, a solid foundation is established to support the research objectives and identify gaps in the current knowledge base (McRae, 2022). To investigate the experiences of elderly individuals with dementia living in the UK during the COVID-19 pandemic, a systematic search of various databases including Pubmed, Cochrane, ProQuest, University Library, and Google Scholar will be conducted. The search will focus on primary research publications that are relevant to the research question.

Inclusion criteria

Articles would include in this review if they met seven inclusion criteria:

- Primary research
- Original research
- Academic articles
- Written in the English language.
- Full-text, published between January 2019 and March 2023.
- People above 65 years old who are living in the United kingdom .
- Focused In the experiences of elderly people with dementia during COVID-19 living in UK .

Exclusion criteria

Exclusion criteria will restrict to reviews

- Secondary research, meta-analyses, randomized controlled trials, abstracts and original clinical trials.
- Articles Published before January 2019.
- Articles in languages other than English.
- People under 65 years old.
- people outside the United Kingdom.
- Duplicate search results will be removed.

- Articles focused on clinical outcomes in terms of incidence and mortality of dementia comorbidities in patients with COVID-19 will also be excluded from this investigation.

Data analysis

This study will utilize thematic analysis to review academic articles. Thematic analysis is a technique that involves identifying, assessing, and documenting themes or patterns from data, enabling researchers to draw conclusions and concepts from the data (Javadi & Zarea, 2016). This method is suitable for analyzing both small and large datasets, with homogeneous or heterogeneous samples, such as case studies or interview studies (Auckland.ac.nz, 2021). To ensure the rigor of this analysis, the study will use the six-step process outlined by Braun and Clarke, which includes familiarizing oneself with the data, generating codes, building themes, reviewing potential themes, defining and naming themes, and finally relating the study's goals and the codes created (Braun & Clarke, n.d.). By following this process, the study aims to derive meaningful insights from the data analyzed.

Keywords Dementia, COVID-19, elderly people. "SARS- CoV2," Cognitive Impairment, Alzheimer's Disease.

Ethical considerations

Ethical considerations are essential in secondary research to ensure that the data used is properly sourced, the authors' intellectual property rights are respected, and participant confidentiality and privacy are protected (Sng, Yip and Han, 2016). Researchers must also be aware of any potential biases or limitations in the data they use and acknowledge them in their analysis.

Results

Author(s), title, and year of publication	Aim of the study	Methods and Sample size and characteristics	Summary of main findings
(Tuijt et al., 2021)	From the perspectives of various dementia patients living at home and their caregivers, discuss the experiences of the COVID-19 restrictions' effects in England.	A study using qualitative methods interviewed 30 dementia sufferers and 31 caregivers remotely, with thematic analysis used to examine the data.	-increased feelings of isolation, loneliness, stress, and anxiety. -importance of technology, such as video calls, in maintaining social connections.
(Dawson et al., 2023)	to investigate the experiences of dementia sufferers and the people who cared for them during the coronavirus pandemic in England and Wales.	Qualitative study with 9 dementia participants using semi-structured interviews conducted through phone/email, analyzed through thematic analysis with framework analysis guidance.	-Negative impacts on the daily lives of people with dementia, including increased social isolation. -Difficulties accessing healthcare services. -Some people with dementia had adapted to the challenges and founded ways to maintain social connections and engage in meaningful activities.

(Dixon et al., 2022)	To determine the difficulties that dementia sufferers believed they had encountered as a result of COVID-19.	Study used a qualitative design, interviewing 21 people with recent dementia diagnosis. Thematic analysis was conducted using a framework.	-Increased social isolation, loneliness -Lack of access to healthcare services. -Some participants also reported increased family support. -Increased social engagement through technology.
(Hicks et al., 2022)	Study of the effect of COVID-19 on the quality of life for dementia patients and the family caregivers.	A UK study examined pre- and post-pandemic data on 114 caregivers and 93 recently diagnosed dementia patients, using latent growth curve modeling	-Negative impact on the quality of life with dementia particularly in terms of mental and social well-being. -Increased feelings of isolation, loneliness, and anxiety during the pandemic. _Healthcare and support services was affected.

The aim of this research was to look at the experiences of older people with dementia during the COVID-19 pandemic while living in the UK. To achieve this aim, a comprehensive and thorough systematic review of 3-5 academic articles was carried out which analyzed and interpreted different statistics and policies related to the experiences of older people with dementia during the pandemic in the UK. Research findings from the systematic review of the literature were synthesized and compared to identify commonalities and differences, and clear and coherent themes were developed based on these findings. Three main themes emerged from the analysis: Family support, negative impact on mental health, and discovering new skills.

Family support

The provision of family support emerged as a crucial factor in offering elderly individuals with dementia comfort and companionship during the COVID-19 pandemic. Numerous research articles have underscored the significance of social support from family members, particularly in situations where professional caregivers are absent. However, it should be noted that pandemic restrictions have hindered family members from visiting and providing care for their loved ones. Studies indicate that practical assistance, emotional support, and financial support from family members have maintained the well-being of dementia patients and provided them with a sense of security. For instance (Tuijt et al. 2021) reported in the article applied to 30 people with dementia living in England that practical support from family members had helped in maintaining the well-being of dementia patients. Similarly (Dawson, 2022) in the study applied to 9 people with dementia found that some patients felt that their families provided them with adequate emotional and financial support, while others preferred additional support through calls and video calls. Furthermore, (Trujillo,2020) highlighted how individuals with recently diagnosed dementia formed "support bubbles" with family members, typically through phone or digital platforms, whenever they felt the need for support.

Negative Impact in Mental Health

The second prominent theme that emerged from the systematic literature review was the negative impact of the pandemic on the mental health of elderly people with dementia. The study found that the pandemic-induced anxiety and isolation had adversely affected the mental wellbeing of people with dementia. The research articles highlighted the critical role of mental health support services for this vulnerable population. The study by (Tuijt et al.,2021) revealed that individuals with dementia who were previously more independent and mobile experienced greater distressing effects on their mental wellbeing, specifically increased anxiety and

irritability. This aligns with the findings of (Dawson, 2022), which reported a marked decline in mental wellbeing for some elderly people with dementia due to prolonged isolation and limited stimulation, especially those aged 81 to 90 who lived alone. (Dixon et al., 2022) identified losing touch with important friends and family as a significant source of distress for people with dementia, requiring treatment in some cases. However (Hicks et al., 2022) found that the quality of life of people with dementia, in general, remained stable throughout the pandemic, except for those caring for people with severe dementia and those residing in underprivileged areas.

Discovering new skills

The COVID-19 pandemic brought about unprecedented challenges for people with dementia and their caregivers. However, one positive outcome that emerged was the theme of discovering new skills. Several studies have noted that elderly people with dementia displayed a remarkable ability to adapt and cope with the restrictions brought about by the pandemic by learning new skills and developing new routines (Hicks et al., 2022). Digital communication has been instrumental in reducing the loss of direct social interaction for people with dementia. They have frequently acquired IT skills to help with this, using resources such as the local library's training resources, the internet, or the remote assistance of friends and family (Dixon et al., 2022). However, caregivers reported that online tools like Zoom or WhatsApp were not always a satisfactory replacement for regular social interaction (Tuijt et al., 2021). Overall, the findings suggest that despite the challenges posed by the pandemic, people with dementia have been able to adapt and learn new skills, providing a glimmer of hope during a difficult time.

Discussion

During the COVID-19 pandemic, individuals with dementia shared their experiences, highlighting the crucial role of family support, negative effects on mental health, and the importance of acquiring new skills. A study showed that family support is highly valued by those with dementia, with over 90% of participants reporting that their family members displayed compassion, listened patiently, and provided emotional and financial assistance (Carey et al., 2022). However, in India, changes in family structure and culture have led to elder abuse, abandonment, neglect, and inadequate care due to migration, financial struggles,

and limited space. As a result, individuals with dementia living alone are at increased risk of theft, exploitation, and eviction (Singh, 2019).

Studies have shown that the pandemic has negatively impacted the mental health of individuals with dementia. A longitudinal study demonstrated a significant increase in depression cases and a decline in anxiety cases (Giebel et al., 2021). In addition, individuals with milder forms of dementia experienced worsening symptoms of depression, anxiety, and insomnia due to heightened awareness of the epidemic's effects (Cohen et al., 2020). Another study reported that living alone or being socially isolated at home during the pandemic was associated with an increase in depressive symptoms among individuals at risk of dementia (Boutoleau-Bretonnière et al., 2020). Moreover, neuropsychiatric symptoms and cognition were found to be related, with individuals with dementia experiencing greater neuropsychiatric symptoms having poorer cognitive performance (Boutoleau-Bretonnière et al., 2020). Loneliness and social withdrawal have also been shown to exacerbate motor problems and neuropsychiatric symptoms (Gaigher, Lacerda and Dourado, 2022). Another study conducted in six European countries, comprising France, Germany, Italy, Portugal, Spain, and the United Kingdom, aimed to investigate the influence of COVID-19 on individuals with dementia. The study found that the pandemic had a considerable adverse effect on the mental health and well-being of people with dementia. They experienced increased confusion, agitation, and behavioral problems, indicating a negative impact of the pandemic on their overall mental and emotional health (Burns et al., 2021).

Despite the significant negative impact of the COVID-19 pandemic on individuals with dementia, digital technologies have been identified as a promising approach to mitigate the adverse effects. Research has revealed that social media and video chatting apps can help to enhance social connectivity, self-actualization, and well-being among individuals with dementia (Talbot and Briggs, 2022). Additionally, these technologies can preserve social abilities and connections with family members, thereby reducing social isolation that the pandemic might worsen (Chirico et al., 2022). Other studies have also developed educational programs to help elderly individuals to educate their peers about cybersecurity threats and how to handle them (Nicholson and McGlasson, 2020). Overall, these findings suggest that digital technologies could be an effective tool to support individuals with dementia during the pandemic and beyond.

Recommendations for future policy and health and social care practice

In order to reduce anxiety brought on by conditions of isolation, such as the pandemic, strategies from the perspective of the health worker and all the stakeholders should be concentrated on reducing loneliness through psychoeducational interventions, engaging patients, their families, and carers (Older, 2020). It is crucial that family members, close friends, and carers have more understanding about how to manage dementia patients and how to handle scenarios like a pandemic supported by local authorities, doctors, and other professionals such as health and social workers. Gaining knowledge from personal experience and understanding that dementia should not define a person's identity or that one should only concentrate on its negative features, such as the loss of capacities. To make technology more widely and effectively used in the treatment of dementia, actions must be taken to remove barriers to its use by older and more vulnerable people around the world.

Importance of the findings for health and social care

The discoveries made in this research are significant and hold great potential for shaping the future of dementia care in older adults facing pandemic conditions. The data gathered provides valuable insights that can inform further investigations and ultimately drive the development of pioneering techniques for managing dementia in these challenging circumstances. By building upon these findings, researchers and healthcare professionals can work towards devising novel approaches that take into account the unique needs and challenges faced by dementia patients during pandemics. These innovative strategies could involve a combination of psychoeducational interventions, caregiver support, and technology-based solutions, among other things. Overall, the insights gained from this study have the power to catalyze a transformative shift in the way we approach dementia care, helping us to better serve and support some of the most vulnerable members of our society during times of crisis.

Limitations

There are a few limitations to be acknowledged in this study, including the small sample size consisting of only four studies, and the fact that the research was conducted by a single researcher, which could potentially impact the interpretation of the results. Furthermore, there were difficulties encountered in finding research within the country where the study was carried out, which may have impacted the analysis.

Conclusion

In conclusion, this study challenges prior assumptions regarding the experiences of older individuals with dementia during the COVID-19 pandemic. The findings indicate that while isolation presented significant challenges for this population, family support and the use of technology were identified as protective factors that contributed to a more positive outlook.

However, it is important to acknowledge that these findings are based on a limited sample size and a single researcher's participation, highlighting the need for further research to confirm and expand upon these results. By carrying out additional investigations into the impact of family involvement and technology on the well-being of individuals with dementia during periods of isolation, we can gain a more comprehensive understanding of their unique needs and develop tailored interventions that address these challenges effectively.

In light of the ongoing COVID-19 pandemic and the potential for future crises, it is crucial to prioritize research efforts that explore the best strategies to provide assistance and social engagement for people with dementia, while also safeguarding their mental health. By doing so, we can improve the quality of life for this vulnerable population and promote their overall well-being.

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