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Quality of life for adult family caregivers of patients with dementia: a Systematic review

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ABSTRACT

Introduction: to evaluate problems and factors related to quality of life (QoL) for adult family caregivers (FCGs) of patients with dementia.

Methods: The study used a systematic review method with the guidelines of PRISMA 2020 and registered in PROSPERO CRD42023464726. The review focused on adult FCGs for people with dementia in the home setting. The literature was searched from four databases, including Scopus, Web of Science, CINAHL, and PubMed. This systematic review examined a subset of fifty-two out of a total of 2,263. The study used a narrative synthesis method to analyze the study.

Results: The result showed that the severity of a patient with dementia's condition had an essential role in the patient's state. It impacted the caregiver's condition indirectly. Personal strategies (coping, resilience, sense of coherence, and expressed emotion) had an essential role in the caregiver situation. A maladaptive strategy would increase the stress of the caregivers and lead to a burden and depression. Those conditions of the caregiver would affect their QoL.

Conclusions: Caring for patients with dementia is a huge psychological distress and burden on FCGs, which may negatively affect their quality of life in many aspects. Therefore, FCGs need education and support programs to maintain their overall aspect of quality of life and enable them to produce care for loved people.

Keywords: caregivers, dementia, quality of life (QoL)

Introduction

Global population aging is a reality. Additionally, as people age, the number of old-age persons with dementia (PwD) has increased. All disorders defined by cognitive and functional impairment fall under the umbrella of dementia, which is a chronic and complicated disease. The occurrence of this disease makes managing it a significant problem for social and health policies in wealthy nations. The significance of dementia issues on a global scale is seen in there were 46.8 million dementia sufferers worldwide in 2015, and by 2050, that number is projected to almost triple (Alzheimer's Association, 2017). Caring for these individuals is expensive, and their families also incur additional costs.

People with dementia suffer a severe lack of control, mental conditions, and behavioral difficulties (Yoro-Zohoun et al., 2020). Wandering behavior is a condition frequently displayed by PwD that entails regular, repeated, time-disordered, and/or spatially-disordered lapping activities, random and/or pacing habits and eloping, or getting lost unless accompanied (Algase et al., 2007). Previous reports showed that 6 out of 10 community-dwelling PwD have wandering activity (Alzheimer's Association, 2017); although incidence rates range by 17.4 percent for community-dwelling seniors, 50 percent for individuals with severe dementia, and 63 percent for community-dwellers (Cipriani et al., 2014). Dangerous wandering activities, such as eloping and getting lost outside (Algase et al., 2004), frequently lead to injuries (Pai and Lee, 2016, Rowe and Bennett, 2003). Family caregivers (FCGs) have the most challenging situation to care for their PwD due to their wandering.

Additionally, the provision of care for individuals with dementia imposes a significant burden on FCGs and is constrained by economic considerations, such as the reduction in productivity, which has a direct influence on the overall quality of life (Shikimoto et al., 2018). It has also been said that dementia is one of the disorders of burdening patients and the population of geriatric diseases (Matsushita et al., 2016). In comparison, the mental health status of older adult dementia FCGs is poor relative to that of older adult dementia-free caregivers. It is also believed that the stress caused by caring for them could be a factor in the collapse of home care and the neglect of the older-adults (Wang et al., 2014, Leggett et al., 2018). For the older adults with dementia, the value of informal human capital such as neighbors, colleagues, district groups and volunteers that will support their families in the neighborhood while strengthening public access is emphasized (Japan Ministry of Health Labour and Welfare, 2015).

Although the demand for caregivers is growing, there is a reality that only family members typically assume their responsibility for caring for the older adults living in their families. However, the strain of caring for the older adults can have a significant effect on FCGs' quality of life, contributing to social alienation, financial challenges, and psychological and physical fatigue (Knodel and Nguyen, 2015). FCGs face multiple challenges to maintain their other positions, including child-rearing, employment, and marriages. The impact on FCGs is very nuanced (Chaobankrang et al., 2019). Many FCGs are unpaid and have no bargaining power (Tamdee et al., 2019). According to the study, most over-stressed FCGs did not undergo any instruction before taking care of them (including those with dementia), and were self-taught mostly from practice, relationship, and appreciation. It has also been stated that the factors associated with stress of FCGs were the health status of FCGs, their faith in their treatment, the partnership between FCGs and the older individual adults, and the economic burden of care, as well as the condition of being elderly with dementia (Tamdee et al., 2019).

Therefore, the goal of this review was to evaluate different aspects of quality of life of FCGs affected by caring for elderly with dementia. As a consequence, it was expected to explain different factors that influence physical, psychological and social aspects of quality of life of community caregivers, especially unpaid caregivers.

Materials and Methods

The study used the systematic review methodology. The procedure involved including the formulation of a research question, establishment of criteria, development of a search strategy, exploration of relevant databases, registration of a protocol, evaluation of titles and abstracts, thorough examination of full-text articles, manual searching for additional sources, extraction of data, assessment of quality, verification of data accuracy, statistical analysis, double-checking of data, and composition of the manuscript.

Search Strategy and Screening

PubMed, Scopus, Web of Science, and CINAHL databases were searched for studies released between 2016 and 2022. Additionally, relevant studies were looked up in reference lists. There were no language restrictions, and translated foreign papers were available. There were both conjunctive and disjunctive relationships between the keywords and their combinations that were employed (and - or): “quality of life,” “family caregivers,” and “elderly/older adults/aged dementia.” The details of search strategy can be seen in Supplementary File 1.

First, the researcher screened for the titles that used the terms "quality of life" and "family caregivers of dementia." The selected articles were filtered using the inclusion criteria by all of the authors. Literature which did not fulfill the inclusion criteria were excluded, and the study population was other FCGs diseases. The study team debated the various findings until reaching an understanding over whether or not each research should be included.

Inclusion and Exclusion Criteria

Studies examining the quality of life of community FCGs of dementia patients were the inclusion criteria for articles. These articles discussed observational studies that were pertinent to the subject under investigation, including cross-sectional, correlational, and survey research. Additionally, papers addressing the burden of care and its impact on caregivers' physical and emotional health were looked for. Unpaid carers were among the specific inclusion requirements, and there was a connection between PwD and FCG (spouse, adult child, relative, and sibling).

Articles published prior to 2016, duplicate registrations, research involving formal (paid) carers, and patients receiving long-term care or in nursing homes were all excluded.

Critical Appraisal

There were 52 articles out of 2,263 articles that matched the inclusion criteria and were critically appraised with tools from the appraisal tool for cross-sectional studies (Alilyyani et al., 2018, Keyko et al., 2016). The dimensions, including introduction, methods, results, discussion, and others, were represented by 20 questions. The answers included yes, no, or do not know/comment. Critical appraisal was done by each author and the result for each article was discussed and categorized as low quality, medium, or high. All articles showed high quality, with scores ranging from 10 to 11. The details of the critical appraisal can be seen in Supplementary file 2.

Data Analyses

Narrative synthesis was employed in the study (Hinchcliff et al., 2012). Data were extracted and recorded using a table consisting of author names, year(s), methods, instruments, and findings, including factors related to, and variable dimensions. In addition, content analysis was used in this study (Nuryani et al., 2022). All of the authors read each article and labeled the meaningful context. Each important labeling was re-read by each author. Authors collected all of the labelings, then mapped and grouped them to categorize and sub-categorize.

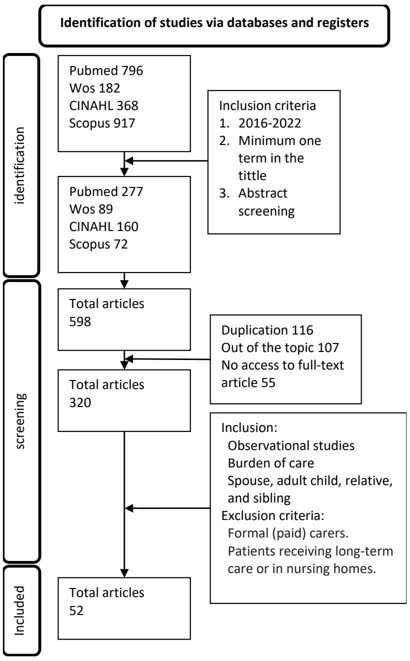

Figure 1 *Literature selection process*

First, researchers categorized problems and its factors. Specific terms were derived into subcategories such as problems were derived into mental and well-being, daily living, comorbid and overall quality of life. Besides, factors were derived into PwD factors and caregiver. PwD factors included type of dementia, impairment, and medication. Meanwhile, FCG factors included individual factors (demographic), health conditions, personality/traits, personal strategies, care activity factors, care activity knowledge, supports, and socioeconomic factors.

If the authors had different notions during categorizing and other opinions when grouping, these were discussed until reaching an agreement. The final results of categorizing can be seen in the results.

Results

A total of 2,263 articles were searched, although 1,665 of them were initially disqualified based on their titles, abstracts, and year published. The remaining 278 were rejected because they lacked full-texts, were out-of-topic, or duplicated. Two hundred and sixty eight studies were removed, leaving a total of 52 articles that met the inclusion criteria. Of the 52 research studies that were included in the final review, 20 studies directly examined quality of life, while the remaining 32 studies

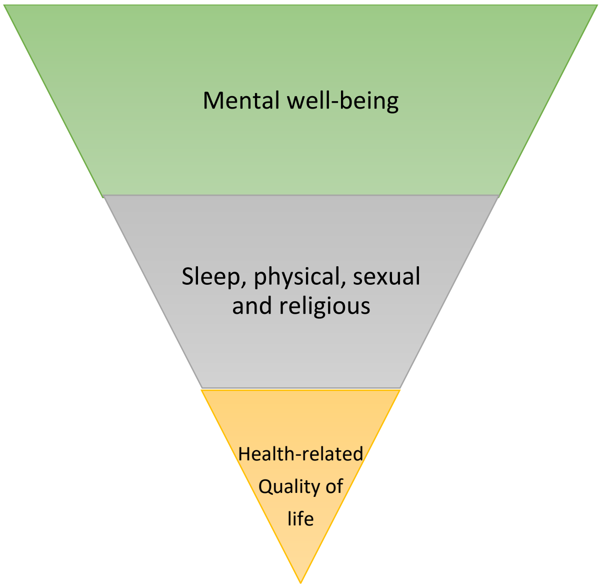

Figure 2 *FCG's problem.*

Table 1 Characteristics of the study

Country	Study
Asian	Chang et al. (2016); Chan et al. (2019); Yu et al. (2016); Kimura et al. (2019); Wang et al. (2020b); Morimoto et al. (2019); Honda et al. (2017); Tay et al (2016); Sittironnarit et al. (2020); Wang et al. (2020a); Liao et al. (2020); Ganapathy et al. (2020); Young et al. (2017); Koyama et al. (2017); Kim et al. (2017); Jeyagurunathan et al. (2017); Wong and Zelman (2020); Saffari et al. (2018); Liu et al. (2017); Khusaifan and El Keshky, (2017); Goren et al. (2016)
European	Joling et al. (2017); Oliveira et al. (2018); Zwingmann et al., (2019); Malak et al. (2016); Häikiö et al. (2020); Kerpershoek et al. (2018); Häusler et al. (2016); Clare et al. (2019); Tulek et al. (2020); Ruiz-Fernandez et al. (2019); Hvidsten et al. (2019); Millenaar et al. (2016); Välimäki et al. (2016); Parrotta et al. (2020); Konerding et al. (2018); Romero-Moreno et al. (2017); Rodríguez-Pérez et al. (2017); Borsje et al., (2016)
American	Polenick et al. (2019); Sutter et al. (2016); von Känel et al. (2019); Weisman de Mamani et al. (2018); Carletti Pessotti et al. (2018); Moon et al. (2017); Corey et al. (2020); Regier and Gitlin (2018); Aravena et al. (2018); Nogueira et al. (2017); Silva Leite et al. (2017b); Laks et al. (2016).
Multi-country	Five multi-country studies
Two eight-countries studies	Kerpershoek et al. (2018); Parrotta et al., (2020)
Two three-countries studies	Clare et al., (2019); Konerding et al. (2018)
One two-countries study	Joling et al. (2017)

were concerned with burden, psychological distress, sleep, and any negative effects of health on the physical, mental, and social aspects of quality of life.

Characteristics of the Study

The majority of the studies came from Asian countries which was 21 studies, followed by 18 studies from Europe and 12 studies from America (Table 1). There were five multi-country studies, including two eight-countries studies, two three-countries studies, and one two-countries study. Additionally, one review article did not include the characteristics of the study. The detailed summary of the studies can be seen in Supplementary file 3.

Analytical Findings

FCG's Problems

A total of eighteen articles consistently demonstrated a general decline in health-related quality of life. There were 15 specific problems that related to the quality of life (Table 1). The majority of FCGs problems were mental well-being problems, sleep,

Table 2 FCG's problems

Problem	Source
Mental well-being	
Mental health problems: psychological distress, psychological problems	Borsje et al. (2016); Goren et al. (2016); Laks et al. (2016); Malak et al. (2016); Millenaar et al. (2016); Sutter et al. (2016); Välimäki et al. (2016); Yu et al. (2016); Jeyagurunathan et al. (2017); Khusaifan and El Keshky (2017); Kim et al. (2017); Koyama et al. (2017); Liu et al. (2017); Rodríguez-Pérez et al. (2017); Romero-Moreno et al. (2017); Aravena et al. (2018); Carletti Pessotti et al. (2018); Regier and Gitlin (2018); Saffari et al. (2018); Chan et al. (2019); Hvidsten et al. (2019); Morimoto et al. (2019); Corey et al. (2020); Parrotta et al. (2020); Wong and Zelman (2020);
Burden/overburden	Sutter et al. (2016); Tay et al. (2016); Yu et al. (2016); Khusaifan and El Keshky (2017); Kim et al. (2017); Young et al. (2017) Liu et al. (2017); Silva Leite et al. (2017b);Young et al. (2017); Aravena et al. (2018); Regier and Gitlin (2018); Saffari et al. (2018); Wong and Zelman (2020); Hvidsten et al. (2019); Häikiö et al. (2020); Liao et al. (2020); Sittironnarit et al. (2020); Tulek et al. (2020); Wang et al. (2020a)
Life satisfaction	Rodríguez-Pérez et al. (2017); Romero-Moreno et al. (2017)
Well being	Konerding et al. (2018); Honda et al. (2017); Polenick et al. (2019)
Living well	Clare et al. (2019)
Health perception	Aravena et al. (2018)
Low self-competence for taking care of PwD	Millenaar et al. (2016)
Daily living	
Sleep problems (Insomnia/sleepiness/quality of sleep)	Goren et al. (2016); Laks et al. (2016); Honda et al. (2017); Liu et al. (2017); Corey et al. (2020)
Environmental problems	Rodríguez-Pérez et al. (2017)
Social problems	Chang et al. (2016); Konerding et al. (2018);Weisman de Mamani et al. (2018);
Physical problems (pain)	Goren et al. (2016); Laks et al. (2016); Kim et al. (2017);Konerding et al. (2018); Wang et al. (2020a)
Sexual problems	Nogueira et al. (2017)
Religious	Carletti Pessotti et al. (2018)
Comorbidity	
Hypertension	Laks et al. (2016)
Diabetes	
Overall quality of life	
Overall low health related-Quality of Life	Häusler et al. (2016); Millenaar et al. (2016); Tay et al. (2016); Välimäki et al. (2016); Jeyagurunathan et al. (2017); Kim et al. (2017); Moon et al. (2017); Oliveira et al. (2018); Saffari et al. (2018); Weisman de Mamani et al. (2018); Hvidsten et al. (2019); Ruiz-Fernandez et al. (2019); von Känel et al. (2019); Ganapathy et al. (2020); Häikiö et al. (2020);Liao et al. (2020); Tulek et al. (2020); Wang et al. (2020b)
Quality of Family Life	Kimura et al. (2019)

Table 3 Description of characteristics of patients with DM (n=300)

Factors related to FCG's problems		Sources
PwD factors	**Type of dementia**	
	YOD/EOD	Millenaar et al. (2016); Wang et al. (2020a)
	Type of dementia	Hvidsten et al. (2019) (FCG's QoL YAD worse than FTD)
	Severity of dementia	
	Severity	Välimäki et al. (2016); Aravena et al. (2018); Carletti Pessotti et al. (2018); Ruiz-Fernandez et al. (2019); von Känel et al. (2019)
	Frequency neuropsychiatric symptom/behavioral symptoms	Borsje et al. (2016); Honda et al. (2017);Koyama et al. (2017); Aravena et al. (2018); Carletti Pessotti et al. (2018); Regier and Gitlin (2018); Saffari et al. (2018);Ruiz-Fernandez et al. (2019); Liao et al. (2020); Parrotta et al. (2020); Wong and Zelman (2020)
	Impairment of older adults	
	Cognitive impairment	Nogueira et al. (2017); Tulek et al. (2020)
	PwD physical condition	Ruiz-Fernandez et al. (2019); von Känel et al. (2019)
	Lower functional status	Liu et al. (2017)
	Medication	
	Number of medications	Tulek et al. (2020)
FCG's factor	**Individual factor**	
	Gender Female	Nogueira et al. (2017); Borsje et al. (2016); Sittironnarit et al. (2020)
	Male	Oliveira et al. (2018); Hvidsten et al. (2019)
	Age 50-70 years	Borsje et al. (2016); Oliveira et al. (2018); Tulek et al. (2020)
	Ethnic	Ganapathy et al. (2020) (Chinese)
	Health condition	
	Medical comorbid/chronic disease	von Känel et al. (2019); Liao et al. (2020); Tulek et al. (2020)
	Physical function/health	Clare et al. (2019); von Känel et al. (2019)
	Psychological health	Clare et al. (2019)
	Somatic well-being	Aravena et al. (2018)
	Personality/traits	
	Personal values	Romero-Moreno et al. (2017)
	Personality traits	Kim et al. (2017); Morimoto et al. (2019)
	Optimism	Sutter et al. (2016)
	Personal strategies	
	Coping (positive factor)	Häusler et al. (2016); Joling et al. (2017); Rodríguez-Pérez et al. (2017); Corey et al. (2020)
	Resilience (positive factor)	Sutter et al. (2016); Carletti Pessotti et al. (2018)
	Sense of coherence	Sutter et al. (2016)
	Expressed emotion	Weisman de Mamani et al. (2018); Wong and Zelman (2020)
	Burden	Hvidsten et al. (2019); Liao et al. (2020)
	Depressive symptom	Hvidsten et al. (2019)
	Care activity factors	
	Management skills	Aravena et al. (2018)
	Care hours	Silva Leite et al. (2017a); Oliveira et al. (2018); Sittironnarit et al. (2020); von Känel et al. (2019); Parrotta et al. (2020); Wong and Zelman (2020)
	Ability to carry out ADL	Ganapathy et al. (2020)
	Adaptability	Kimura et al. (2019)
	Having a limited space	Tulek et al. (2020)
	Caregiver pain	Polenick et al. (2019)
	Caregiving competence	Kimura et al. (2019)
	Care activity knowledge	
	Experience caregiving	Clare et al. (2019)
	Health literacy	Häikiö et al. (2020)
	Level of needs	Kerpershoek et al. (2018)
	Satisfaction towards psychiatric care	Sittironnarit et al. (2020)
	Support	
	Family	Clare et al. (2019); Ruiz-Fernandez et al. (2019); Ganapathy et al. (2020); Liao et al. (2020)
	Relatives	Wong and Zelman (2020)
	Informal social support	Khusaifan and El Keshky (2017) Morimoto et al. (2019)
	Formal social support	
	Religious	Wong and Zelman (2020)
	Social economy	
	Education (positive)	Sittironnarit et al. (2020)
	Job (positive)	Sittironnarit et al. (2020)
	Working hours	Wang et al. (2020b)
	Financial problems	Sittironnarit et al. (2020)
	Taking care of another dependent	Sittironnarit et al. (2020)
	Stigma	Chang et al. (2016)

physical, sexual and religious. Overall low health-related to quality of life was reported by 18 studies and one study reported quality of family life.

The highest problem was mental health problems followed by burden/overburden. Three studies found FCG's well-being, and two studies found life satisfaction were degraded. Living well, health perception, and low self-competence for taking care of PwD were found in one study for each category.

Daily living problems included sleep problems, environmental, social, physical (pain), sexual, and religious. The majority of daily living problems were sleep problems, and physical. Meanwhile comorbidities included hypertension and diabetes. However, the comorbidities were not clear because the studies did not identify whether FCGs got the comorbidity during taking care or before.

According to Figure 2, the major problems of FCG's are mental well-being, followed by daily living problems, including sleep, physical, sexual, and religious. All those problems would affect health related to quality of life. Mental health problems are psychological distress and psychological problems. Furthermore, the problems increased to be burden/overburden. Those situations impact FCG's daily living and health related to quality of life.

Factors Related to FCG's QoL

Factors related to FCG's quality of life involved two main factors, including PwD's and FCG's condition. PwD's condition included type of dementia, severity and impairments. On the other hand, FCG's factors are individual factors, health status, personality trait, personal strategy, care activity, support, and social economy.

FCG's Relationship

Nine studies found that the FCGs relationship was significant to their quality of life. On the contrary, six studies found that it was not significant (Liu et al., 2017, Regier and Gitlin, 2018, Hvidsten et al., 2019, Ruiz-Fernandez et al., 2019, Liao et al., 2020, Polenick et al., 2019, Chan et al., 2019). The majority of the studies did not identify and did not measure it, three studies focused on the spouse (Nogueira et al., 2017, von Känel et al., 2019, Häusler et al., 2016) and one focused on the child as caregiver (Wang et al., 2020b). Borsje et al. (2016) found being spouse has higher psychological distress than child. This was supported by Jeyagurunathan et al. (2017) and Clare et al. (2019) who found caring for spouse was significantly associated with lower psychological domain quality of life. A study from Turkey found spouse caregiver had higher burden and lower physical composite than non-spouse (Tulek et al., 2020). Otherwise, spouse caregiver with higher income had significantly impacted higher quality of life (Moon et al., 2017). Millenaar et al. (2016) found spouse YOD had significantly more impact than LOD.

PwD's Factors

Type of dementia

Type of dementia included age of PwD who was diagnosed with dementia (Millenaar et al., 2016); (Wang et al., 2020a) and the type of dementia (Hvidsten et al., 2019).

Severity

The majority of the studies found that severity (Välimäki et al., 2016, Carletti Pessotti et al., 2018, von Känel et al., 2019, Ruiz-Fernandez et al., 2019, Aravena et al., 2018) and frequency neuropsychiatric/behavioral symptoms have significant impact to FCG's quality of life (Borsje et al., 2016, Parrotta et al., 2020, Wong and Zelman, 2020, Koyama et al., 2017, Carletti Pessotti et al., 2018, Ruiz-Fernandez et al., 2019, Liao et al., 2020, Honda et al., 2017, Aravena et al., 2018, Regier and Gitlin, 2018, Saffari et al., 2018).

Impairments

Several studies found that impairment of the older adults had a significant influence to FCG's quality of life. The impairments were cognitive impairment (Nogueira et al., 2017, Tulek et al., 2020), PwD physical condition (von Känel et al., 2019, Ruiz-Fernandez et al., 2019), and lower functional status (Liu et al., 2017).

FCG's Factors

Individual

Individual factors were unmodifiable factors, including gender (Nogueira et al., 2017, Borsje et al., 2016, Sittironnarit et al., 2020, Oliveira et al., 2018, Hvidsten et al., 2019), age (Koyama et al., 2017, Tulek et al., 2020, Oliveira et al., 2018, Borsje et al., 2016), ethnicity (Ganapathy et al., 2020) (Chinese), and relationship status.

Health Condition

Health conditions included medical comorbid/chronic disease (von Känel et al., 2019, Liao et al., 2020, Tulek et al., 2020), physical function/health (von Känel et al., 2019, Clare et al., 2019), psychological health (burden and depressive symptoms) (Clare et al., 2019) and somatic well-being (Aravena et al., 2018) which were the health conditions of FCG's that influenced quality of life.

Personal

Personality of FCGs had significant impact to quality of life. Personality factors included personal values (Romero-Moreno et al., 2017), personality traits (Kim et al., 2017, Morimoto et al., 2019), and optimism (Sutter et al., 2016).

Personal Strategies

Personal strategies when facing the problem included coping (Rodríguez-Pérez et al., 2017, Corey et al., 2020, Häusler et al., 2016, Joling et al., 2017), sense of coherence (Carletti Pessotti et al., 2018, Sutter et al., 2016), resilience (Sutter et al., 2016) and expressed emotions (Wong and Zelman, 2020, Weisman de Mamani et al., 2018). However, their strategy might become negative if FCGs felt burdened (Hvidsten et al., 2019, Liao et al., 2020) and had depressive symptoms (Hvidsten et al., 2019).

Care Factors

Care factors were divided into two, including care activity and care knowledge. Care activity factors included management skills (Aravena et al., 2018), care hours (Silva Leite et al., 2017a, Parrotta et al., 2020, Wong and Zelman, 2020, von Känel et al., 2019, Sittironnarit et al., 2020, Oliveira et al., 2018), ability to carry out ADL (Ganapathy et al., 2020), adaptability (Kimura et al., 2019), having a limited space (Tulek et al., 2020), caregiver gain (Polenick et al., 2019), and enjoying spending time (Kimura et al., 2019). While, care knowledge is related to experience in caregiving (Clare et al., 2019), health literacy (Häikiö et al., 2020), level of needs (Kerpershoek et al., 2018), and satisfaction toward psychiatric care (Sittironnarit et al., 2020).

Support

Eight studies found that support can help FCG's struggle from suffering from their condition. Support includes social support (Ruiz-Fernandez et al., 2019, Ganapathy et al., 2020, Liao et al., 2020, Clare et al., 2019), family and relatives (Wong and Zelman, 2020), informal social support (Khusaifan and El Keshky, 2017), and formal social support (Morimoto et al., 2019). Additionally, religious found FCG's positive belief of their situation (Wong and Zelman, 2020)

Social Economy

Social economic situation was found in three studies. It included education (positive) (Sittironnarit et al., 2020), job (positive) (Sittironnarit et al., 2020), working hours (Wang et al., 2020b), and financial problems (Sittironnarit et al., 2020). Those are related to each other. Good education and flexible job working hours would help FCGs solve financial problems. Otherwise, low education and unemployment would bring negative impact. Additionally, stigma from environment has negative impact also (Chang et al., 2016).

Discussions

Quality of life exploration is important to human health and life. This study is the first systematic review that has explored FCGs' problems and the factors related to them. This systematic review found complex factors became FCGs' QoL problems, including mental well-being problems, sleep, environment, social, physical, sexual, and religious. Those conditions impact health-related QoL and quality of family life. Those problems could not be separated from the factors related to them. Generally, factors were divided into PwD's and FCG's factors. A PwD's condition has a huge impact to their FCG's QoL. The impact is not only limited to FCG, but also quality of family life (Steenfeldt et al., 2021).

The biggest problem for FCGs was mental health. Mental health problems become serious problems if they are not resolved as soon as possible. Unmodifiable factors, specifically PwD's severity, was the biggest problem. Otherwise, this study considered the modifiable factors, including support, social economy, and care activity, would give significant positive impact to mental health. Further longitudinal study might be needed to investigate over a long time period.

Meanwhile, burden as the second problem might appear, but it is not limited to knowledge, family or relatives' pressure, and financial situations. All of those situations if combined with negative coping would lead to mental health problems because FCGs could not solve them in appropriate ways. Additionally, this study considered social stigma was a slightly heavy factor that FCGs face from the life environment. The previous studies in Asian countries found social stigma has significant impact to FCGs because it is related to the culture and religion (Chang et al., 2016). A systematic review study (Nguyen and Li, 2020) found that individuals diagnosed with dementia, as well as their familial carers, have reported experiencing adverse perceptions, prejudiced attitudes, and discriminatory behaviors from both the general public and healthcare practitioners. Participants in the study exhibited self-perceptions characterized by negative effects and displayed a propensity to postpone seeking assistance. The self-stigma experienced by individuals with dementia and their family is mostly influenced by psychological issues, rather than sociodemographic factors.

Based on all those findings, this study assumed all the problems could not be separated, and the outcome was low health-related to quality of life. Three studies found that FCGs with comorbidities or chronic disease (von Känel et al., 2019, Liao et al., 2020, Tulek et al., 2020) had poor QoL, but it is not clear, when the FCGs started to suffer from their comorbidity. A further study related to FCGs' comorbidity is highly recommended. Mental, sleep, and physical problems would lead to disease (Kabaya et al., 2023).

FCGs' relationships are not really clear relationships with their problems. Local culture could influence this situation, because some studies found it was a significant factor, but some studies deny it (Liu et al., 2017, Regier and Gitlin, 2018, Hvidsten et al., 2019, Ruiz-Fernandez et al., 2019, Liao et al., 2020, Polenick et al., 2019, Chan et al., 2019). A meta-analysis study revealed that those who had a spouse had better QoL. A limited number of the studies, 12 of 50 studies, have limitations. Further study needs to explore FCGs relationship and culture.

Interestingly, religion and religious problems have become a problem and factor. This shows different perspective of FCGs would lead to different results. This problem cannot be separated into personality and personal strategies. Instead, it is important to acknowledge that religious beliefs and practices can greatly influence individuals' attitudes and behaviors (Teahan et al., 2018). Therefore, it is crucial to consider the role of religion in addressing and finding solutions to these problems. By recognizing the impact of religious beliefs, more inclusive and comprehensive strategies can be developed that take into account diverse religious perspectives and promote understanding and cooperation among individuals of different faiths.

Personality and personal strategies have an important role in FCG's problems. Those factors would lead to a positive or negative impact on QoL. Positive values will give a positive coping to solve their problems (Rodríguez-Pérez et al., 2017, Corey et al., 2020, Häusler et al., 2016, Joling et al., 2017). Otherwise, negative values will give maladaptive coping which in the long term might become QoL problems (Teahan et al., 2018). For example, in the context of developing inclusive strategies in a diverse religious community, a detailed example could be creating interfaith dialogue sessions where individuals from different faith backgrounds come together to share their perspectives and engage in respectful discussions (Chan, 2022). These sessions can help foster understanding, promote cooperation, and ultimately contribute to a higher quality of life for all individuals involved. This study encourages further study to explore these factors to increase FCGs' QoL.

This study found that there are several positive factors that would have a positive impact on QoL. Optimism (personality/traits) (Sutter et al., 2016), coping (personal strategies) (Corey et al., 2020, Joling et al., 2017, Rodriguez-Perez et al., 2017), resilience (personal strategies) (Carletti Pessotti et al., 2018, Sutter et al., 2016), support, education (social economy) (Sittironnarit et al., 2020), and job (social economy) (Sittironnarit et al., 2020). These factors were all found to significantly contribute to an individual's overall quality of life. This study revealed that individuals with an optimistic outlook, effective coping mechanisms, and resilience were likelier to experience a higher quality of life (Teahan et al., 2018). Moreover, having a solid support system, access to education, and a stable job were also identified as crucial factors that positively influenced one's quality of life (Farina et al., 2017).

Findings from this study can be used to prepare the appropriate interventions to maintain FCGs' QoL. Positive determinants become the concern of the intervention. Specifically, community nurses or public health nurses could prepare FCGs on how to face the dementia caring situation. They can provide education and support to enhance the FCGs' knowledge and skills in caregiving, as well as offer resources and referrals for additional assistance. Additionally, the intervention could involve creating a support network for FCGs, such as support groups or online forums, where they can connect with others who are in similar caregiving roles. By addressing the positive determinants identified in the study, the intervention can help improve the overall quality of life for FCGs and ensure they have the necessary support to continue providing care for their loved ones.

Policies related to FCGs should be well-prepared. By providing FCGs with knowledge and skills through structured training, they can better understand and accept their condition. This will enable FCGs to effectively navigate the challenges they face and improve their overall quality of life. Additionally, policies that are specifically tailored to address the unique needs of FCGs should be implemented to ensure they receive the necessary support and resources to adequately care for their loved ones. This holistic approach, combining professional healthcare and policy interventions, will contribute to maintaining FCGs' quality of life and well-being.

The scope of this review had several limitations. First, the majority of the investigations included in the current evaluation were carried out in Western nations. It is crucial to look at how cultural and religious differences affect carers and HRQoL. Family carers should receive support that is culturally sensitive since different racial and ethnic groups of caregivers may react to assistance differently or require varied forms of assistance. Second, this study searched literature from 2016, and earlier studies might have different problems that this study did not explore.

Conclusion

Mental well-being has become a big problem of carers. It is impacted by their PwD's condition, and specifically severity of dementia. Personal values, personality traits, and optimism would help carers to choose positive strategies for taking care of their PwD. In addition, formal or informal support would provide positive impact for carers. Findings of this study will help further study to employ the intervention of the modifiable factors, such as care factors and supports. Social stigma that is related to culture might need national health education of dementia. Education of carers in how to care for dementia relatives is related to country policy.

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