The story of an emerging crisis: the impact of COVID-19 on care home residents with dementia in the UK

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The impact of COVID-19 in UK care homes has been significant – for staff, residents and people with dementia. Given the rapidly changing circumstances, the media (limitations notwithstanding) have reported vital insights from the front line. A qualitative analysis of news articles across three time points reveals the story of an emerging crisis in UK care homes, beginning with a sole focus on hospital care and resulting in tragically high death rates. This public-facing narrative has potential to: advocate for increased resources in care homes; drive government accountability; highlight improvements for care practices; and bear witness to the experiences of a vulnerable population.

Key words dementia • care homes • COVID-19 • media

Introduction

People with dementia living in care homes in the UK have proven to be particularly vulnerable to the effects of the COVID-19 pandemic (Alzheimer’s Society, 2020). They are at risk of increased social isolation resulting from lockdown and shielding policies, as well as being susceptible to poorer health outcomes. These circumstances have ethical implications for the care of people with dementia. There is a moral duty to communicate and highlight the impacts of COVID-19 on vulnerable populations, with the hope that their needs will be met in any future outbreaks.

The importance of public-facing media narratives

The COVID-19 pandemic has escalated with an unprecedented degree of speed and severity, quickly being declared a global health emergency by the World Health

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Organization (WHO). Within this climate of uncertainty, academics, policymakers and media outlets have attempted to inform the general public about the virus and its impact. Given the rapidly changing circumstances, the media (limitations notwithstanding) have reported vital insights from the front line.

Public-facing media narratives matter, especially in times of crisis. They have the potential to drive transparency and accountability. They can offer live facts and hard-hitting truths, breaking critical news stories as they happen. For care home residents living with dementia, the media can have a critical advocacy role by giving citizens a voice. In this way, media narratives can be politically and sociologically charged, helping to drive changes in policy and resource allocation (Anwar et al., 2020).

**Analysing news articles during COVID-19**

This qualitative media review aimed to explore early public-facing narratives about COVID-19 and care home residents with dementia. Specifically, this review sought to understand the initial impacts of COVID-19 that were being communicated to members of the public by the media in real time as events unfolded. This review was inspired by qualitative media analysis and tracking discourse (Altheide and Schneider, 2013) to map the emerging public-facing narratives about COVID-19 and care home residents with dementia during the first few months of the pandemic.

Qualitative media analysis seeks to recognise meanings and patterns within media content, including its contribution to social and cultural contexts and narratives. Identifying distinct journalistic frames, interpretations or slants on particular stories demonstrates how topics are discussed in the media and how these narratives may change over time (Altheide and Schneider, 2013).

In order to conduct a timely review in a rapidly changing field with evolving public-facing narratives, three literature searches were performed at three distinct time points by the first author. Online searches were performed for reasons of pragmatism: due to lockdown restrictions, it was not possible to obtain printed media for hand searching.

The wave one searches took place between 2 and 9 April 2020, during the first stage of the UK’s lockdown measures, and included articles published up to 9 April 2020. The wave two searches took place between 27 and 28 April 2020, during the second-stage extension of the UK’s lockdown, and included articles published between 10 and 28 April 2020. The wave three searches took place between 1 and 2 June 2020, and included articles published between 29 April 2020 and 2 June 2020.

**Table 1** shows the databases and search terms that were used, as well as the resulting number of articles identified from each, which were predominantly UK news stories. A number of academic articles, and some international articles, were included where relevant to supplement the UK media articles, provide additional context and cross-check their reliability. Online search engines featured heavily in the search strategy to access easily available, widely circulated materials that were shaping public-facing narratives. Furthermore, conducting search engine searches via the Internet replicates how members of the public look for information. The final selection of 47 articles was analysed, coded and synthesised using qualitative thematic analysis.

It is important to recognise the intrinsic bias that can exist in news and media articles. News reporting can be selective, and stories may be produced for newsworthiness, sensationalism or political motives. This can affect the credibility and rigour of media sources. This review sought to balance these concerns by also including a selection
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Framing a changing narrative: the emergence of the crisis in UK care homes

Table 2 shows the 17 themes that were identified in the articles. In addition, three media frames were evident for each of the three distinct time points, showing how the public-facing narrative evolved in the UK as the pandemic progressed. Media content from the first time point was framed by an emphasis on hospital care. The second time point was framed by the plight of care homes. The third time point was framed more specifically by the death rate in care homes. This cumulative story represents how the impact of COVID-19 on care home residents living with dementia was being communicated to members of the public.
Frame one: the dominance of hospital care

When conducting the wave one literature searches, the majority of media articles focused on hospital care or hospital admissions relating to COVID-19. There was a strong focus on acute COVID-19 healthcare being delivered in hospitals, with politically motivated messages about saving the National Health Service (NHS) and concerns that intensive care demand would outpace bed availability. It was reported that work had begun on building the Nightingale field hospitals in anticipation of large numbers of patients requiring acute hospital care. Some clinicians warned of resource shortages potentially impacting on hospital triages. It was also reported that general practitioners (GPs) felt pressure to avoid hospital admissions of patients with COVID-19 to avoid overwhelming hospitals (Iacobucci, 2020).

Of course, ‘protecting the NHS’ – for patients and staff – was the right thing to do. However, this one-dimensional pandemic response was not sufficient and should perhaps have been recognised at the time. Yet, the government failed to act strategically and to consider the needs of the wider health and care economy – to the detriment of care home residents and staff. In these early days, social care was barely mentioned, though some concerns were expressed that the newly publicised death toll data only related to hospitals (Booth, 2020). While the first harrowing
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stories were emerging of care home residents in Spain being found by the military (Williamson and Badcock, 2020), these were framed by the British media as exceptional and isolated cases.

Frame two: the plight of care homes

Media articles identified in wave two illustrate that the plight of care homes was unfolding as a narrative of critical importance. There was now a fairly unanimous view in the news that care homes had been overlooked, undervalued and ignored by policy responses and the government up to that point. Care homes were framed as the new front line of an emerging crisis (Triggle, 2020). In the British media, the focus shifted from the healthcare system, and the NHS, to the social care system. Directors from the Alzheimer’s Society, Marie Curie, Age UK, Care England and Independent Age wrote an open letter to the secretary of state during this time addressing the devastating effects of COVID-19 on older people, including those with dementia, and care homes (Lee et al, 2020).

Stories began to emerge about the impact of COVID-19 on care home residents with dementia and care home staff. The pandemic caused a number of safety issues for care home residents with dementia. Several articles noted the challenge of confining people with dementia to their rooms, to allow for social distancing, due to wandering (Booth, 2020). Likewise, it was reported that people with dementia often forgot about the need for physical distance from others and increased safety measures such as handwashing, meaning that transmission of COVID-19 was likely higher among this population. Other articles recognised that people with dementia may find it harder to communicate symptoms of COVID-19 to care staff, meaning that they were more susceptible to the virus going undetected and untreated.

Loneliness was also a significant theme for care home residents with dementia. There were sad reports of care home residents dying alone due to staff shortages or the need for social distancing (Williamson and Badcock, 2020). Family visits and group activities were stopped, leaving care home residents more isolated than before. The tension between social distancing and meeting emotional needs was noted.

Meanwhile, care home staff experienced unprecedented challenges, which had a substantial impact on their well-being. News stories showed that staff were facing a severe lack of COVID-19 resources, testing, personal protective equipment (PPE) and government guidance (Mitchell and Hill, 2020). This compromised the safety of staff and those they cared for, leading to stress and anxiety (Booth, 2020). It was reported that many care staff were experiencing exhaustion and burnout, without any time to grieve for residents who had passed away. This was impacting on staff morale. Media articles rightly recognised that more support was needed for those delivering care. Even where testing had been made available for care staff, the provision had been impractical. For example, some testing in the UK required care staff to travel excessive distances to facilities unreachable by public transport (Chakelian et al, 2020).

Care home staff have been admirably unrelenting in their dedication and sacrifice to care home residents during the pandemic. However, system-level failings, which the government are ultimately accountable for, have significantly impacted on staff and residents. Media articles began to criticise the relaxed guidance produced by the UK government, which lagged behind international expertise, with measures for care homes being advised too late (Chakelian et al, 2020).
Frame three: the death rate in care homes

By wave three, the media articles were widely publicising the death rates in care homes, as well as the number of excess deaths (the number above those that would be expected based on previous records). By now, it was firmly established in the media that the death rate in care homes had been underestimated, while early indications of high daily death tolls in care homes had not been emphasised enough. News articles about the crisis now appeared in tabloid media, which had been noticeably absent in previous searches (Blanchard, 2020). There was also particular visibility given to the disproportionate impact of COVID-19 on people with dementia, particularly those living in care homes (Alzheimer’s Society, 2020).

As well as reporting daily headlines, media articles also began to produce analysis, asking how such high numbers of deaths had occurred in care homes and scrutinising the policies and decision-making that had caused them. Critically, the media made a distinction between people with dementia dying from COVID-19 (contracting the virus) and their dying as a result of COVID-19 (wider system pressures caused by the pandemic). Several articles pointed to an impending public enquiry into the death rate in care homes to hold the government to account for its policies (Connolly and McKeown, 2020).

During the final wave three searches, there was substantial media interest in the death rates among care home residents with dementia, resulting from newly published data. The Office of National Statistics (ONS) in the UK showed that dementia was the main underlying condition for COVID-19 deaths, accounting for 20 per cent of total deaths (Alzheimer’s Society, 2020). Moreover, aside from COVID-19, deaths from dementia in April 2020 were 80 per cent higher in England, and 50 per cent higher in Wales, than usual (Alzheimer’s Society, 2020). The development and framing of the public-facing media narrative surrounding this crisis continues, and will doubtless evolve in the future.

Conclusion

This qualitative media review tells the story of an emerging crisis that details the impact of COVID-19 on care home residents with dementia, as told through a series of public-facing narratives reported in news articles. Through the early stages of the pandemic, media reports focused on hospital care and politically motivated concerns about overwhelming NHS resources. Gradually, there was recognition of the plight of care homes, including the experiences of residents and the overwhelming circumstances for staff. As awareness grew, death rates in care homes were rising exponentially, and this became a leading news story. Drawing attention to these public-facing narratives is important for a number of reasons: first, to provide anecdotal evidence with which to advocate for increased resources in care homes; second, to drive government accountability for the crisis in care homes, so that lessons can be learned for future public health policy; third, to reflect on the early experiences of the pandemic and highlight improvements for care practices; and, finally, to bear witness to the experiences of a vulnerable population, as well as pay tribute to the exceptional staff who cared for them.

Conflict of interest

The authors declare that there is no conflict of interest.
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References