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Stigma of dementia during the COVID-19 pandemic: a scoping review protocol

Juanita-Dawne R Bacsu,1 Zahra Rahemi,2 Kate Nanson,1 Claire Webster,3 Myrna Norman,4 Raymond J Spiteri5

ABSTRACT

Introduction Dementia-related stigma reduces the quality of life of people living with dementia and their care partners. However, there is a dearth of literature synthesising knowledge on stigma of dementia during the COVID-19 pandemic. This scoping review protocol outlines a methodology that will be used to understand the impact of stigma on people living with dementia during the pandemic. Addressing dementia-related stigma is critical to promoting timely dementia diagnoses and enhancing the quality of life for people living with dementia and their care partners.

Methods and analysis This review will follow the Arksey and O’Malley methodological framework and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews checklist. The review will focus on English-language, peer-reviewed literature published between 13 January 2020 and 30 June 2023. Stigma will be broadly defined according to pre-established components (stereotypes, prejudice and discrimination). We will search six databases including CINAHL, EMBASE, Google Scholar, Medline, PsycINFO and Web of Science. We will also hand-search the reference lists of relevant articles to identify additional manuscripts. Two reviewers will develop the data extraction table, as well as independently conduct the data screening. Any disagreements will be resolved through open discussion between the two researchers, and if necessary, by consulting the full team to achieve consensus. Data synthesis will be conducted using an inductive thematic analysis approach.

Ethics and dissemination This review will be the first to explore the impact of dementia-related stigma during the COVID-19 pandemic. An advisory panel including a person living with dementia and a care partner will be consulted to inform our review’s findings and support the data dissemination process. The results of this scoping review will be shared and disseminated through publication in a peer-reviewed journal, presentations at academic conferences, a community workshop and webinars with various stakeholders.

INTRODUCTION

People living with dementia and their care partners have experienced severe upheaval and disruption during the COVID-19 pandemic. Studies show that people living with dementia face heightened mortality from COVID-19. More specifically, research indicates that dementia is one of the most common comorbidities associated with deaths due to COVID-19. Dementia is also associated with increased mortality during the pandemic even if the individual does not have COVID-19. Beyond having an increased risk of mortality, people living with dementia have faced substantial challenges to their social, emotional and physical well-being during COVID-19. Consequently, there is a growing evidence on the negative implications of COVID-19-related isolation and confinement on reduced psychological well-being (worsening neuropsychiatric symptoms), cognitive function and physical health.

Research shows that the COVID-19 pandemic has perpetuated stigmatisation towards groups deemed as being more at risk to the virus, such as people living with dementia. Stigma is defined as any negative stereotypes, prejudice, or discriminatory actions or behaviour towards people living with dementia. During the COVID-19 lockdowns, some claimed that the pandemic restrictions were unnecessary since the virus predominately impacted the mortality of older adults, and especially older adults...
lending with dementia. Lichtenstein asserts that blatant discrimination and ageist isolation policies were largely accepted, especially as a tool to end financial crises and COVID-19 lockdowns. This ageism was often linked to the ableist myth that dementia is a complete erasure of oneself and the notion that people with dementia are better off dead.

Stigma of dementia has critical consequences such as anxiety, depression, poor mental health and a decreased quality of life. More specifically, COVID-19 research indicates that the human rights and fundamental needs (e.g., access to adequate housing, safe drinking water and sanitation, and nutritious foods, social connection and right to the highest attainable standard of health) of people living with dementia were compromised in the pandemic. Moreover, there was a lack of consensus related to the required duration of the COVID-19 restrictions and how long visitation restrictions and institutional confinement orders should remain in place. Consequently, forced COVID-19 confinement and ongoing isolation made it difficult for people living with dementia and their family care partners to access essential health services and supports such as cognitive rehabilitation programmes and social support. However, there is a dearth of research synthesising knowledge on the impact and consequences of stigma towards people living with dementia during the COVID-19 pandemic.

Understanding the impact of COVID-19-related stigma of dementia is essential to informing future pandemic policies to reduce stigma of dementia. Moreover, examining dementia-related stigma within the context of the COVID-19 pandemic sheds light on the pre-existing issues of dementia-related stigma that often remains undiscussed. Only through education, understanding and evidence-informed knowledge can we begin to address COVID-19-related stigma towards people living with dementia to inform future pandemic policies and planning.

This scoping review protocol outlines a methodology that will be used to examine stigma of people living with dementia during the pandemic. Guided by Arksey and O’Malley’s framework and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews (PRISMA-ScR), our scoping review will provide a comprehensive understanding of the COVID-19-related consequences of stigma of dementia. Accordingly, our findings will provide evidence-informed knowledge to enhance COVID-19 policy responses and pandemic planning to reduce stigma towards people living with dementia and their care partners.

**METHODS AND ANALYSIS**

This scoping review will be guided by Arksey and O’Malley’s scoping review framework and the PRISMA-ScR checklist. Our protocol was registered with the Open Science Framework on 29 May 2023 (osf.io/5bcgd).

Drawing on Arksey and O’Malley’s scoping review framework, we will organise our study in five stages: (1) identification of the research question; (2) examination of relevant studies; (3) study selection; (4) extraction of data; and (5) collating, summarising and reporting the research findings.

**Step 1: identification of the research question**

The overarching research objective of this study is to understand the impact of stigma on people living with dementia during the COVID-19 pandemic. To accomplish this objective, this study will address the following research question:

**Primary research question**

How has stigma affected people living with dementia during the COVID-19 pandemic?

**Secondary research questions**

1. What are the consequences of stigma of dementia during the pandemic?
2. What types of stigma (stereotypes, prejudice and discrimination) have increased since the onset of the COVID-19 pandemic?

**Step 2: examination of relevant studies**

Studies will be retrieved by searching six electronic databases including CINAHL, EMBASE, Google Scholar, Medline, PsycINFO and Web of Science. An expert librarian will be consulted to provide insight to ensure that no relevant databases are excluded. Studies will also be identified through searching relevant bibliographic references. The keywords that will be included in our search strategy are outlined in Table 1. The timeframe of our search will focus on articles published between 13 January 2020 and 30 June 2023. January 13 was chosen as the start date for our search timeline as public health officials confirmed the first reported case of COVID-19 outside of China on 13 January 2020.

**Inclusion and exclusion criteria**

Articles will be included in this review if they meet the following four criteria: (1) full text, peer-reviewed journal articles; (2) written in the English language; (3) relevant databases. The keywords that will be included in our search strategy are outlined in Table 1. The timeframe of our search will focus on articles published between 13 January 2020 and 30 June 2023. January 13 was chosen as the start date for our search timeline as public health officials confirmed the first reported case of COVID-19 outside of China on 13 January 2020.

**Table 1**

<table>
<thead>
<tr>
<th>Concept</th>
<th>Keywords</th>
<th>Databases and search engines</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia</td>
<td>Dementia</td>
<td>CINAHL, EMBASE, Medline, PsycINFO, Web of Science and Google Scholar</td>
</tr>
<tr>
<td>Stigma</td>
<td>Stereotypes* OR Stigma* OR Prejudice* OR Discrimination*</td>
<td></td>
</tr>
<tr>
<td>COVID-19</td>
<td>COVID-19* OR Pandemic* OR Coronavirus*</td>
<td></td>
</tr>
</tbody>
</table>

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published between 13 January 2020 and 30 June 2023; and (4) address stigma (stereotypes, prejudice or discrimination) of dementia during the COVID-19 pandemic. We will include articles that focus on original research such as qualitative, quantitative and mixed methods studies. Exclusion criteria will consist of the following: (1) articles that do not report on empirical research; (2) published in languages other than English; (3) not published between 13 January 2020 and 30 June 2023; (4) does not address both stigma of dementia and the COVID-19 context; and (5) does not address the study’s objective but focuses on other topics such as COVID-19-related mortality of dementia.

**Step 3: study selection**
A total of six electronic databases (CINAHL, EMBASE, Medline, PsycINFO, Web of Science and Google Scholar) will be searched for relevant literature and the results will be imported into Refworks (https://www.refworks.com/refworks2/). After this step, Covidence will be used (https://www.covidence.org/) to help organise and manage our collaboration in the study selection and screening process. Two reviewers will independently perform the study selection (title and abstract screening and full-text screening of articles) that will follow the inclusion guidelines. Any disagreements will be resolved through open discussion between the two researchers, and if necessary, by consulting the full team to achieve consensus. A PRISMA diagram will be used to document our scoping review’s study identification, selection and screening process.

**Step 4: extraction of data**
A data extraction table will be developed in Microsoft Word. The table will consist of different categories to help organise the data such as author, publication year, country of origin, purpose, methods and stigma findings/consequences. The table will be pilot tested by two reviewers to ensure usability and clarity during the extraction process. The lead author and a coauthor will complete the data extraction for all of the articles.

**Step 5: collating, summarising and reporting the findings**
Guided by Braun and Clarke, thematic analysis will be conducted to examine the main patterns and themes related to the impact of stigma of dementia during the COVID-19 pandemic. A separate table will be created to identify the stigma theme(s) in each article and the type of stigma addressed in each article.

**Patient and public involvement**
We are working in collaboration with an advisory panel including a person living with dementia and a former family care partner of a person living with dementia. This panel will provide guidance and insight throughout the development of our study’s review to help inform the study’s research priorities, methods and data analysis, and knowledge translation activities. For example, a meeting was held with our advisory panel to determine this study’s research questions and discuss the scoping review method. We will continue to work to ensure that the advisory panel’s perspectives and insight are prioritised throughout our scoping review. More specifically, the advisory panel will participate in all team meetings and collaborate in the scoping review processes (such as contributing to the theme development during thematic analysis and supporting knowledge dissemination and exchange). For example, they will provide lived experience, critical insight and actively participate in our knowledge dissemination and exchange activities such as co-presenting at conferences and webinars. The team has worked together previously and has experience collaborating on other research projects on dementia.

In our advisory panel, the person living with dementia and the former care partner of a person living with dementia were invited to collaborate based on their strong advocacy and outstanding contributions to supporting dementia care. For example, the person living with dementia is a national advocate and strong speaker dedicated to educating others on how to reduce dementia-related stigma to improve the quality of life of people living with dementia. More specifically, she serves on numerous national committees and regularly speaks at conferences, webinars and on podcasts. She has also given invited presentations to the provincial government to advocate for people living with dementia. Similarly, the former care partner of a person living with dementia is a strong national advocate for people living with dementia. She is a Certified Alzheimer Care Consultant, Certified Professional Consultant on Ageing, and an international speaker at conferences, podcasts and webinars focused on the field of dementia care. She is the founder and president of a consulting firm that provides support services and education to help individuals navigate the journey of Alzheimer’s disease and/or dementia-related illnesses. The team is honoured to partner and collaborate with this outstanding advisory panel and will work to ensure that their voices are prioritised throughout the scoping review processes (from identifying the research priorities to data dissemination).

**Limitations**
Although our review will be conducted in a rigorous manner, it will not be without limitations. For example, this review will be limited to literature published in peer-reviewed journal articles. Consequently, it is possible that relevant grey literature or preprint articles will be excluded from our study. Future reviews may consider expanding their search to include grey literature or preprint databases. However, these reviews must exercise caution because preprints and grey literature often do not undergo a peer-review process. Moreover, recent literature shows a high retraction rate among preprint articles, particularly related to the COVID-19 pandemic. Specifically, the reasons for retraction included ethical concerns and study misconduct.
Another limitation is that our review will only include English language articles. However, over 55 million people have dementia globally, with over 60% of whom reside in low-income and middle-income countries. Thus, the impact of the COVID-19 pandemic on people living with dementia could be even greater in such countries. Accordingly, further research is needed to examine COVID-19 studies in other languages to develop a more comprehensive understanding of stigma of dementia in other countries and cultures.

ETHICS AND DISSEMINATION

Ethics approval will not be required because our review focuses on analysis of existing literature and does not include human subject research. For example, our advisory panel are not research participants but are core members of our research team. Results from our scoping review will be disseminated through publication in a peer-reviewed journal article, conference presentations, community workshops, policy briefs and webinars with various stakeholders. In addition, our advisory panel will be consulted to provide expert insight and lived experience to support the review’s data dissemination and knowledge translation process.

The results from this scoping review will provide community leaders, health professionals and policymakers with crucial insight and evidence-informed knowledge of dementia-related stigma during the COVID-19 pandemic. We will explore the impact and types of dementia-related stigma during the pandemic, as well as identify research gaps that need to be addressed in subsequent studies. Addressing the impact of COVID-19-related stigma of dementia is essential to informing future pandemic policies and planning to reduce stigma towards people living with dementia.

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Contributors J-DRB conceptualised the manuscript idea and the drafted the initial manuscript. ZR, KN, CW, MN and RJS aided in developing the research questions and methods, and contributed to reviewing and approving the final manuscript.

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Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting or dissemination plans of this research. Refer to the Methods and analysis section for further details.

Patient consent for publication Not applicable.

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