ARTICLE DETAILS

TITLE (PROVISIONAL)
Stigma of dementia during the COVID-19 pandemic: A scoping review protocol

AUTHORS
Bacsu, Juanita-Dawne; Rahemi, Zahra; Nanson, Kate; Webster, Claire; Norman, Myrna; Spiteri, Raymond

GENERAL COMMENTS
The study planned in the protocol paper would have a potential to contribute to dementia friendly societies amid the long-term restrictions.
Main questions arise around its methodology:

1. Primary research question (page 7 lines 13-16)
   Although it may be sometimes combined with the impact on people with dementia, it still needs to be clarified on what types of stigma appeared (worsened) since the onset of the COVID-19 pandemic.
The authors described three main categories of stigma (stereotype, prejudice, and discrimination) in Table 1. Results might be presented based on these categories.

2. Exclusion criteria (page 8 lines 16-26)
   Some “reports” and “letters to the editor” can include original data. The exclusion criterion i) might be rephrased to indicate that articles other than empirical researches would be excluded.

3. Step 5: Collating, summarizing, and reporting the findings (page 9 lines 18-28)
   Thematic analysis would be applicable to qualitative data or categories of outcomes, however, it may remain questioned how to summarize results from quantitative data.

4. Limitations (page 10 lines 11-19)
   Exclusion of non-English articles matters as the authors mentioned in the limitations. It would be noted that low- and middle-income countries have more people living with dementia than high income countries (typically Northern America and Europe), and the impact of COVID-19 pandemic could be even greater in such countries.

5. Ethics and dissemination (page 10 lines 32-37)
   Involving the advisory panel is the strength of this study: it would be helpful to mention how the authors ensure persons with...
cognitive impairment can voice their needs and perspectives in the panel discussion.

**REVIEWER**
Warren, Alison  
George Washington University, Clinical Research and Leadership

**REVIEW RETURNED**
24-Jun-2023

**GENERAL COMMENTS**
Thank you for the opportunity to review this manuscript. This is a timely subject in dire need of attention. The overall protocol is thorough and well-thought out. As such, my sparse suggestions are below.

Pg. 4:
Lines 17-24: These statements are very important and correct and as such, a brief mention of contributing factors would add to the impact – i.e., owing to isolation, stigma-related behaviors/malignant social psychology, misperceptions regarding the disease itself that lead to family members misperception that persons with dementia won’t be affected by isolation because they won’t remember, lack of exposure/support etc, consequential depressed immune system etc.

Line 33: a brief operational definition of stigma (other than the parentheses) would be helpful at this juncture.

Line 52: If including to date of this manuscript, please specify considering the lack of consensus of the pandemic.

Pg 8:
Line 33: It would be helpful to know how you are selecting the person with dementia for consultation – this is a crucial perspective, and understanding the type and stage might be helpful, particularly for future studies.

**REVIEWER**
Matsumoto, Hiroshige  
The University of Tokyo, Department of Community Health Nursing

**REVIEW RETURNED**
10-Jul-2023

**GENERAL COMMENTS**
I appreciate the opportunity to peer review the protocol paper for the authors’ scoping review. The protocol is mostly appropriately written for an important study reviewing the impact of dementia-related stigma during the COVID-19 period.

I submit three minor comments to clarify and improve the paper. It is hoped that the authors will address these comments.

1) Research question or study objective: Introduction
Please add a description of the necessity to explore dementia-related stigma limited to the COVID-19 pandemic period. Can it be assumed that the impact of stigma during the COVID-19 period will be different from the impact of other periods before or after it?
Without a hypothesis or rationale for the stigma of dementia increasing or changing in nature during the COVID-19 period, it is difficult to understand the purpose of this review.

Although Bacsu et al. (2021), cited in the paper, summarizes the effects of COVID-19 on people with dementia, the impact of stigma is not mentioned in it.
However, Bacsu et al. (2022) and Lagacé et al. (2021) cited in the paper seem to address the characteristics of dementia-related
stigma in COVID-19. Specifically describing the necessity to explore the stigma of dementia in COVID-19, citing the findings that have already been identified, will contribute to the reader's understanding of the significance of the present review.

2) Study design: Methods - inclusion and exclusion criteria
Please explain how the authors determine the "inclusion criteria iv) address stigma (stereotypes, prejudice, or discrimination) of dementia during the COVID-19 pandemic".
How do the authors determine that the time period covered by the collected studies is the COVID-19 pandemic period?
Some studies published between January 13, 2020 and June 30, 2023 may not be affected by COVID-19, depending on the region and time period. For example, if a study is conducted in the U.S. in 2019 and published in February 2020, it would not seem appropriate to treat that study as a COVID-19 epidemic study. This is because the stigma investigated in that study would not be affected by COVID-19.

3) Research ethics: Methods - Step6 Consultation, Ethics and dissemination
The authors declare that ethics approval is not required. Please ensure that the members of the advisory committee, including the dementia patient being consulted, are not research participants. Also, working with the advisory panel would be significant and would be a strength of this review. I suggest adding a description of the details of the collaboration, i.e., when and how to work with them.

REVIEWER | Werner, Perla
---|---
Univ Haifa, Community Mental Health

REVIEW RETURNED | 16-Jul-2023

GENERAL COMMENTS | I suggest to accept the ms as is.

VERSION 1 – AUTHOR RESPONSE

Reviewer: 1
Dr. Miharu Nakanishi, Koeki Zaidan Hojin Tokyo-to Igaku Sogo Kenkyujo
Comments to the Author:
The study planned in the protocol paper would have a potential to contribute to dementia friendly societies amid the long-term restrictions.
Main questions arise around its methodology:

1. Primary research question (page 7 lines 13-16)
Although it may be sometimes combined with the impact on people with dementia, it still needs to be clarified on what types of stigma appeared (worsened) since the onset of the COVID-19 pandemic. The authors described three main categories of stigma (stereotype, prejudice, and discrimination) in Table 1. Results might be presented based on these categories.
Response: Excellent point, we have updated the secondary research question to address this suggestion. For example, it now states, “What types of stigma (stereotype, prejudice, and discrimination) have increased since the onset of the COVID-19 pandemic?” We will also add a column in our data extraction table to identify the type of stigma to ensure that we can discuss these findings (stigma stereotypes, prejudice, and discrimination) in our results section of our full scoping review.
2. Exclusion criteria (page 8 lines 16-26)
Some "reports" and "letters to the editor" can include original data. The exclusion criterion i) might be rephrased to indicate that articles other than empirical researches would be excluded.
Response: We agree, and we have rephrased our criteria to exclude articles that do not report on empirical research. For example, our sentence now states: "Exclusion criteria will consist of the following: i) articles that do not report on empirical research; ii)"

3. Step 5: Collating, summarizing, and reporting the findings (page 9 lines 18-28)
Thematic analysis would be applicable to qualitative data or categories of outcomes, however, it may remain questioned how to summarize results from quantitative data.
Response: We appreciate the reviewer’s concern, but we respectfully disagree. Thematic analysis is often used to analyze data in scoping reviews, and it is a relevant tool that can be used in quantitative research. For example, thematic analysis emphasizes identifying, analyzing, and interpreting patterns and themes in data. It can be used to identify relationships between the data and other variables, recognize patterns in the data, and provide in-depth insight into the data which may otherwise be missed. Below are some recent examples of scoping reviews using thematic analysis to analyze qualitative, quantitative, and mixed-method studies by focusing on the themes identified within the data.

4. Limitations (page 10 lines 11-19)
Exclusion of non-English articles matters as the authors mentioned in the limitations. It would be noted that low- and middle-income countries have more people living with dementia than high income countries (typically Northern America and Europe), and the impact of COVID-19 pandemic could be even greater in such countries.
Response: Excellent point, we have added this information and a statistical reference to better address this in our limitations section and highlight the need for further research to focus on low-and middle-income countries. For example, we now state: “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-and middle-income countries (World Health Organization, 2023). 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 dementia in other countries and cultures.”

5. Ethics and dissemination (page 10 lines 32-37)
Involving the advisory panel is the strength of this study: it would be helpful to mention how the authors ensure persons with cognitive impairment can voice their needs and perspectives in the panel discussion.
Response: We have added additional information on the advisory panel to address how the authors will ensure the person with dementia and the former family care partner can voice their perspectives. We also added a relevant reference on supporting engagement in research with people living with dementia.
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 [23]. 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 prioritized 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 (PAC), Certified Professional Consultant on Aging (CPCA), as well as 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 honored to partner and collaborate with this outstanding advisory panel and will work to ensure that their voices are prioritized throughout the scoping review processes (from identifying the research priorities to data dissemination).

Reviewer: 2
Dr. Alison Warren, George Washington University

Comments to the Author:
Thank you for the opportunity to review this manuscript. This is a timely subject in dire need of attention. The overall protocol is thorough and well-thought out. As such, my sparse suggestions are below.

Pg. 4: Lines 17-24: These statements are very important and correct and as such, a brief mention of contributing factors would add to the impact – i.e., owing to isolation, stigma-related behaviors/malignant social psychology, misperceptions regarding the disease itself that lead to family members misperception that persons with dementia won’t be affected by isolation because they won’t remember, lack of exposure/support etc, consequential depressed immune system etc.
Response: Excellent suggestion, we rewrote the introduction and added new paragraphs and references to address the consequences of the COVID-19 pandemic on people living with dementia. We also added information to address the contributing factors owing to isolation related consequences, such as: “There is 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 [7, 8].” In addition, we added information about the misinterpretation/myths about dementia during the pandemic, such as: “During the COVID-19 lockdowns, some claimed that the pandemic restrictions were unnecessary since the virus predominately impacted the mortality of older adults [12, 13, 14], and especially older adults living with dementia [6, 15]. Lichtenstein asserts that blatant discrimination and ageist isolation
policies were largely accepted, especially as a tool to end financial crises and COVID-19 lockdowns [14]. 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 [15, 8].”

Line 33: a brief operational definition of stigma (other than the parentheses) would be helpful at this juncture.
Response: We agree, and a definition and references for stigma have been added to the manuscript rather than the parenthesis.

Line 52: If including to date of this manuscript, please specify considering the lack of consensus of the pandemic.
Response: A sentence and a reference have been added to address the lack of consensus of the pandemic. For example, we added that: “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 [16].”

Pg 8: Line 33: It would be helpful to know how you are selecting the person with dementia for consultation – this is a crucial perspective, and understanding the type and stage might be helpful, particularly for future studies.
Response: Excellent suggestion, we have added a section to provide more information on the selection of our advisory panel.
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 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 (PAC), Certified Professional Consultant on Aging (CPCA), as well as 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 honored to partner and collaborate with this outstanding advisory panel and will work to ensure that their voices are prioritized throughout the scoping review processes (from identifying the research priorities to data dissemination).

Reviewer: 3
Dr. Hiroshige Matsumoto, The University of Tokyo

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Without a hypothesis or rationale for the stigma of dementia increasing or changing in nature during the COVID-19 period, it is difficult to understand the purpose of this review.

Although Bacsu et al. (2021), cited in the paper, summarizes the effects of COVID-19 on people with dementia, the impact of stigma is not mentioned in it.

However, Bacsu et al. (2022) and Lagacé et al. (2021) cited in the paper seem to address the characteristics of dementia-related stigma in COVID-19. Specifically describing the necessity to explore the stigma of dementia in COVID-19, citing the findings that have already been identified, will contribute to the reader's understanding of the significance of the present review.

Response: Excellent suggestions, we rewrote the introduction and provided additional paragraphs and references to discuss the existing literature and emphasize the study’s rationale and the importance of studying dementia-related stigma within the context of the COVID-19 pandemic. We have added some of the new paragraphs below.

Research shows that the COVID-19 pandemic has perpetuated stigmatization towards groups deemed as being more at risk to the virus, such as people living with dementia [8, 9]. Stigma is defined as any negative stereotypes, prejudice, or discriminatory actions or behavior towards people living with dementia [10, 11]. During the COVID-19 lockdowns, some claimed that the pandemic restrictions were unnecessary since the virus predominately impacted the mortality of older adults [12, 13, 14], and especially older adults living with dementia [6, 15]. Lichtenstein asserts that blatant discrimination and ageist isolation policies were largely accepted, especially as a tool to end financial crises and COVID-19 lockdowns [14]. 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 [15, 8].

Stigma of dementia has critical consequences such as anxiety, depression, poor mental health, and a decreased quality of COVID-19 care [16] 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 [6, 16, 17]. 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 [16]. 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 programs, and social support [5]. However, there is a dearth of research synthesizing 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 [18]. 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.

2) Study design: Methods - inclusion and exclusion criteria

Please explain how the authors determine the "inclusion criteria iv) address stigma (stereotypes, prejudice, or discrimination) of dementia during the COVID-19 pandemic".

How do the authors determine that the time period covered by the collected studies is the COVID-19 pandemic period? Some studies published between January 13, 2020 and June 30, 2023 may not be affected by COVID-19, depending on the region and time period. For example, if a study is conducted in the U.S. in 2019 and published in February 2020, it would not seem appropriate to treat that study as a COVID-19 epidemic study. This is because the stigma investigated in that study would not be affected by COVID-19.
Response: Excellent question, our team has discussed this issue about papers being published during our selected timeframe (e.g., conducted in 2019 but published in 2020, or even published more recently in 2023) but does not address the context of the pandemic. Thus, if a study addresses stigma of dementia but does not address the COVID-19 pandemic context, it will be excluded. We have added this intersection between dementia-related stigma and the pandemic context within our exclusion criteria (“does not address both stigma of dementia and the COVID-19 context…”).

3) Research ethics: Methods
The authors declare that ethics approval is not required. Please ensure that the members of the advisory committee, including the dementia patient being consulted, are not research participants.
Response: The members of the advisory committee are not research participants, rather they are members of the research team. Additional information has been added to discuss the advisory panel.

Also, working with the advisory panel would be significant and would be a strength of this review. I suggest adding a description of the details of the collaboration, i.e., when and how to work with them.
Response: Excellent suggestion, we have added additional paragraphs and a relevant reference to address the details of collaboration and more information about the advisory panel.

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 [23]. 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 prioritized 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.

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Reviewer: 4
Dr. Perla Werner, Univ Haifa
Comments to the Author:

I suggest to accept the ms as is

Response: Thank you for the comment, greatly appreciated.

### VERSION 2 – REVIEW

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<th>Koeki Zaidan Hojin Tokyo-to Igaku Sogo Kenkyujo</th>
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