Understanding the Well-Being of Family Caregiver for Elderly With Dementia: Findings From a Literature Study

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Abstract: Being the caregiver for elderly with dementia is a challenging task. Studies reported that elderly with dementia experienced cognitive and behavioral disorders, along with the need for assistance and continuous supervision. These adverse conditions can make the caregivers having problems with their well-being. The aim of this article is to identify factors contributing to family caregivers' well-being for elderly with dementia. A systematic literature review based on PRISMA guidelines was conducted. Three databases, PubMed, ScienceDirect, and Google Scholar were systematically searched using specific keywords and Boolean operators. There were 1.061 hits emerged during the initial search. Following screening for duplication, title and abstract review, and further review based on the relevance to the study purpose, 21 studies were included for synthesis. The studies reviewed were conducted in many countries with varied customs, beliefs, and cultures, hence, many caregivers' well-being factors were found. In order to get a better understanding to the results, we used the Social Ecological Model and clustered these factors into three levels: intrapersonal level, interpersonal level, and community level. These findings may help professionals in determining targets and strategies to provide the more effective psychological interventions and important skills to support the family caregivers' well-being.

1 INTRODUCTION

Indonesia is the fourth most populated country in the world with a population of more than 270 million people (Badan Pusat Statistik, 2021). From that latest census result there is an interesting thing that we found. There is an increase in the percentage of the number of elderly people to 9.87% of the total population, which corresponds to 26.7 million people. This increase is like two sides of a coin. On one side, it is a sign that there has been progress in the fields of science, technology, as well as health facilities in Indonesia. But on the other side, if the elderly are not healthy and independent, they will have a negative impact on the socio-economic conditions of the country.

One of the most common public health problems that existed in elderly is Dementia (World Health Organization, 2017). Dementia is an umbrella term to describe a syndrome that is characterized by progressive declines in mental functioning, which can lead to the gradual loss of the elderly's cognitive, emotion, social, and physical functions (O'Connor, 2011). Alzheimer's Disease International estimated that in 2019, there are more than 55 million people living with dementia globally. This number is predicted to increase to 152 million in 2050. In Indonesia itself, Alzheimer's Disease International expects that there will be a substantial increase in the number of people living with dementia from 1.2 million in 2015 to 1.9 million in 2030, and 3.9 million in 2050 (Gauthier et al., 2022).

World Health Organization (2017) stated that dementia is the major cause of disability and independence in the elderly worldwide, which has a significant impact not only on the elderly but also on families, communities, and society. Between those groups, families are the primary source of support for the elderly. Family caregivers are defined as informal, usually also unpaid, family members, relatives, or partners who provide daily in-home assistance, support, monitoring, management, supervision, or treatment of the elderly. Caregiving is not a new role for family members. They always

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provided support to one and another from time to time. What has changed in this case is the duration, intensity, and the complexity of the care provided (Schulz et al., 2020). Kristjanson and Aoun (2004) stated that family caregivers invest a great deal of energy and effort toward the health and well-being of the care recipient, but on the other hand, their own well-being is often being neglected.

Schulz and Sherwood (2008) found that being the caregiver for elderly with dementia is very challenging and causes more severe negative effects than other types of disease. This is because the elderly with dementia experience cognitive and behavioral disorders, as well as the need for continuous assistance and supervision every single day. Gupta and Solanki (2015) stated that caregivers often have to take care of elderly with dementia for a long time, even until they die. The longer the condition of the elderly the worse the dementia, so that their dependency increases and requires a more complex level of care by time (Adelman et al., 2014). Caregivers often feel that they have no other choice and feel burdened. In addition, elderly people with dementia tend not to express gratitude for the help they received, so it feels like there is no reciprocity felt by the caregivers (Pinquart & Sörensen, 2007). The combination of these things makes caregivers experience strain on their mental and physical health as well as their social and economic situation, or in other words they experience low well-being (Vitaliano et al., 2003; Schulz & Martire, 2004; Schulz & Sherwood , 2008; Adelman et al., 2014; Allen et al., 2017).

On the other hand, a study conducted by Schulz & Sherwood (2008) had the opposite finding where family caregivers experience a lot of positive feelings. In their study the family caregivers report that caregiving makes them feel needed, adds meaning to their lives, gives them opportunities to learn new skills, strengthens their relationships with others, and seems to be able to have a high well-being.

The difference in those well-being outcomes in the family caregiver raises questions about what exactly causes these distinctions. By knowing the factors contributed in family caregivers' well-being, it may help professionals in determining targets and strategies to provide more effective psychological interventions and important skills to support them to maintain their well-being.

The concept of well-being has a long history stretching back to Aristotle, Epicurus, Bentham, and Locke's attempts to understand aspects to fulfill the goal of life (Kashdan et al., 2008; La Placa et al., 2013). Despite the presence of numerous and sometimes complex philosophies, modern research defines well-being via two complementary perspectives: hedonic and eudaimonic. Hedonic views the goal of one's life reflects on the happiness or pleasure, while eudaimonic aims more to the actualization of human potentials.

Most research within the present hedonic psychology has used assessment of subjective well-being (Ryan & Deci, 2001). Diener and Ryan (2009) define subjective well-being as the term to describe the level of well-being that is assessed by individuals according to the subjective nature of their lives. Diener and Ryan (2009) further divides the subjective well-being component into two, namely the cognitive component and the affective component. The cognitive component is an assessment of the individual's satisfaction with his own life, while the affective component consists of the presence of positive mood and the absence of negative mood, which we usually call happiness (Eid & Larsen, 2008).

Eudaimonic considers well-being to consist of more than just happiness. People reports of being happy (high level of positive affect and low level of negative affect) do not necessarily mean that they are psychologically well (Deci & Ryan, 2008). Ryff (2013) suggests a new approach on how people should measure well-being based on characteristics of one's positive functioning named psychological well-being. His model of psychological well-being consists of six components: autonomy, personal growth, self-acceptance, life purpose, mastery, and positive relatedness. These components will lead people to their greater meaning of life.

Despite those two perspectives in well-being, evidence from a number of researchers has indicated that well-being is best conceived as a multidimensional phenomenon that includes aspects of both the hedonic and eudaimonic concepts (Ryan & Deci, 2001). Kashdan et al. (2008) also suggest the same view that hedonic and eudaimonic well-being represent psychological mechanisms that operate together, which is just as important as one another.

In this study, we will review both types of well-being without distinction. We will also add other concepts that relate to the cognitive evaluative aspects of well-being, namely satisfaction with life and quality of life to provide valuable insights into caregivers' overall well-being.

2 OBJECTIVE

The aim of the study is to systematically identify the factors contributing the well-being of family caregivers for elderly with dementia.

3 METHOD

3.1 Protocol

A systematic review based on Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines was conducted in this study. PRISMA was designed to help systematic reviewers transparently report why the review was done, what the authors did, and what they found (Liberati et al., 2009).

3.2 Literature Search

Relevant published studies between 2010 - 2022 were sourced using the databases from PubMed, ScienceDirect, and Google Scholar. An integrative search using specific keywords "dementia, alzheimer, caregiver, carer, family caregiver, well-being, wellbeing, satisfaction with life, mental health" and Boolean operators "AND" and "OR" was performed. In addition to that, lateral searches such as checking the reference and citation lists from the primary studies was also used in this literature search strategy to help identifying other relevant studies.

3.3 Literature Selection

Literature selection began with downloading the selected studies into Mendeley^{TM} bibliographic software where the duplicate titles were deleted. The next step was screening the articles based on the title and abstract. The last step consisted of analyzing the articles' full-texts based on the objectives and criteria of this study.

We only selected studies that are published in English and Indonesia. The inclusion criteria for the family caregivers were that they had to be informal or unpaid caregivers and had a kin relationship with the elderly with dementia. While the inclusion criteria for the caregiving recipients were that they are ≥60 years old and had any dementia diagnosis. We did not exclude studies based on the characteristics of the dementia (e.g. subtype, severity). However, any editorials, conference proceedings, intervention studies, thesis or dissertation were excluded.

3.4 Literature Appraisal

Each articles' quality is appraised using the Mixed Methods Appraisal Tool (MMAT). MMAT is designed for systematic literature review, which has mixed studies, i.e. qualitative, quantitative, and mixed methods studies (Hong et al., 2018). Thus, MMAT is a proper option taking into account the variety of study designs in this review. This tool assessed various aspects in a literature, e.g. the clarity of research questions, comprehensiveness of the data collection, and representativeness of the participants. At present, there is still no consensus method for the articles' exclusion based on MMAT. However, we adopted a similar approach as in Farina et al. (2017) study, which excluded any article that failed either on screening questions or scored 25% or lower on the following questions. Each questions were rated with "0 (no)" representing "not fulfilled", "1" "can't tell' and "2 (yes)" as "good compliance".

3.5 Data Extraction

The characteristics of each included studies were extracted the following: author, year, country, objectives, research design, sample, measurements, and key findings (Table 1). A narrative synthesis method was used due to the heterogeneity of the study designs and results. This approach utilizes the textual reported outcome in the results sections regardless of significance, then divides the results of the studies into thematic headings of factors that affect the well-being of family caregivers of elderly with dementia.

4 RESULT

4.1 Literature Characteristics

The literature search based on the strategy abovementioned was conducted between October to November 2022. There were 1.061 hits emerged during the initial search. Following screening for duplication, title/abstract review, and further review based on the relevance to the study purpose, 21 studies were included for the synthesis (Figure 1).

Table 1. Summary of Literature Studies Review.

No	Author	Method	Subjects	Measurements	Key Findings	Quality rating
1	Altamirano and de Mamani, 2020 (USA)	Cross-sectional study	107 caregivers	• Depression: The Beck depression Inventory. • Anxiety: The Beck Anxiety Inventory. • Stress: DASS – Stress Scale.	Well-being factors: • Expressed emotion. • Family functioning. • Patient severity. • Emotional overinvolvement and criticism.	13
2	Aravena et al., 2017 (Chile)	Cross-sectional study.	94 caregivers	• Subjective burden: Zarit burden scale. • Perception of health stage: The EuroQoL-5D Questionairre (EQ-5D). • Distress: Neuropsychiatric Inventory (NPI-Q). • Well-being: Perceived change Index (PCI-S).	Well being factors: • Burden. • Daily care challenges. • BPSD. • Poor perceived health. • Poor physical functioning • Dementia severity.	12
3	Basu et al., 2020 (India)	Cross-sectional study	131 caregivers	• Stress: Cohen’s Perceived Stress Scale. • Depression: Patient Health Questionnaire. Anxiety: Hamilton Anxiety Rating Scale.	Well being factors: • Level of support. • Sex (male). • Kin relationship (spouse). • Age (older age). • Education. • Income.	12
4	Clare et al., 2018 (UK)	Cross-sectional study	1283 caregivers	• Quality of life: World Health Organization QoL-BREF • Satisfaction with life: Satisfaction with Life Scale (SwLS). • General well-being: World Health Organization-Five Well-Being Index (WHO-5).	Well-being factors: • Personality. • Optimism. • Self-efficacy. • Health. • Competence. • Coping. • Social restriction. • Relationship with PwD.	13
5	de Amorim et al., 2017	Cross-sectional	41 caregivers	• Quality of life: World Health Organization QoL-BREF. • Burden: Zarit Burden Interview (ZBI).	Well being factors: • Social skills (coping and self-assertion with risk; self-assertion in the	11

No	Author	Method	Subjects	Measurements	Key Findings	Quality rating
	(Brazil)	study			expression of positive affect).	
6	Fauth et al., 2012 (USA)	Cross-sectional and longitudinal	133 family dyads	• Well-being: Affect Balance Scale (ABS). • Depressive symtomps: The Beck Depression Inventory. • Physical and mental health: Healt survey SF-12.	Well-being factors: • Closeness between caregiver and PwD.	12
7	Fauth et al., 2016 (USA)	Cross-sectional study.	234 caregivers	Depressive symtomps: Center for Epidemiologic Studies - Depression scale (CES-D).	Well-being factors: • RTC. • ADL impairments. • Gender (women).	12
8	Gorostiaga et al., 2022 (Spain)	Cross-sectional study	146 caregivers of PwD, 73 primary caregivers and 73 secondary caregivers.	• Health: Self-rated health questionnaire. • Anxiety and depression: Anxiety and Depression Scale.	Well-being factors: • Caregiving role (primary caregivers). • Frequency of problem behaviour. • Subjective burden. • Health.	13
9	Kaufman et at., 2010 (USA)	Cross-sectional study	141 dementia caregivers (52% White, 48% African American).	• Caregiver burden: Consequences of Care Index (CCI). • Life satisfaction: Quality of Life Inventory (QOLI).	Well-being factors: • Social support	13
10	Lethin et al., 2017 (8 countries in Europe: England, Estonia, Finland, France, Germany, the Netherlands, Sweden and Spain)	Longitudinal study (Cohort)	1223 family dyads in 8 European countries (England, Estonia, Finland, France, Germany, the Netherlands, Sweden and Spain)	• Psychological well-being: GHQ12. • Burden: Zarit Burden Scale • Health related quality of life: EuroQoL. • Health - EQ-VAS.	Well-being factors: • Positive experience. • Burden. • PwD sex (male). • Caregiver experience. • Quality of Life.	13

No	Author	Method	Subjects	Measurements	Key Findings	Quality rating
11	Messina et al., 2022 (Italy & Switzerland)	Cross-sectional study.	571 caregivers: from Italy and Switzerland - 425 were Italian and 146 were Swiss.	• Burden: Zarit Burden Scale. • Mental health: Short version of DASS-21. • Loneliness: The UCLA Loneliness scale (UCLALS3).	Well-being factors: • The change during pandemic.	13
12	Orgeta et al., 2013 (UK)	Cross-sectional study	170 family caregivers	• Well-being: The Warwick–Edinburgh Mental Well-Being Scale (WEMWBS). • Anxiety and depressive symptoms: The HADS. • Caregiving stress: The Relative's Stress Scale (RSS). • Physical health status: Visual Analogue Scale (EQ-VAS) of the EQ-5D.	Well-being factors: • Age. • Gender (male higher). • Physical health. • Caregiving stress. • Dysfunctional coping strategies. • Social support	12
13	Quinn et al., 2019 (UK)	Cross-sectional study	1,283 caregivers	• General well-being: World Health Organization-Five Well-Being Index. • Satisfaction with Life: SwL Scale	Well-being factors: • Satisfaction with life. • Caregiving competence • Positive aspect of caregiving. • Caregiving stress. • Role captivity.	13
14	Raivio et al., 2015 (Finland)	Cross-sectional study	728 spouse of Azheimer's patients	Questionnaire about caregivers' subjective health and well-being.	Well-being factors: • Age (older poorer). • Education. • Subjective health. • Feeling isolated. • Relationship quality.	13
15	Rippon et al., 2020 (UK)	Longitudinal study (Cohort)	1283 dyads	• Life satisfaction: Satisfaction with Life Scale. • Well-being: WHO-5 Well-being Index.	Well-being factors: • Perception of the quality of the caregiving relationship.	13
16	Sanchez-Terual et al., 2022 (Spain)	Cross-sectional study	310 caregivers	Well-being - WHO-5 Well-being Index.	Well-being factors: • Resilience. • Coping strategies. • Emotional regulation.	13

No	Author	Method	Subjects	Measurements	Key Findings	Quality rating
					• Employment situation. • Type of dementia. • Recent diagnosis. • Self-efficacy. • Social support.	
17	Shabrina et al., 2020 (Indonesia)	Qualitative study	4 caregivers in Indonesia.	Semi-structured interviews	Well-being factors: • Acceptance in caregiving role. • Living arrangement. • Social relationship.	10
18	Sheehan et al., 2021 (USA)	Cross-sectional study	251 caregivers: 117 for dementia and 140 for non-dementia in USA.	• Appraisals of stress and burden: Several widely used single-item indicators of subjective strain. • Depressive symptoms: Center for Epidemiologic Studies Depression scale. • Health-related quality of life: Short Form Health Survey (SF-12).	Well-being factors: • Duration of care. • Provided assistance. • Cognitive and disruptive behaviors. • Burden.	12
19	Snyder et al., 2015 (USA)	Longitudinal study	226 caregivers	• Caregiver coping strategies: the Ways of Coping Checklist-Revised. • Caregiver anxiety: The Beck Anxiety Inventory (BAI). • Caregiver's health: Medical health-Q	Well-being factors: • Coping strategies.	13
20	Välimäki et al., 2016 (Finland)	Longitudinal study	236 caregiver–patient dyads	The National Health 2011 Health Examination Survey data.	Well-being factors: • Severity of demenia.	12
21	Yeh et al., 2022 (Taiwan)	Cross-sectional study	270 caregivers in Taiwan.	• Quality of Life: WHO QoL-BREF • Depression: The Taiwanese Depression Questionnaire (TDQ). • Burden: The Caregiver Burden Inventory (CBI) • Anxiety: Beck Anxiety Inventory (BAI)	Well-being factors: • Age, level of independence, and psychiatric symtomps. • Education. • Socioeconomic status. • Experience in caregiving. • Burden.	12

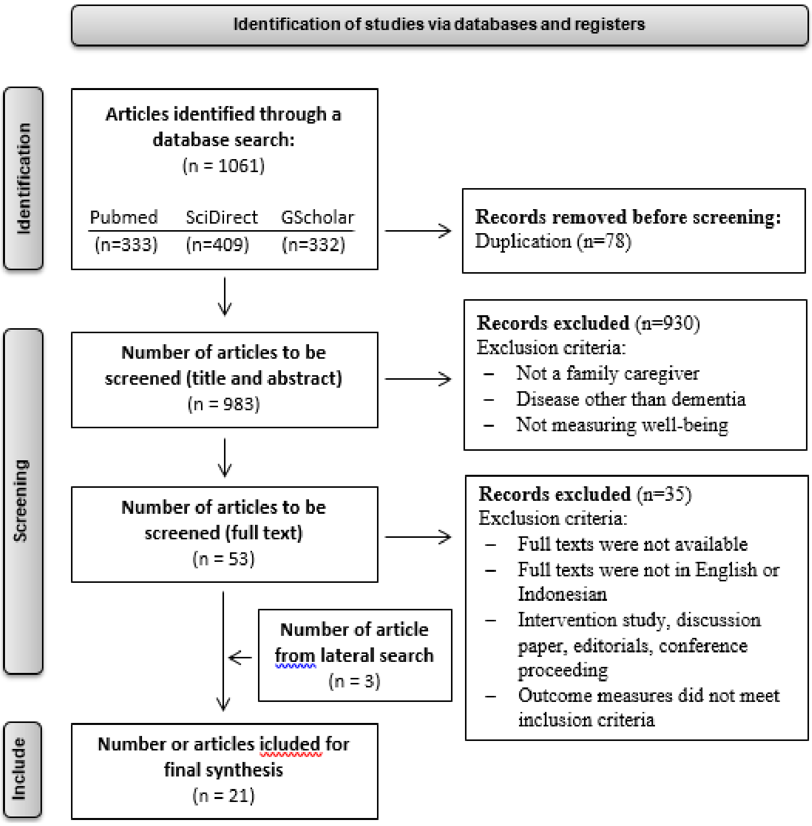

Figure 1. PRISMA Systematic Literature Search.

Out of the 21 studies (n = 8.865), fifteen studies employed cross-sectional study, four with longitudinal study, one with qualitative study, and the other one with mixed methods study (cross-sectional and longitudinal). The majority of the studies were published in English and only one in Indonesian. Most of the studies were conducted in the USA (6), the rest were in UK (4), Spain (2), Finland (2), Indonesia (1), Brazil (1), India (1), Chile (1), Taiwan (1), Italy and Swiss (1), and 8 countries in Europe (1).

4.2 Factors Contributing the Well-Being of Family Caregivers

The Social Ecological Model (SEM) was used to cluster contributing factors into three levels (intrapersonal, interpersonal, and community) and two main type factors (modifiable and non-modifiable) (Table 2).

4.2.1 Intrapersonal Level

Intrapersonal level defines as a characteristic of an individual that influences behavioral change. Most of the factors contributing the well-being of the family caregivers were found within this intrapersonal level. Modifiable factors that were identified in this level were health, coping stress strategies, caregiving experience, self-efficacy, emotional regulation, mastery, and optimism. The number of studies on health ranked the highest (6 studies), including both perceived physical health and psychological health (Orgeta et al., 2013; Raivio et al., 2015; Aravena et al., 2017; Clare et al., 2018; Quinn et al., 2019; Gorostiaga et al., 2022). Coping stress strategies were also mentioned several times (5 studies), where the use of problem-focused and positive coping strategies lead to better well-being outcome (Orgeta et al., 2013; Snyder et al., 2015; de Amorim et al., 2017; Clare et al., 2018; Sánchez-Teruel et al., 2022). Caregiving experience was mentioned next (4 studies). If the caregivers were able to identify their experience positively and experience more positive aspects of caregiving, they were more likely to perceive higher well-being (Lethin et al., 2017; Quinn et al., 2019; Shabrina et al., 2020; Yeh et al., 2022). Two studies mentioned self-efficacy and two others mentioned emotional regulation as being associated with lower psychological negative affect, which led to a better family caregiver's well-being (Clare et al., 2018; Quinn et al., 2019; Altamirano & de Mamani, 2020; Sánchez-Teruel et al., 2022). The last factor in this level was optimism. Optimism has been identified as related to greater life satisfaction, which is one of the components of high well-being (Clare et al., 2018).

Non-modifiable factors of the family caregivers were divided into two categories: family caregivers-related and people with dementia (PwD)-related. For the family caregiver-related, the majority of the identified factors were mostly demographic, which include caregivers' sex, education, economic status, and kin relationship. Sex was mentioned in four studies. Those studies had different results where three of them found that male family caregivers had higher well-being compared to women (Orgeta et al., 2013; Fauth et al., 2016; Lethin et al., 2017), who reported the opposite (Basu et al., 2020). Four studies showed that lower education level and lower economic status of the family caregiver resulted in lower caregivers' well-being (Raivio et al., 2015; Basu et al., 2020; Sánchez-Teruel et al., 2022; Yeh et al., 2022). The last non-modifiable factor of the caregiver was kin relationship, where the spouse was more prone to have negative outcome on well-being (Basu et al., 2020).

Behavioral and psychological problems, age, severity of dementia, level of assistance and the duration of illnesses were the PwD-related non-modifiable factors. Behavioral and psychological problems of PwD were mentioned to be the most in this level (five studies), where the higher frequency of elderly's exhibited behavioral and psychological problems indicated poor well-being of the caregivers (Fauth et al., 2016; Aravena et al., 2017; Sheehan et al., 2021; Gorostiaga et al., 2022; Yeh et al., 2022). Age of the PwD was reported to be related to family caregivers' well-being, where the older the age at the point of time where the PwD got their dementia diagnosis, the lower the caregiver's well-being (Orgeta et al., 2013; Basu et al., 2020; Yeh et al., 2022). Four studies suggested that the severity of dementia had negative effects on the caregiver's well-being. They found that greater symptom severity is linked to greater caregiver strain, which can make them have a poorer well-being outcome (Välimäki et al., 2016; Aravena et al., 2017; Altamirano & de Mamani, 2020; Sánchez-Teruel et al., 2022). Level of assistance given had different impact on the family caregiver's well-being. Level of assistance given had the same impact on the family caregiver's well-being, all four studies found that the greater care provision the lower the well-being outcome (Fauth et al., 2016; Basu et al., 2020; Sheehan et al., 2021; Yeh et al., 2022). The last non-modifiable factor of the PwD was the duration of the illness. Study found that the earlier the diagnosis is predicted, the higher is the level of well-being (Sanchez-Teruel et al., 2022)

4.2.2 Interpersonal Level

Interpersonal level refers to formal or informal network systems that influence the individual's interpersonal level, including family, friends and peers. In this systematic review, there are two modifiable factors: quality of relationship and family functioning. On the other hand, there is one non-modifiable factor: role restriction. The first modifiable factor was quality of relationship between the family caregivers and PwD. Most of the family caregivers reported that their relationships were not ideal and that they were dissatisfied it, which indicates the decline over time in caregiver well-being (Fauth et al., 2012; Raivio et al., 2015; Clare et al., 2018; Rippon et al., 2020). The next modifiable factor was family functioning. A study indicated that better family functioning was related to better caregivers' well-being (Altamirano & de Mamani, 2020). Lastly, role restrictions served as the only non-modifiable factor for the caregivers' well-being. Three studies mentioned how the caregiving role made the caregivers feel like they are only able to perform limited activities, not being able to act as freely as before and therefore feeling isolated because of it (Raivio et al., 2015; Clare et al., 2018; Quinn et al., 2019).

4.2.3 Community Level

Community level factors include relationships among institutions, organizations, and the informational networks into the community level, for example environmental factors, community leaders, social integration, shared values and stigma. There was only one factor that was identified in this level, which is social support as the modifiable caregiver-related factor. Social support played an important role in community-level family caregivers' well-being. Higher social support was associated with lower anxiety, burden and health strain, as well as higher life satisfaction, which lead to better well-being (Kaufman et al., 2010; Orgeta et al., 2013; Shabrina et al., 2020; Sánchez-Teruel et al., 2022).

Table 2. Contributing Factors Based on the Social Ecological Model.

Level and Type of Factors	Factors Contributing	#	Studies
Intrapersonal			
Modifiable factors	Health	6	2, 4, 8, 12, 13, 14
	Coping stress strategies	5	4, 5, 12, 16, 19
	Caregiving experience	4	10, 13, 17, 21
	Self-efficacy	2	4, 16
	Emotional regulation	2	1, 16
	Mastery	2	4, 13
	Optimism		
Non-modifiable factors			
Caregiver-related	Sex	4	3, 7, 10, 12
	Education	3	3, 14, 21
	Economic status	3	3, 16, 21
	Kin relationship	1	3
PwD-related	Behavioural psychological problem	5	2, 7, 8, 18, 21
	Age	4	3, 12, 14, 21
	Severity of dementia	4	1, 2 , 16, 20
	Level of assisstance	4	3, 7, 18, 21
	Duration of illness	1	16
Interpersonal			
Modifiable factors	Quality of relationship	4	4, 6, 14, 15
	Family functioning	1	1
Non-modifiable factors	Role restriction	3	4, 13, 14
Community			
Modifiable factors	Social support	4	9, 12, 16, 17

5 DISCUSSION

The primary goal of this study is to examine the factors determining the well-being of family caregiver for elderly with dementia. Our results showed that family caregivers' well-being is multi-dimensional construct that we need to address holistically. Dementia is a neurodegenerative disorder that will get worse as they get older which will also affect the role of the family caregivers in the future. Family caregivers are the backbone of the daily care for dementia, this means that they need to get prepared and have sufficient provisions for their ever changing long-term role.

Behavioral and psychological problem (BPP) is one of the most frequently occurring factors for the well-being of family caregivers, it mentioned five times during the synthesis. This result is consistent with previous literature review on similar topic area that suggested BPP as the highest factor associated with global caregivers' well-being (Fauth & Gibbons, 2014). BPP is a variety of symptoms that can be difficult to handle or manage by the family caregivers and at some stage they often affect the family caregivers' capability to provide daily support for the elderly (Braun et al., 2018). These symptoms may include apathy, aggression, agitation, confusion, repetitiveness, wandering, strange and embarrassing behaviors, or emotional distress. With the emergence of these symptoms, it feels like family caregivers encounter dual challenges: the elderly daily assistance and their behavioral and psychological problem. The accumulation of this daily stress will lead to over-burden feeling and eventually poorer caregivers' well-being (Fauth et al., 2016).

Family caregivers experienced stress in a daily basis during the caregiving process. Coping stress strategies have been reported as the factor of positive outcomes in caregiving stress. Kramer conceptualized coping stress strategies into two categories: problem-focused coping and emotion-focused coping, where problem-focused concerned on taking action to individual's relationship to the stressors, while emotion-focused emphasized on reducing the level of emotional distress after the stressors (Snyder et al., 2015). Previous studies still cannot find consensus on which coping stress strategy is the best for the caregivers. Kneebone and Martin (2003) and Di Mattei et al. (2008) found that problem-focused coping associated with lower emotional distress and more positive outcome, while Cooper et al. (2008) and Gallagher et al. (2011) also found similar results, that emotion-focused coping reduced psychological distress. In this literature study, coping stress strategy was mention 5 times during the synthesis. Four of the studies suggested the use of problem-focused coping (Sánchez-Teruel et al., 2022) and positive coping (Clare et al., 2018) were the most predictive factor for perceived well-being while emotion-focused coping (Snyder, et at., 2015) and dysfunctional coping (Orgeta et al., 2013) were associated with depressive and anxiety symptoms in family caregivers. The rest did not specifically mention which coping strategies they used in their study (de Amorim et al., 2017).

Findings also identified that health is another factor that determining family caregivers' well-being, it mentioned six times during the synthesis. Family caregivers on average spend approximately 16 hours each day on their care-related activities (de Amorim et al., 2017). This great amount of time must come with health side effect for the caregivers' health, both their physical or mental health. Previous study highlighting the physical morbidity of dementia caregiver showed that dementia caregivers are more likely to have cardiovascular problems, higher level of chronic disease (e.g. diabetes, arthritis, and anemia), more often to doctor visit and use of medications (Brodaty & Donkin, 2009). While for mental health, studies reported that the prevalence rate for caregiver anxiety was 32.1% and 31.2% for depression (Kaddour & Kishita, 2020). The result in this literature study was in line with the previous ones where family caregivers are prone to have health problems and it affecting their well-being. The most reported mental health problem that happened in family caregivers are anxiety and depression. While the physical health was not specified in more detail, but clearly suggested that perceived physical health influencing the family caregivers' well-being.

In the introduction part of this literature review, we highlighted the importance of knowing the factors contributed in family caregivers' well-being, since it's related to the future interventions that can be carried out. This was also why we adopted the approach using the Social Ecological Model, which is to facilitate professional providing the more effective psychological interventions and important skills based on each level of factors. In regards of this, we encourage to take more attention to the modifiable factors instead of non-modifiable factors or factors that did not meet the consensus.

Factors we found in the intrapersonal level suggesting that health, coping stress strategies, caregiving experience, self-efficacy, emotional regulation, mastery, and optimism were the modifiable factors in the caregivers intrapersonal level. These factors were also positive attributes of a psychological construct called psychological capital and theoretically be amendable or modifiable by interventions (Luthans et al., 2015). Based on previous meta-analysis some of the intervention that we can do in this intrapersonal level are psycho-education, provision skill training, problem-solving skills, leisure and physical activity intervention, psychotherapy such as Cognitive Behavioral Therapy or Mindfulness-Based Stress Therapy (Wiegelmann et al., 2021; Gao et al., 2022; Pasquini et al., 2022; Felstead, at al., 2023). In this intrapersonal level, interventions also should be tailored to the desired outcome to get more significant impact (Walter & Pinquart, 2020). The second level is interpersonal level with quality of relationship and family functioning as the modifiable factors. Intervention that we can suggest for this level for instance family support program and family counseling (Cheng et al., 2019; Lee, at al., 2022). While for the community level with social support as the determining modifiable factor we can propose psychosocial support, such as community education and we could also activating social media networks to raise awareness about this issue (Gao et al., 2022). Multilevel approaches are also encouraged for sustained effect over time (Walter & Pinquart, 2020).

We should acknowledge that the findings and implications of this study have its limitations. First, the amount of the selected studies was generally small. Second, studies conducted in several countries with varying characteristics of the family caregiver caregivers, which will limit the generalization of the results obtained. Lastly, three of the included studies used the data from the Improving the experience of dementia and Enhancing Active Life (IDEAL) studies, so same dataset might have been used multiple times.

6 CONCLUSION

This current literature review investigated factors contributing the well-being of family caregivers for elderly with dementia. There were several factors found and we clustered them into three levels (intrapersonal, interpersonal, and community) and two main type factors (modifiable and non-modifiable). Health, coping stress strategies, caregiving experience, self-efficacy, emotional regulation, mastery, and optimism being the modifiable intrapersonal level factors. For the non-modifiable factors, we divided it into 2 categories, sex, education, economic status, and kin relationship as the non-modifiable caregiver-related factors, and behavioral psychological problem, age, severity of dementia, level of assistance, and duration of illness as the non-modifiable PwD-related. In the interpersonal modifiable factors there were quality of relationship and family functioning, while the non-modifiable factor was role restriction. The last one is social support as the community modifiable level.

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