Original Research Article

EXPERIENCES OF FAMILIES CARING FOR THE ELDERLY WITH DEMENTIA: SCOPING REVIEW

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ABSTRACT

Introduction. The increase in life expectancy of the elderly continues to increase, which has implications for the increase in the incidence of Alzheimer's dementia in the elderly. The elderly with Alzheimer's dementia will experience changes that cause them elderly to be different from their previous personality and behaviour. This will be a burden for the family.This study was to obtain an overview of families' experiences in caring for the elderly with Alzheimer's dementia. **Methods.**The studyused is a scoping with conducting a focusing review with the PEOS framework (Population, Exposure, Outcome and Study Design), conducting literature searching using relevant databases. Select relevant studies, perform data extraction, analyze and report results. PRISMA Flowchart (Preferred Reporting Items for systematic reviews and Meta-Analyses) was used to describe the literature search flow about experiences of families caring for the elderly with dementia. **Results & Analysis.** Eight (8) literatures were selected, and positive and negative themes emerged. The upbeat theme is that religious and cultural beliefs patiently cause families to care for the elderly with Alzheimer's dementia. While the negative themes that emerged were Caregiver experiences (emotional and psychological), Loss and stress. **Discussion.** The most common theme in this study is a negative theme, so it is necessary to be aware of the importance of mentoring and support assistance for families who care for the elderly with dementia.

Keywords: family, experience, elderly, alzheimer's dementia

INTRODUCTION

Life expectancy in Indonesia continues to increase, along with the number of elderly people. In 2000 the number of elderly population reached 7.28% and increased in 2020 to 11.34%. This increase in the number of elderly should be watched out for because there may be an increase in diseases caused by degenerative processes, such as Alzheimer's. If the elderly with Alzheimer's cannot live independently, it will become a burden for the family. The worldwide incidence of Alzheimer's dementia is increasing rapidly. It is currently estimated to approach 46.8 or 50 million people diagnosed with dementia worldwide, 20.9 million in the Asia Pacific (Alzheimer's Disease International, World Health Organization, 2017). There are about 10 million new cases every year. In Indonesia alone, it is estimated that

there are around 1.2 million people with dementia in 2016, which will increase to 2 million in 2030 and 4 million people in 2050 (Alzi, 2019).

Elderly with Alzheimer's dementia will experience memory impairment on things that have just happened, difficulty focusing, unable to do usual daily activities, experiencing disorientation or confusion over time, some difficulty understanding visuospatial, communication problems, putting things away -personal items are not in place, to make wrong decisions, withdraw from association until there is a change in behaviour and personality. Changes in the elderly who are so different from their previous personality and behaviour, of course, will be troublesome for the family who takes care of them and will be a burden to the family (ALZI, 2019). Caring for someone with Alzheimer's disease is a unique experience and not an easy one. Challenges in caring for the elderly can lead to stressful conditions because they have to deal with changes in the behaviour and personality of people with Alzheimer's. Daily activities such as bathing, dressing, and eating, which can be done quickly, become difficult for sufferers. Families as caregivers for people with dementia at home tend to experience bio-psycho-socio-cultural-spiritual friction during the treatment

process. Conditions of physical and psychological exhaustion, changes in roles and relationships in daily life, and the lack of knowledge of the caregiver's family about the condition of dementia experienced family members can affect the quality of care for people with dementia(Anung Ahadi Pradana, 2019).

METHOD AND ANALYSIS

The method used is scoping review. Scoping review is used to identify in-depth and comprehensive literature obtained through various sources with various research methods and has relevance to the research topic (O'Malley, 2005). This review uses a methodology for clustering review as suggested by Arksey and O'Malley (2005) and further developed by Levac (Danielle Levac 1, 2010). There are four reasons to conduct a scoping review: (1) to examine the scope and nature of the research activity, and (2) to determine the value of conducting a full systematic review. (3) to summarize and disseminate research findings, and (4) to identify research gaps in the existing literature. The stages carried out in this scoping review consist of: (1) identifying the focus of the review, (2) developing a review focus and search strategy using the PEOS (Population, Exposure, Outcome and Study Design) format, (3) identifying

relevant studies, (4) Mapping data using PRISMA Flowchart (Preferred Reporting Items for Systematic reviews and Meta-Analyses) (5) Data Extraction by compiling, summarizing and reporting the results and discussion.

Step 1: Identify the focus of the review

Using the question "How is the family's experience in caring for elderly clients with Alzheimer's?". For this study, *scooping review* was defined as a research synthesis that aims to map the literature on the topic of family experiences in caring for elderly clients with Alzheimer's and identify key concepts, research gaps, and as a source of evidence to inform practice, policy, and research about families caring for the elderly with Alzheimer's.

Step 2: Develop a review focus

Using PEOS In developing a review focus and search strategy, the researcher uses the Population, Exposure, Outcome, and Study Design (PEOS) format in managing and solving the review focus. The use of PEOS assists in identifying key concepts in the review's focus, developing appropriate search terms to describe the problem, and determining inclusion and exclusion criteria. The focus of the search for articles is qualitative research, so PEOS is considered appropriate to use (Josette Bettany, 2012).

Tabel. 1 Framework PEOS

Population	Exposure	Outcome	Study Design
Family Care-Giver Family's	Elderly with Alzheimer Elderly with Dimentia	Experience Perspective insight	All research studies /study design related the experience of family/care-giver with Elderly with Alzheimer

Step 3: Identify relevant studies

The article search strategy was developed using several databases. The database used is Google Scholar, Pubmed, and Proquest. The data were filtered according to the criteria that the researcher determined. The data filtering process uses PRISMA Flowchart. PRISMA is the

Preferred Reporting Item for Systematic reviews and Meta-Analyses, developed to assist authors in reporting Systematic Reviews (SR) and MetaAnalyses (MA) (Jeroen P. M. Peters, 2015). The selection of studies was determined using the inclusion and exclusion criteria. The Inclusion criteria are research journal in 2022, Quantitative and qualitative research and s systematic review, meta-analysis, and exclusion criteria book and Research journal under 2022.
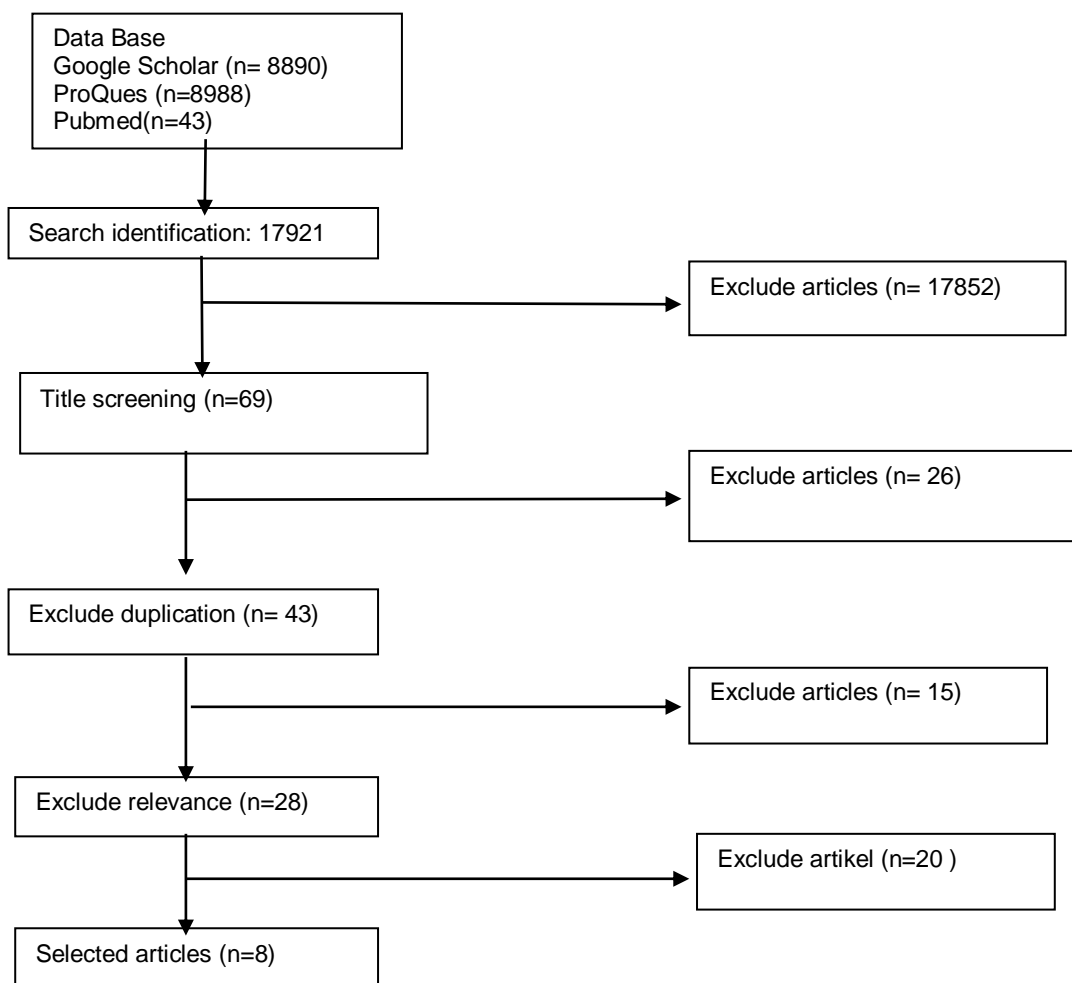
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Figure 1. PRISMA Flow Chart of Experiences of Families Caring for The Elderly With Dementia

Step 4: Mapping Data

Data from 8 articles were extracted to include critical criteria such, study population, research objectives, methodology, and significant findings or recommendations. The authors independently recorded the information and then compared the extracted data. The author also consults with the supervisor

until all content is analyzed and becomes a theme.

Step 5: Compile, summarize and report the results and discussion.

Similar to Levac et al. 2010, the authors used a three-phase approach to compile, summarise, and report the results. First, a descriptive numerical analysis includes the number of articles, year of publication, and type of study. Second, strengths and weaknesses in the literature were identified through a thematic analysis of the studies included in the report. The final phase of this stage is a review of the implications of the findings concerning future research, practice and policy(Danielle Levac 1, 2010).

RESULT

The following table presents a summary of detailed content analysis from eight sources that focus on the experiences of families caring for the elderly with dementia (Stefanny Guerra, 2022; Iveris L Martinez, 2022; Melissa L. Harris, 2022; Suzanne H. Hammad, 2022; Sunshine M Rote, 2022; Chejor, 2022; FrankKyei-ArthurI, 2022; Arantxa Gorostiaga,2022)

Table 3. Themes and Sub-Themes

Theme 1: Negative Feelings	
Caring expectations lead to incompatibility with legal services and a reluctance to leave.	(Stefanny Guerra, 2022)
The belief that the family should serve as an older adult's natural support structure could cause the health and social systems of care to disregard the unique requirements of the Latino population.	(Iveris L Martinez, 2022)
1. Caregiver experiences (emotional and psychological), 2. Dementia patient responses (emotional, psychological, and behavioural), 3. Dementia patient cognition, 4. Loss, 5. Future concerns, 6. Reliance, 7. Learning to the caregiver, 8. Caregiver perspectives, 9. Caregiver perspectives, 10. Care strategies. Before and during the epidemic, caregivers described numerous difficulties in providing care	(Melissa L. Harris, 2022)
1. Time limits, 2. Lack of support 3. The high expense of proper care. 4. However, more than half of the carers expressed stress due to these three factors.	(Sunshine M Rote, 2022)

1. Living with dementia and caring for others 2. Impediments to dementia care services 3. Stigma and prejudice; and legal and financial difficulties. 4. Elderly immigrants with dementia and their families face numerous difficulties due to living with dementia and providing care.	(Chejor, 2022)
Among primary caregivers, depression and anxiety were associated with the frequency of problem behaviour, subjective burden, health, and the comorbidity between anxiety and depression	(Arantxa Gorostiaga, 2022)

Theme 1: Positive Feelings	
Rewarding aspects of caregiving	(Melissa L. Harris, 2022)
Reasons and motivations for providing care, the role of the extended family, socio-demographic characteristics of caregivers, their responsibilities, and how these intersect, socio-religious attitudes toward providing care for the elderly, social stigma, firsthand experience with dementia, and coping mechanisms are just a few of the topics covered.	(Suzanne H. Hammad, 2022)
Over 90% of survey respondents stated that they offer care to assist family members and out of religious conviction, which supported these themes	(Sunshine M Rote, 2022)
1. Caring for older people brought both primary and secondary caregivers tangible and intangible benefits. 2. The intangible benefits include blessings 3. Skill development 4. Better personal qualities 5. Family cohesiveness, and health awareness. 6. The physical benefits included gifts. 7. Positive experiences can lessen caregiver stress and burnout. In order to improve the good experiences of family carers, policymakers and social workers should develop innovations.	FrankKyei-ArthurI, 2022)

DISCUSSION

The emotions that affect families who care for loved ones with dementia share specific common patterns, according to several studies that provided the data for this study. The study results make two of these themes-the actual ramifications of the numerous hidden emotions-clear. The results show that the sub-theme of unfavourable feelings in the caregiver's family is far more common than the sub-theme of favourable feelings. Researchers, in particular health professionals, are obligated to emphasize the impact of unpleasant feelings on the family members of the care even when the prior understanding is not a norm.

The finest care for adults with dementia can be hindered by negative emotions like sadness, solitude, the risk of self-harm, violence toward people with dementia, and ignorance about the dementia disease process.If you look closely, you will notice that a sub-theme that appears in the researcher's eight publications brings together a variety of negative emotions that caregivers go through. It can be concluded that all dementia caregivers experience sad emotions to some extent. The picture above cannot be used as a standard to verify the reality of the situation because it depicts a family of values that is both too broad and too narrow for researchers to identify themes and sub-themes of experience of families caring for family members with dementia. Health professionals may better understand the benefits of coaching and supporting families of at-home caregivers as a result of the findings from the sub-themes.

Religious and cultural reasons are positive themes. Families hold cultural and religious beliefs in caring for the elderly with dementia. Cultural and religious aspects are the basis and motivation for them to continue caring for their parents with dementia. So that the family can be patient with the changes that occur to their parents who have dementia. In human life, behaviour or treatment in the family cannot be separated from the culture adopted by the family. As is known, quoted from the definition of culture put forward by Prof. Koentjaraningrat (one of the Indonesian anthropologists) that culture is the whole system of ideas, actions and human creations in the context of community life, which is made into the human property by learning. This implies that what humans do is a series of ideas and actions recognized by the community as something that has happened from generation to generation for a long time. Furthermore, in that culture, there is what is called the cultural value system, which is the highest level and the most abstract of customs. However, cultural values serve as guidelines for human life in society. On this basis, what family members do in family life has been outlined in their culture and passed down from generation to generation. Ethnographic descriptions of ethnic groups in Indonesia provide an overview of parents' position in the kinship system and society. The elderly are a respected and valued social group. Attitudes and treatment of parents are expressed symbolically in the marriage ceremony (Achmad, 2018).

For the Nias people, old age in the family is considered a time to be an advisor, respected by all members of the

family and community and become a person who in the legend of the Nias people is called TodoHia. His advice is always obeyed because he is considered a person who should be trusted and wise. An older adult has much experience and is a source of stories, legends and myths. Old age is termed in Nias, Bawapasseso, which means the grave's gate. According to them, death was near for them. Therefore the children and their descendants always take good care of them and care. Children will serve good food and excellent and proper clothes and obey their orders, and serve them with respect (Achmad, 2018).

In the Javanese ethnicity, the elderlyareentitled to high respect. Many live solely by receiving respect because of their excess knowledge of spiritual and practical matters. Nevertheless, respect can be reduced for those who are elderly and senile. The relationship of respect can be seen in the use of high language (krami) when speaking to parents, and in traditional *"priyayi"* families, people worship first before speaking. The life of the elderly is generally calm. They are beneficial for raising children in the family, and there is usually a warm and comfortable relationship between those older and those younger in the home. In fact, as part of the closeness of grandchildren and grandfather, it is necessary to make or buy pets so that the grandchildren and grandfather together take care of them (Achmad, 2018).

CONCLUSION

The theme that most often appears in this study is a negative theme, this can be used as a basis for researchers and other researchers to realize the importance of mentoring and assistance for families of caregivers of the elderly with dementia at home. It is necessary to develop further research, how health workers can create models to provide mental strengthening for families who have elderly people with dementia.

REFERENCES

Achmad, N. (2018). PERLAKUAN BUDAYA TERHADAP LANSIA : Studi Kasus Kehidupan Lansia Batak Karo, di Desa Lingga Sumatera Utara. *Prosiding Seminar Hasil Penelitian (SNP2M) 2018 (pp.240-244) 978-602-60766-4-9* (pp. 240-244). Medan: Bidang Ilmu Administrasi, Akuntansi, Bisnis, Dan Humaniora.

ALZI. (2019, 04 22). *10 gejala awal Demensia Alzheimer*. Retrieved from Alzheimer Indonesia: https://alzi.or.id/10-gejala-awal-demensia-alzheimer/

Alzi. (2019, 04 22). *Statistik tentang Demensia*. Retrieved from Yayasan Alzheimer Indonesia: https://alzi.or.id/statistik-tentang-demensia/

Anung Ahadi Pradana, J. S. (2019). Pengalaman Keluarga dalam Merawat Anggota Keluarga dengan Demensia: A Systematic Review. *Jurnal Penelitian Kesehatan Suara Forikes*, 80-87.

Arantxa Gorostiaga, I. E. (2022). Primary and Secondary Caregivers of People with Dementia(PwD): Differential Patterns and Implications forPsychological Support. *Healthcare*, 1-18.

Chejor, P. B. (2022). Experiences of older immigrants living with dementia and their carers: a systematic review and meta-synthesis. *BMJ Open* , 1-11.

Danielle Levac 1, H. C. (2010). Scoping studies: advancing the methodology. *PubMed.gov*, doi: 10.1186/1748-5908-5-69. PMID: 20854677; PMCID: PMC2954944.

FrankKyei-ArthurI, S. D. (2022). Exploringpositiveexperiencesofprima ryandsecondarycaregiversofolderpers onsinresource-limitedurbansettingsinAccra,Ghan. *PLOS ONE*, 1-17.

Iveris L Martinez, E. A. (2022). The Experience of Alzheimer's Disease Family Caregivers in a Latino Community: Expectations and Incongruences in Support Services . *The Journals of Gerontology: Series B*, 1083-1093.

Jeroen P. M. Peters, L. H. (2015). Reporting Quality of Systematic Reviews andMeta-Analyses of OtorhinolaryngologicArticles Based on the PRISMA Statement. *PLOS ONE / DOI:10.1371/journal.pone.0136540* , 1-11.

Josette Bettany, S. (2012). *How to do systematic Literature Review in Nursing A Step-by-step guide.* London: RCN Publising Company.

Melissa L. Harris, M. G. (2022). Experiences of Family Caregivers of People with Dementia during the COVID-19 Pandemic. *Western Journal of Nursing Research*, 269-278.

O'Malley, H. A. (2005). Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, 19-32.

Stefanny Guerra, T. P. (2022). Experience of UK Latin Americans caring for a relative living with dementia: A qualitative study of family carers . *Sage Journal*, 1574-1595 .

Sunshine M Rote, H. E. (2022). Exploring Coping Strategies and Barriers in Dementia Care: A Mixed-Methods Study of African American Family Caregivers in Kentucky. *Sage Journal*, 1-10.

Suzanne H. Hammad, S. D.-W. (2022). Sociocultural insights on dementia care-giving in Arab and Muslim communities: the perspectives of family care-givers. *Published by Cambridge University Press* , 1-28.