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Research Article

Quality of Life in Alzheimer's Dementia and its Caregiving in Southeast Asia

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Abstract

Introduction: Alzheimer's Disease is a brain disorder characterized by Dementia, having several adverse consequences for Quality of Life (QoL). We conducted a systematic review of the literature to study the overall Quality of Life of patients and their caregivers and caregiving of this dementia in Southeast Asia.

Methodology: We conducted a systematic review of full-text articles which addressed QoL in patients with Alzheimer's disease, published in English from January 2000 to 8th September 2022, using PubMed, Google Scholar, Psych INFO, and Research Gate; in accordance with PRISMA guidelines. The search keywords included: quality of life, QOL, Alzheimer's disease, Alzheimer's dementia, and Southeast Asia. The quality of the studies was assessed by using Joanna Briggs Institute Critical Appraisal Tool. Studies with similar characteristics were grouped together and findings were summarized.

Results: There exists a positive correlation between the QoL of Alzheimer's dementia patients and their caregivers. Mean patient-rated QoL was found to be higher than proxy-rated QoL. The severity of the disease a had negative influence. Satisfaction with the relationship with the caretaker showed a positive influence. Caregivers' quality of life was affected by the carer's age, education, sex, relationship with the patient, income, and underlying diseases. Decreased disease awareness, late diagnosis, inadequate caregiving facilities, and lack of specialist training are big hurdles in improving the QoL of said, disease patients.

Conclusion: There is an unignorable research void related to QoL of dementia patients which presses on the need to explore various health aspects relevant to it. Moreover, more investment in dementia care provision, dementia-specific research fields, and dementia specialist training should be made.

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INTRODUCTION:

Alzheimer's disease (AD) is one of the ten most burdensome conditions for older people worldwide, with over 60 million people living with it as of 2020(1). The total healthcare costs for the treatment of Alzheimer's disease in 2020 are estimated at $305 billion, with the cost expected to increase to more than $1 trillion as the population ages. It is a brain disorder that deteriorates memory, cognition, behavior, and eventually the ability to perform daily tasks (2). Pathogenesis is associated with extracellular aggregates of amyloid beta plaques and intracellular neurofibrillary tangles made of hyper-phosphorylated tau protein in cortical and limbic areas of the human brain (3). In mild AD, people suffer memory and personality changes but as the disease progresses, they face difficulty in language control, reasoning, sensory processing, recognizing family members and ultimately making patients bedridden.

Although the number of Alzheimer's patients is increasing day by day, there is a lack of effective single-target FDA-proved treatment (4). Enhancing and maintaining the quality of life (QOL) in persons with dementia is thus a major priority in dementia care (5). QOL has emerged as an important outcome measure of dementia treatment by the International Working Group on Harmonization of Dementia Drug Guidelines. QOL has become a very important political issue insofar as it can be used to justify healthcare costs directed toward ameliorating the effects of dementia (6). QOL encompasses both objective elements such as health and functional abilities and subjective elements such as perceived health and satisfaction (7). Lawton's model has been the most influential, and it comprises four domains that contribute to QOL: (1) behavioral competence, (2) psychological well-being, (3) objective environment, and (4) self-perceived QOL. With particular reference to AD, the QOL scale assessment of the patient might not be reliable owing to deficits in their memory, insight, communication, and judgment (7). However, the assessment of QOL by proxy responders (caregivers, family members) are liable to be affected by their (and not the patients' themselves) mood, belief, and expectations (8) An optimal method to assess the QOL of AD subjects may therefore be based on the assessment of both the caregivers and the patient's responses. The Logsdon QOL-AD scale which is comprised of 13 items (physical health, energy, mood, living situation, memory, family, marriage, friends, self, ability to do chores, and fun) is most frequently used. The study has shown that depression in patients with Alzheimer's disease adversely affects the performance of their daily life activities and cognitive abilities, ultimately leading to lower QOL (9). Psychological morbidity and mood factors also have been shown to influence QOL (10) (11). Contrary to that, social activities, good family functioning, and interpersonal relations are related to better QOL (12) (13).

The current prevalence of dementia in South-East Asia is 5% out of which AD accounts for 59.8%(14). The point of concern is a further increase in these numbers in low- and middle-income countries and scanty knowledge about existing post-diagnostic care and support (15). The number of researches assessing the QOL in Alzheimer's patients in China, Thailand, Malaysia, the Philippines, and Singapore provides limited data with huge variability and discrepancies making it substantial to explore and analyze current data qualitatively. This study aims to present an overall picture of the quality of life in Alzheimer's patients and their caregivers in South-East Asia so that this knowledge may be used by healthcare providers, researchers, and policymakers for better healthcare provision for Alzheimer's patients in this region

METHODS AND METHOD:

Search strategy:

This study was conducted in accordance with Preferred Reporting Items for Systematic Review and Meta-analysis guidelines (16).PubMed, Google Scholar, PsychINFO, and Research Gate; these electronic databases were thoroughly searched for publications from January 2000 till 8th September 2022. Our search strategy was designed in a comprehensive way to include all available data and included the following terms: "quality of life", "QOL", "Alzheimer's disease", "Alzheimer's dementia" and "South-east Asia". The detailed search strategy is given in an online supplementary file. We also checked the reference list and "cited by" option of primary research articles to ensure no relevant study was missed. Initially, no filters in terms of study design and language were used to retrieve all data.

Selection of studies:

Two authors (BR and BN) screened studies by reading the title and abstract based on the following criteria.

Inclusion Criteria:

Our study population was people who were diagnosed with Alzheimer's dementia irrespective of the severity of the disease, age at presentation and residents in Southeast Asian regions receiving hospital or home care. All studies with cross-sectional, longitudinal, and qualitative designs that reported the quality of life of Alzheimer's patients and their caregivers using validated scales were included. Studies that described different scales for assessment of the quality of life (QOL) in Alzheimer's patients were labeled eligible to be included. Qualitative studies describing Alzheimer's dementia caregiving were also included.

Exclusion Criteria:

Our exclusion criteria involved:

1. Studies that didn't mention any validated tool used for QOL assessment in Alzheimer's patients and caregivers.
2. Case reports, systematic review, meta-analyses and opinion papers
3. Studies that described forms of dementia other than Alzheimer's disease.
4. RCTs or experimental studies concerned with measuring the efficacy of different drugs and treatments in Alzheimer's patients using the QOL scale.
5. Abstracts of studies (where full text wasn't available).

Data Extraction:

After title and abstract screening, 33 studies were assessed for eligibility by reading full text by two independent reviewers (BA and FS). Disagreements were resolved via negotiation with a 3rd reviewer (BN). The following relevant data were extracted from studies in form of an excel spreadsheet: title, authors, study settings, study design, sample size (male/female), mean age of participants, scales used for QOL assessment of patients and caregivers cognitive assessment tools, main findings and limitations. Then we grouped studies with similar characteristics into the following categories to make our literature review more organized:

1. Factors associated with QOL of Alzheimer's patients
2. Quality of life of caregivers
3. Caregiving and burden of Alzheimer's dementia
4. Self-rated vs proxy-rated QOL
5. Scales used for QOL measurement
6. Covid-19 and QOL of Alzheimer's patients

Quality Assessment of included studies:

All included studies were evaluated for their quality using Joanna Briggs Institute critical appraisal tool for cross-sectional studies (17). The JBI checklist assesses the quality of studies based on 8 items. Response options are 'yes', 'no', 'unclear', and 'not applicable'. The number and percentage of studies meeting various assessment criteria will be sumarized.

RESULTS

Results of literature review:

The initial search yielded 17,871 results (PubMed; 456, Google Scholar; 17,400, PsycINFO;15).471 duplicate records were removed. After screening on the title and abstract bases, 36 articles were sought for retrieval. Only 30 were retrieved. These articles were further assessed for eligibility by reviewing the full text and only 18 studies met our inclusion criteria. PRISMA flow diagram of our study selection process can be seen in fig 1.

Quality Appraisal:

Out of 18 studies reviewed;8 studies scored 8 points on JBI Checklist,9 studies scored 6 points and 1 study got 5 points. The table showing the scores of individual studies can be retrieved from the online supplementary file, figure (2)

Scales used for QOL assessment:

Multiple scales were used to assess the Quality of life in patients with Alzheimer's dementia. Among them, the QOL-AD scale was most frequently used (32,34,35). It has also been adapted into Malay (32) and Thai (33) languages. WHO QOL-8 (21), and Euro QOL-5D (19,20,24) were other scales used. The severity of dementia was assessed most commonly by MMSE (21,24,30,32,34,35), NPI (24,24), Bristol Activities of daily living scale (34), and DAD (19). WHO-QOL BREF scale was most commonly used to evaluate the caregiver's quality of life (18,24,28). Other scales used for their QOL assessment were CASP-19 (22), QOL-AD (23), and SCQOLS-D (31).

Factors affecting the quality of life of Alzheimer's patients:

After a thorough literature search, the following main factors were found to be associated with the

QOL of these patients:

a. Quality of life of caregivers: A positive correlation was found between the QOL of Alzheimer’s dementia patients and their caregivers in the environmental, social, physical, and psychological domains. The physical and social relationship domain of caregiver QOL also had a strong effect on the patient’s cognitive level (18). Caregiving by a spouse specifically improves the patient’s QOL (19).

b. Severity of disease: The patient’s severity of the disease is assessed via three domains: functional (measured by DAD; disability agreement for dementia), cognitive (measured by MMSE: mini-mental state examination), behavioral (measured by NPI: neuropsychiatric inventory) were associated with the debilitation of health-related QOL in Alzheimer’s disease. With the severe stage of the disease, there was also increased demand for care-giver’s time (19). The level of cognitive impairment in Alzheimer’s disease is also one of the major predictors leading to the worsening of QOL (19,21).

c. Medication adherence status: Prevalence of non-adherence determined by MALMAS; Malaysian Medication. Adherence Scale and MPR: medication possession ratio was 69.2%. The most common reason is forgetfulness and difficulty in taking medicine. Patients with medication adherence showed improved QOL (20).

d. Depression: Though depression was found to be prevalent in Alzheimer’s patients, there was no evidentiary support that depression was a significant determinant of QOL in these patients (21).

e. Others: Satisfaction of relationships with children, friends, relatives, and level of social activities also showed a positive influence on patients’ QOL (18,21).

QUALITY OF LIFE OF CAREGIVERS:

The 7 studies included discussed the quality of life of caregivers of Alzheimer’s Disease patients. The mean quality of life of caregivers of patients with Alzheimer’s disease was found to be less than that of caregivers of people without dementia (22). The burden of care (23) and psychological strain (27) were negatively related to the quality of life of caregivers of patients with Alzheimer’s disease (23). The caregivers of patients with Alzheimer’s disease were unable to perform their activities of daily life (22) Caregivers’ quality of life was affected by the carer’s age, sex, level of strain, family income, and filial piety. Caregiving burden and psychological, and environmental domains of WHOQOL showed variation across regions of Vietnam as compared to the physical domain of the stated tool. It was also seen that caregivers spent less time with Dementia patients who had a higher level of mobility. Also, age and gender were not found to be predictors for the caregiver's quality of life (24). The carer’s education, relationship with the patient (25,26), social support (22,26), and underlying caregivers' disease were important effects (26). There was a high level of strain on caregivers of patients with Alzheimer’s Disease and this strain was greater in younger children of patients with Alzheimer’s Disease (25). Female caregivers had lower quality of life as compared to male caregivers (26). Family income also affected caregivers' quality of life, the lesser the income, the lower the quality of life (26,28). Different coping strategies had a positive effect; among these, approach coping, reframing, and passive appraisal was significant (27,28) while avoidance coping had a negative impact on QOL.

-3-Care-giving of Alzheimer's disease:

Diagnosis of dementia was mostly by chance during consultations with general physicians or investigations for some other disease. Post-diagnostic treatment was mostly pharmacological. Since it is costly, it negatively affected the family preferences for drug-based treatment. In addition to the medicated treatment, the counseling of the family caregivers was found to be equally important. Some social support and community benefits to caregivers were also present. A low-level awareness of dementia was found in the general population (29). Care-giver's high level of awareness was found in the Philippines followed by Singapore and Thailand. Awareness was found to be more if the caregiver was young, educated, the patient's children, and if the patient was older with severe dementia (30). General physicians were also found to be lacking in training regarding the diagnosis and treatment of Alzheimer's dementia. Dementia care services although improving, were still not sufficient, especially in rural areas (29). Caregiving burden (measured by the ZBI scale) was found to be high if the patient was male, old, with a low MMSE score, a high CDR (clinical dementia rating), and if the caregiver was female (30)

Development of new scales:

In Singaporean caregiver QOL scale- Dementia, QOL total, and domain scores correlated with negative personal impact except Experience and meaning and there is a correlation between hours spent on caregiving. Cronbach alpha is within the acceptable range (31). In QOL-AD in Malay language, Cronbach alpha is within an acceptable range and there is a strong correlation between patients and caregivers on physical health, energy, marriage, friend, money, and life and a weak link on mood, memory, family, and self (32). In Thai QOL-AD Cronbach alpha shows good internal consistency and correlation between scores of all questions, except life as a whole, are in the acceptable range (33).

SELF-RATED VS PROXY-RATED QOL:

Studies included in this review provide a comparison between self-rated vs proxy- rated QOL (22,34). Mean patient-rated QOL was found to be higher than caregiver-rated QOL. The magnitude of the discrepancy was dependent on the patient's education level, depressive symptoms, and severity of neuropsychiatric symptoms. Depression and care provided by relative other than a spouse or adult child was associated with poorer self-predicted QOL.

COVID-19 AND QOL OF AD PATIENTS:

Changes in habits during the Covid-19 pandemic affected the QOL of Alzheimer's patients. One study conducted in Jakarta showed that the QOL of Alzheimer patients was poor to fair during the Covid-19 pandemic (35).

Figure: PRISMA flow diagram of included studies

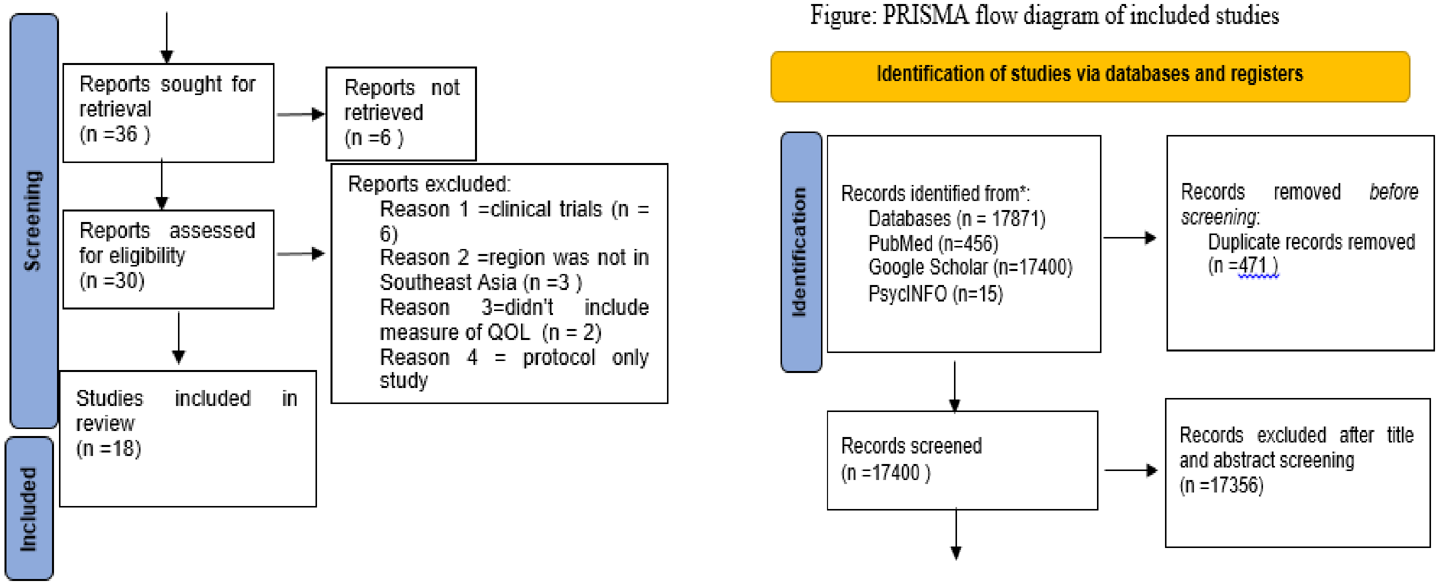

Table 1: Summary of included studies:

Study	Country	Settings	Population and Sample size (male/female)	Mean age (years)	Tools for quality of life assessment	Tools used for severity of disease assessment	Other tools used
Quang et al. (24)	Vietnam	Communities	**1st survey:** Caregivers:153(56/97) Patients:153(64,89) **2nd survey:** Caregivers:694(274/420) Patients:347(210/137)	49.25 75.92 48.44 79.3	WHOQOL-BREF	NA	ZBI, Barthel Index KBSA SOC Filial piety scale Positive aspects of caregiving instruments
Yong et al. (30)	Philippines Singapore Thailand	Hospital based	**Philippines:** Caregiver:23(4/19) Patients:23910/13) **Singapore:** Caregivers:52(20/32) Patients:52(15/37) **Thailand:** Caregivers:6(2/6) Patients:6(1/5)	46.3 78.52 54.21 75.65 56.67 81.17	NA	MMSE CDR	CAS ZBI
Martina et al. (18)	Indonesia	Geriatric clinic	Caregiver:42(11/31) Patients:42(17/25)	50.93 77.17	EQ- 5D-3L EQ-VAS WHOQOL-BREF	MMSE	NA
Kwai et al. (32)	Malaysia	clinic	Patients:65(26/39)	77.37	QOL-AD(Malay)	MMSE(Malay)	NA

Junaid et al.(20)	**Malaysia**	**clinic**	**Patients:13**	**53.5**	**EQ- 5D-3L** **EQ-VAS**	**NA**	**MALMAS** **MPR**
Azlina et al. (21)	Malaysia	Nursing homes	Patients:111(55/56)	71.8	WHO-8	SMMSE	CSDD
Asnelia et al. (35)	Indonesia	hospital	Patients:24(10/14)	40->80	QOL-AD	MMSE	MOCA-INA
Michael et al. (23)	Indonesia	community	Caregivers:50(14/36)	46.68	QOL-AD	NA	HPQ ZBI
Christina et al. (27)	Indonesia	Community	Caregivers:45	41	WHOQOL-BREF	Bartel index	BAS Brief COPE MSPSS
Michaela et al. (29)	Malaysia	community	11 healthcare professionals, 4 traditional medicine practitioners, and 5 social support providers	NA	NA	NA	Interview based
Shubash et al. (22)	Malaysia	community	Patients:408(166/242)	60->80	CASP	NA	Barthel index DSSI
Gobhathai et al. (26)	**Thailand**	**hospital**	**Patients:155(43/112)** **Caregiver:155 (26/124)**	**79.2** **52.2**	**PTQL**	**NA**	**ZBI**
Khachen et al. (19)	Thailand	hospital	Patients:153(48/105) Caregivers:148(37/111)	80.1 55.1	EQ-5D-3L Thai 36 item short health survey	MMSE NPI DAD	NA
Elaine et al. (25)	Malaysia	community	Caregivers:207(42/165)	50.4	NA	NA	Brief resilience scale BRS Katz ADL CSI
Laura et al. (34)	Singapore	clinic	Caregiver:165(59/106) Patient:165(74/91)	58.1 76.8	QOL-AD	Chinese MMSE NPI CDR	Bristol ADL CSDD ZBI
KAY et al. (28)	Singapore	community	Caregiver:84(26/58)	50.89	WHOQOL_BREF	NA	FBIS F-COPES GPSE
Yin et al. (31)	Singapore	hospital	Caregiver:102(20/82)	55	SCQOLS	NA	BASC
Nopporn et al. (33)	Thailand	hospital	Caregivers:136(38/98) Patients:136(45/91)	51.8 76.4	QOL-AD(Thai version)	NA	NA

BASC: *Brief Assessment Scale for Caregiver* ***BAS:*** *Burden Assessment Schedule* ***BRS:*** *Brief Resilience Scale* ***Bristol ADL:*** *Bristol Activities of Daily Living* ***CASP-19:*** *Control, Autonomy, Self- Realization and Pleasure* ***CDR:*** *Clinical Dementia Rating* ***CSDD:*** *Cornell Scale of Depression in Dementia* ***CSI:*** *Clinical Strain Index* ***DAD:*** *Disability Assessment for Dementia* ***DSSI:*** *Duke Social Support Index* ***FBIS:*** *Family Burden Interview Scale* ***F-COPES:*** *Family Crisis Oriented Personal Evaluation Scale* ***GPSE:*** *General Perceived Self Efficacy Scale* ***HPQ:*** *Health Perception Questionnaire* ***KSBA:*** *Kingston Standardized Behavioral Assessment* ***Katz-ADL:*** *Katz index of Independence in Activities in Daily Living* ***SOC:*** *Sense of Coherence* ***ZBI:*** *Zarit Burden Interview.*

DISCUSSION:

Quality of life is not only a significant measure of the effectiveness of dementia treatment but also maintaining it is a major goal in dementia care, so this systematic literature review was conducted to identify various scales that are used for QOL assessment in individuals with Alzheimer's dementia and of their caregivers in Southeast Asia and to find different factors which influence their QOL. We also evaluated the caregiving of Alzheimer's patients and the caregiving burden. Variations were found in QOL assessment in the following domains: scale used, assessment strategy i.e. self-rated, proxy rated, or both, the severity of disease and settings i.e. community-dwelling or hospitalized.

Although different scales have been used in literature to measure the quality of life in people with dementia and none has been regarded as the gold standard (36), our review found that QOL-AD was the most commonly used tool. This corroborates the findings of previously conducted systematic reviews (37,38,39). It is a 13-item scale that measures patients' QOL concerning both self-rated and proxy-rated scores. Major reasons for its use are that it's a convenient method taking 5 to 10 minutes for caregivers and 10-15 minutes for the patient (36). It can be measured for all stages of severity of the disease and in all settings (40). It is Malay (32) and Thai (33) versions were region-specific. EQ-5D was used in two studies to report the quality of life of patients with dementia. It is a standardized, non-disease-specific instrument that describes the health-related quality of life in five dimensions: mobility, self-care, usual activities (e.g., work, study, household, family, or leisure activities), pain /discomfort, and anxiety/depression (41,42). Although it is a simple questionnaire that has a short completion time making it easy for patients with dementia to fill it and also measures the cost of dementia care and the carer's burden, it is not designed specifically for dementia and cannot markedly differentiate between mild and severe cognitive impairment (43). These reasons make it to be used for complementing other scales. Studies in this systematic review (22,34) show a discrepancy in the rating of QOL scores between patients and their caregivers. The patient-rated QOL was higher than the caregiver-rated QOL. The patient's educational level, neuropsychiatric symptoms, and depression accounted for this change. The poor rating of the self-perceived quality of life was associated with low caregiver contribution, no-spousal care, and the severity of neuropsychiatric symptoms (34). The most commonly used measure of disease severity was a 30-score-instrument MMSE which assesses only the cognitive domain. Its strongest merit may be ruling out dementia in primary care and community studies but it does not appear to be a good choice for clinicians to identify cases of Alzheimer's against mild cognitive impairment (44,45). Other disease severity indicators e.g. NPI, DAD, and Bristol Activities of daily living scale were used in a few studies. As new disease-modifying agents are believed to act in the early stage of disease, these indicators are used to assess the efficacy of drug treatment so it becomes very important to evaluate disease severity. As domains and scoring vary between different QOL instruments, it can lead to variation in results yielding different quality-adjusted life years QALYs and cost-effectiveness ratios and ultimately influence important decision-making (45). Moreover, the literature shows that the use of more than one instrument in the measurement of quality of life can increase the possibility of chance 1 error (36). So there always remains the need to incorporate various domains into one instrument. The quality of life of caregivers of Alzheimer's dementia patients is inseparable from theirs. The brief version of the WHO-QOL scale was yielded to be the most commonly used tool for the assessment of a caregiver's QOL (18,24,28). It is a 26-item scale measuring four domains of quality of life i.e. physical, social, psychological, and environmental. It has been developed for cross-cultural comparisons of quality of life and translated into more than 40 languages. It not only reduces the burden on respondents but is also useful when time is restricted, making it one of the frequently used tools for caregivers' QOL evaluation.

To improve the quality of life of Alzheimer's patients, it's very important to assess the factors affecting it. We found that the severity of disease, quality of life of a caregiver, relationship with family and friends, level of social activities, and comorbidities e.g. depression and medication adherence status were the main factors that were found significantly affect the QOL of these patients in our included studies. As the caregiver's duties are to help the patient of dementia doing their daily activities and planning their medication and treatment, their quality of life strongly correlates with that of the patients and vice versa. Our included study (18) measured this association in the environmental, physical, social, and psychological domains and found a positive correlation. This makes sense as the inability to do activities of daily living is related to lower QOL ratings. Also, literature shows that person-centered care interventions decrease agitation, neuropsychiatric symptoms, and depression and ultimately improve the quality of life of dementia patients. Moreover, our studies (18,21) depicted that maintaining good relations with spouses, children, and friends and engaging in social activities and tasks also improve the QOL of dementia patients. This was in accordance with the findings of previously conducted studies. Lack of opportunity to talk or interact with others, feeling loneliness, rejection, and uncomfortable with close family can deteriorate their QOL. So the family is an important part of support in dementia care. As the disease severity progresses (measured by functional, cognitive, and behavioral status), HR-QOL declines (19) and it indirectly increases the caregiving burden. This is consistence with already published literature. So people with dementia with good health status, physical activity, and no chronic diseases tend to have good QOL. Although among comorbidities, depression is most prevalent and negatively influences the quality of life of dementia patients; our included study (21) couldn't find any effect of depression on the QOL of these patients. Authors have attributed it to self-reported interviews rather than proxy-rated scores. Medication adherence was shown to be positively influencing the QOL (20). Literature has shown that the main factors influencing the quality of life in dementia patients also vary with settings i.e. home care vs institutional care, so more research needs to be done in this domain in this region. Covid-19 was shown to lower the quality of life of Alzheimer's patients and it was attributed to changes in habits, lockdown, and no social and physical activity (35)

As family caregivers are an important means of providing care to dementia patients, improving their quality of life is of utmost importance. In most of our included studies, the caregivers were spouses or children and most of them were female (18,19,23,25,26,27,28,30,34). The average quality of life of caregivers of patients with Alzheimer's disease was found to be less than that of caregivers of people without dementia. These findings corroborate that of a previous systematic review. Changes in the behavior of people with dementia, their loss of ability to communicate, and functional deterioration lead to a decline in the caregiver's quality of life (25). Due to the burden of caregiving, most of the caregivers were found unable to perform activities of their daily living. There came the role of support from family and society as QOL was reported lower in those caregivers with low financial and social support in comparison to those with high social support (22,26,28). This result was also supported by another study. So social support intervention for both patients and their caregivers must be a top priority in dementia caregiving in this region. Carer's age, sex, level of strain, family income, filial piety (24), carer's education, relationship with the patient (25,26), duration of caregiving, employment (23), and underlying caregivers' disease (26) were other factors affecting the quality of life of caregivers. Most of the caregivers were female and their QOL was reported lower as compared to male caregivers as stated also by previous research. So more attention needs to be derived towards female caregivers QOL and teaching them coping strategies. Caregivers with high educational levels tend to have high QOL, a finding consistent with previous research as they are better aware of different resilience and coping mechanisms. Another finding that needs to be mentioned is the duration of caregiving as it is negatively associated with the caregiver's quality of life Caregiving for more than 15 hours a week severely disturbs the caregiver's health according to family caregiving alliance, 2016. Coping strategies especially approach coping and reframing are significant in improving a caregiver's overall quality of life (27,28). So awareness of overall resources available should be increased in caregivers to prevent maladaptive coping strategies that can affect the well-being of them and their caregivers.

To understand the situation of Alzheimer's dementia in this region, we took an account of dementia caregiving facilities, access to them, awareness about these facilities, and cost-related burden. A lack of public awareness was found in Malaysia. Less number of specialist care services were available, with referrals mainly to geriatricians or psychiatrists who were available only in major urban care settings and hospitals. Infrastructure and workforce capacity for dementia care provision was also insufficient in Malaysia (29). Data about dementia care provision in other countries of this region is lacking. A report by lancet shows that mental health has been a low priority in this region due to a lack of attention and investment. Poor provinces and districts have neither a mental hospital nor community services.

Our review has some limitations. It includes studies only from PubMed, PsycINFO, Google Scholar, and Research Gate. We didn't have access to other databases like Scopus, Embase, and Cochrane library. Data published in languages other than English, gray literature, and conference papers were also not searched for. The use of a variety of tools for the measurement of QOL of Alzheimer's patients and their caregivers is another limitation of our study. As each tool measures somewhat different domains of QOL, it can lead to variation in QOL scores among different studies making it difficult to compare results. Though, the tools used in all studies, the tools used were valid and reliable.

CONCLUSION:

Our review has summarized the overall quality of life of Alzheimer's dementia patients and caregivers in Southeast Asia. Different scales used for its assessment, factors influencing it, and the caregiving provided in this geographic region have been described. We have found that there exists a gap in research in this region, related to the effect of dementia on QOL in different severity stages and more aspects of physical, environmental, social, and psychological health that can affect the quality of life should be explored. Moreover, more investment in dementia care provision, dementia-specific research arenas, and dementia specialist training are proposed to be of utmost importance to improve the overall quality of life of these patients and their caregivers in this region.

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