PEER REVIEW HISTORY

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ARTICLE DETAILS

| TITLE (PROVISIONAL) | Protocol for a scoping review of resilience of family caregivers of people with dementia in South Korea |
|---------------------|--------------------------------------------------------------------------------------------------|
| AUTHORS             | Seo, Hyun-Ju; Choi, Min-Jung; Park, Song-I; Park, Jeong-hwan                                   |

VERSION 1 – REVIEW

| REVIEWER             | Robles-Bello, María                                                                            |
|----------------------|------------------------------------------------------------------------------------------------|
|                      | University of Jaen                                                                            |
| REVIEW RETURNED      | 21-Nov-2021                                                                                    |

GENERAL COMMENTS

With regard to the definition of resilience, I must say that the reference used by the authors does not correspond to any of the authors of the different currents of study within resilience. It is important that they focus on what theoretical perspective they are going to follow for their study as it is a complex construct due to the variations in psychological functioning between areas and between risk situations (intra- and inter-individual variability) and due to the instability of the phenomenon of resilience. Therefore, there are person-centred definitions, outcome-centred definitions, and process-centred definitions, each with representative authors. I insist, this reference number 8 does not represent it:

8. Herrman H, Stewart DE, Diaz-Granados N, et al. What is resilience? Can J Psychiatry 2011;56(5):258-265.

With regard to Confucian values, you should specify them with regard to the family, for example, do you mean that the elderly tend to be cared for in the family and not in residential care, if that is the case, you should provide data on this.

Before talking about research on resilience in the field of family caregivers in this group of people in your country, you should do it globally in the world, for example, in the reference Sánchez-Teruel, D., Robles-Bello, M. A., Sarhani-Robles, M., & Sarhani-Robles, A. (2021). Exploring resilience and well-being of family caregivers of people with dementia exposed to mandatory social isolation by COVID-19. Dementia, 0 (0), 1-16. http://dx.doi.org/10.1177/14713012211042187

Resilience in family caregivers of people with dementia is studied.

With respect to the objectives the research questions asked are appropriate to the object of study. It is relevant to know which research theories are used to study the resilience of family caregivers of Koreans with dementia? Although here I would have added which psychological variables (e.g. optimism, self-efficacy, etc.) modulate resilience? The authors also add the questions:

What instruments are used to measure the resilience of family
caregivers of Koreans with dementia, what are the correlates and health outcomes of resilience in this population, what interventions enhance the resilience of family caregivers of Koreans with dementia, and what interventions improve the resilience of family caregivers of Koreans with dementia?

The study period is appropriate, covering the period from 2000 to 2021, but it is already becoming outdated, and needs to be updated, since in that period at least there has been a global pandemic caused by COVID-19, which we are still suffering from and about which nothing is said. The last two years (2020-2021) the effect of COVID-19 has undoubtedly been tragic for the elderly population and this may have had a traumatic effect on the family carers who looked after them. Please reflect on this, you could also devote a section to the data in a differentiated way in recent years. Unfortunately I am not an expert in the type of methodology used by the authors but I understand that in any study presented as a systematic review they should not leave us wanting to know what is going to happen, what I understand is that they are showing us how they are going to do it. The authors say that "The results of this review will be presented at conferences and published in a scientific journal". I don't quite understand this, and I apologise to the authors.

| REVIEWER                     | Rivera-Navarro, J.                     |
|------------------------------|---------------------------------------|
|                              | Univ Salamanca, Sociology              |
| REVIEW RETURNED              | 05-Jan-2022                           |

| GENERAL COMMENTS             | This is paper which sets out a protocol for a scoping review of resilience of family caregivers of people with dementia in South Korea. I think the theoretic frame of the paper is perfect; the research question are very appropriate and the approach on ethics and dissemination are aso appropriate. I expect your copping review is publisched also and you are able to clarify the development of resilience in informal caregivers of persons wity dementia in South Korea |

| REVIEWER                     | Tedrus, Gloria                        |
|------------------------------|---------------------------------------|
|                              | Pontifícia Universidade Católica de Campinas |
| REVIEW RETURNED              | 22-Jan-2022                           |

| GENERAL COMMENTS             | Study protocols: Protocol for a scoping review of resilience of family caregivers of people with dementia in South Korea. The article is well structured for the evaluation of a study according to the guidelines suggested by followed the methodological framework introduced by Arksey and O’Malley and the methodology manual published by the Joanna Briggs Institute for scoping reviews. The topic is clearly discussed. The only point that needs to be included in the selection of studies to be analyzed is the classification of the disease - dementia (CDR). Another limitation that was observed is that there are other databases that were not included. |

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| REVIEW RETURNED              |                                       |
With regard to the definition of resilience, I must say that the reference used by the authors does not correspond to any of the authors of the different currents of study within resilience. It is important that they focus on what theoretical perspective they are going to follow for their study as it is a complex construct due to the variations in psychological functioning between areas and between risk situations (intra- and inter-individual variability) and due to the instability of the phenomenon of resilience. Therefore, there are person-centred definitions, outcome-centred definitions, and process-centred definitions, each with representative authors.

I insist, this reference number 8 does not represent it: Translated with www.DeepL.com/Translator (free version)8. Herrman H, Stewart DE, Diaz-Granados N, et al. What is resilience? Can J Psychiatry 2011;56(5):258-265.

**Answer:** Yes, you made a good point. However, because there is no scoping or systematic review study regarding definitions and theories of resilience in the context of dementia caregiving in Korea, we do not know what theoretical perspectives have been used in Korean resilience research. Therefore, we will examine the theories and definitions that have been used in Korean resilience studies. That is the main reason we plan to conduct a scoping review of resilience of family caregivers of people with dementia in South Korea. Based on your inquires of definitions and theories in resilience, we added the following comments in the manuscript:

Because resilience is a complex multidimensional construct, it may not be clearly delineated.\(^\text{16,17,20}\) Depending on biological, psychological, sociocultural, and environmental factors, the definitions of resilience are diverse.\(^\text{16,21,22}\) There are three dominant theoretical models that address resilience and those summarize resilience as a personal trait that enables an individual to overcome adversity, as a dynamic process to promote positive adaptation, and as an outcome itself as a consequence of a stressful event.\(^\text{16,17,20,23}\)

We want to comment on the reviewer’s comment regarding three definitions of resilience. We added the following comments in the manuscript:

In a recent review of studies to identify existing theoretical models and measures of resilience in caregivers living with dementia patients, there was significant variability and inconsistency in definitions and measures of resilience.\(^\text{17,37}\) The reviewer pointed out that three comprehensive theoretical frameworks that regard resilience as a personal trait, process, and outcome require additional validation and conceptualization in the circumstance of dementia caregiving. In addition, the researchers highlighted a lack of a widely accepted resilience theory or conceptual framework. However, most of the studies included in the review were conducted among Caucasian populations in Western countries,\(^\text{16,17,20,37}\) and we do not know how caregiver resilience may be conceptualized and theorized in other cultures. Due to a lack of research regarding definitions and theories of resilience in the context of dementia caregiving, we do not know what theoretical perspectives have been used in Korean research on resilience.

With regard to Confucian values, you should specify them with regard to the family, for example, do you mean that the elderly tend to be cared for in the family and not in residential care, if that is the case, you should provide data on this. Before talking about research on resilience in the field of family caregivers in this group of people in your country, you should do it globally in the world, for example, in the reference Sánchez-Teruel, D., Robles-Bello, M. A., Sarhani-Robles, M., & Sarhani-Robles, A. (2021). Exploring resilience...
and well-being of family caregivers of people with dementia exposed to mandatory social isolation by COVID-19. Dementia, 0 (0), 1-16. Resilience in family caregivers of people with dementia is studied.

**Answer:** You made a good point. We didn’t explain about Confucian values in detail in the first manuscript. In Confucianism, the elderly usually tends to be cared for by and within the family, especially by adult children who care for their elderly parents within their home. Korean elderly may be also sent to residential care. However, Korean children still feel a cultural responsibility to take care of older parents and as a result, may experience depression, helplessness, and guilty feelings if they feel like they “abandoned” their parents because they sent them to a residential facility for skilled care. In the manuscript, we explained this issue in detail (pp. 4-5).

➢ For your inquiry about data related to the elderly being cared for in the family, please see the following sentence in the manuscript: “approximately 55%-85% of people with dementia are taken care of by family members in Korea (Lee, 2019; Oh, 2020).

-Regarding this point: “Before talking about research on resilience in the field of family caregivers in this group of people in your country, you should do it globally in the world” You are right. We put the following sentences in the manuscript (p 4-5) “Caretaking role for parents varies from country to country and people in some cultures often take care of elderly family members without Confucianism.7-8,11-12 However, Confucianism has a strong impact on caregiving in Korean culture. Confucianism adds an extra level of expectation of responsibility in caretaking and also adds to the caregiver burden.”

-We also want to focus on filial piety, moral, and ethical norms for parent-child relationships in Confucianism related to caregiving in our Korean culture. A more detailed explanation is provided in the manuscript (pp. 4-5), as seen below.

In Korea, the concept of resilience was introduced in the late 1990s and has been studied across disciplines, mostly among Koreans with specific health problems.24 Because resilience is influenced by diverse sociocultural factors,25 it is especially crucial to understand the phenomenon of resilience from a cultural perspective. Caretaking role for parents varies from country to country and people in some cultures often take care of elderly family members without Confucianism.7-8,11-12 However, Confucianism has a strong impact on caregiving in Korean culture. Confucianism adds an extra level of expectation of responsibility in caretaking and also adds to the caregiver burden. For example, in Korea, resilience among family caregivers for people with dementia is dominated by Confucian values and beliefs. The family is regarded as the first agent of care for the elderly, an idea based on the traditional Confucian practice of filial piety, moral, and ethical norms for parent-child relationships.26,27 Adult children view taking care of older parents as an obligation and responsibility, according to traditional Confucian beliefs.28-30 Due to the traditional Confucian value of strong family bonds, approximately 55%-85% of people with dementia are taken care of by family members in Korea.31,32 As a result, when older parents are sent to residential facility care, Korean children experience depression, helplessness, and guilty feelings about “abandoning” their parents.33-35 Thus, the phenomenon of resilience for Korean family caregivers with dementia patients also needs to be understood within a Korean cultural context.

With respect to the objectives the research questions asked are appropriate to the object of study. It is relevant to know which research theories are used to study the resilience of family caregivers of Koreans with dementia? Although here I would have added which psychological variables (e.g. optimism, self-efficacy, etc.) modulate resilience?

The authors also add the questions: What instruments are used to measure the resilience of family caregivers of Koreans with dementia, what are the correlates and health outcomes of resilience in this population, what interventions enhance the resilience of family caregivers of Koreans with dementia, and what interventions improve the resilience of family caregivers of Koreans with dementia?

**Answer:** Thank you for your comments. You mentioned “which research theories are used to study the resilience of family caregivers of Koreans with dementia?” The review question regarding research theories is in the first manuscript.
1. What research theories have been used to study the resilience of family caregivers for Koreans with dementia?

➢ The reviewer wants to add which psychological variables (e.g. optimism, self-efficacy, etc.) modulate resilience. However, we don’t know which variables have used for family caregivers of Koreans with dementia yet. This study will be the first scoping review on this topic. We will study moderator or mediator of resilience in a future study.

The study period is appropriate, covering the period from 2000 to 2021, but it is already becoming outdated, and needs to be updated, since in that period at least there has been a global pandemic caused by COVID-19, which we are still suffering from and about which nothing is said. The last two years (2020-2021) the effect of COVID-19 has undoubtedly been tragic for the elderly population and this may have had a traumatic effect on the family carers who looked after them. Please reflect on this, you could also devote a section to the data in a differentiated way in recent years.

Answer: You’re right. We missed the COVID-19 pandemic effect on family caregivers with dementia patients. Therefore, we added the following in the introduction:

According to the Ministry of Health Welfare in South Korea, the coronavirus disease 2019 (COVID-19) resulted in 13, 375, 818 patients and 16, 590 deaths in South Korea as of April 1, 2022. Those aged over 70 years accounted for approximately 82% of deaths from COVID-19. In particular, the COVID-19 global pandemic put patients with dementia in a vulnerable situation. Social distancing and self-isolation during COVID-19 have a serious effect on worsening cognitive symptoms and behavioral disturbances to patients with dementia. In addition, dementia was a significant risk factor for mortality among COVID-19 patients in South Korea. Taken together, family caregivers of dementia patients are facing new challenges due to COVID-19.

Dementia is a clinical syndrome that encompasses a variety of neurological disorders including cognitive, behavioral, emotional, and social impairment, which requires high caregiving demands in long-term care. People with dementia and their family caregivers can experience psychological, physical and economic difficulties. During the COVID-19 pandemic, family caregivers with people with dementia experienced higher levels of anxiety, depression, stress, and caregiver burden than before the pandemic.

➢ We will also update our search strategy in each database to include current research evidence on the resilience of family caregivers of patients with dementia during the COVID-19 pandemic. As a result, we deleted the search date of our sample search strategy for ovidMedline, described in appendix A.

Reviewer: 3

The only point that needs to be included in the selection of studies to be analyzed is the classification of the disease - dementia (CDR).

Answer: Thank you for your accurate comment. We will additionally extract and present the data of studied populations, including dementia type, severity of the dementia, and relationship with the patient (line 1 and line 23, page 10). We added the following in the manuscript:

4. Studied population(s) (e.g., dementia type, severity of the dementia, relationship with the patient)

The tables will display the results based on study publication year and study designs, care recipient characteristics (diagnosis, severity), properties of resilience measures, factors significantly affecting resilience among family caregivers, interventions to improve resilience of Korean family caregivers, control group, outcomes, and study findings. In addition, a narrative description of study results will accompany the descriptive presentation of the results by grouping the data into summaries of review questions for a better exposition of the findings.
Another limitation that was observed is that there are other databases that were not included.

**Answer:** We will add the PsycINFO database in order to improve the comprehensiveness of searches as you advise. Therefore, we revised the methods section in the Abstract (11 lines, 1 page) and in METHODS AND ANALYSIS (19 lines, 7 pages).

We truly appreciated the thoughtful and critical comments by reviewers. This revision has been made based on reviewers’ comments, which improved the quality of the manuscript. We appreciate your efforts.