

## A review of family caregiving challenges in Malaysia

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### Abstract

Family caregiving often involves family members, relatives, and partners with whom the patients have a personal relationship to assist the care. The roles of caregivers are extensive and require a lot of effort, time, and commitment. These demands might possibly affect the life of caregivers. This paper aimed to identify how family caregiving in Malaysia might have jeopardized the caregiver's life. A systematic approach analysis was employed in this study while including seventeen articles. The exclusion criteria were articles published in reputable journals containing the research topics with the keywords “burden”, “finance”, and “stress”. The focus of the study was on the impact, mental health status, quality of life, and burden related to caregivers in Malaysia. The articles were categorized into four themes: mental health status, impact, quality of life, and burden towards family caregiving in Malaysia. The results showed that in the theme of mental health status, caregivers experienced significant stress, and one of the factors is the family's lack of knowledge in dealing with stress. Meanwhile, in terms of impact, the results indicated that caregivers experienced negative impacts on their emotions and health. In the quality of life theme, the results presented that family caregiving had a positive impact on increasing bonding between patients and caregivers. The results also showed that caregivers experienced burdens on financial issues and lack of social support. This study recommends mental health professionals provide support, knowledge, and training for caregivers to maintain their psychological well-being.

**Keywords:** *caregiving, challenges, family, Malaysia*



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## Introduction

Family care can be defined as any family member, relative, and partner with whom a patient has a personal relationship to assist care recipients for the elderly, adults suffering from chronic illnesses, or disability conditions (Family Caregiver Alliance, 2019). Caregivers are not limited to people who take care of physically sick people but also people who suffer from mental disorders. Family care can also be thought of as an extension of the health care system in which they work together to perform complex medical and therapeutic tasks while ensuring patients follow all curative orders (American Psychological Association, 2011; Richard Schulz & Sherwood, 2008). As an extension of health services, caregivers are tasked with accompanying sick people and providing support as conventional health services providers. The existence of this care allows hospitals or health services to provide more adequate access to those who need intensive care.

The role of a caregiver can vary from taking care of household tasks, self-care, supervision, and mobility. Even caregivers are expected to help provide emotional and social support, health and medical care, advocacy, care coordination, and surrogacy (R. Schulz & Eden, 2016). Responsibilities as a family caregiver can be seen as a broad one. These tasks may require considerable effort, time, and commitment because balancing the caregiver's demands for care and personal needs is not easy. Parenting affects the physical, mental, and social health of caregivers (S. L. Chan et al., 2017).

Many studies related to caregivers have been carried out to investigate various issues on their welfare. The high burden of caring while balancing other roles such as work is not a manageable thing. However, the results of the study do not always show the negative effects that arise from caregiving. A study by Bjørge et al. revealed that 208 dyad caregiver-patients showed distress and stable mood as dementia symptoms increased (Bjørge et al., 2019). The result indicates that there is no correlation between caregivers' mental health status and the increase in illness or symptoms, although it is undeniable that there are other studies that show counterproductive effects experienced by caregivers. Research by Northouse et al. shows that caregivers of cancer patients experience stress which can cause psychological disturbances, sleep problems, and changes in their physical health (Northouse et al., 2012). These two studies show different trends in each caregiver and it is possible that this really depends on what disease is experienced and the level of resilience of the caregivers.

During the pandemic, people's attention to mental health issues has also increased. In relation to caregiving during a pandemic, a study by Russell et al. showed that there was a significant relationship between parental caregiving burden, mental health, and young people's perceptions of stress (Russell et al., 2020). The results of this study conclude that in general, exposure to pandemic disasters has a negative impact on family mental health. It is even predicted that over a long period of time it can lead to increased anxiety and depressive symptoms.

Further research related to the challenges faced by caregivers was also carried out by Akbari et al. (Akbari et al., 2018). The research shows that there are six main challenges faced by caregivers, namely the unfulfilled needs of caregivers, burnout, high burden of care, high social stigma, low social support for caregivers, and caregivers' low quality of life. The research refers to

the narrative review study of 39 articles with a setting in Iran. In general, studies on the issue of caregiving show varying results and are very specific in the background of the data and the research setting.

Various problems on parenting arise. Considering not only the time and effort needed, emotional and psychological resilience is very important so that caregivers do not experience excessive stress. Therefore, this study aims to identify the challenges experienced by caregivers when accompanying people with illness in Malaysia. Various studies have been conducted to see how it affects caregivers psychologically and physically or in general life. In particular, this study investigates how family parenting patterns in Malaysia and how parenting tasks affect caregivers' lives. It is expected that with this study, optimizing support through training and transfer of knowledge to caregivers is a concern and can be used as a recommendation for mentoring models.

**Method**

This study used a systematic review approach to critically look at selected articles on the topic of family care more thoroughly based on the empirical studies that had been conducted in Malaysia. This approach was enable researchers to carry out a systematic and objective procedure for identifying studies relevant to the topic being explored (Patton et al., 2017). The analytical process was carried out by identifying, finding, and discussing studies that were considered relevant to the guiding questions. The question in this study was what are the challenges experienced in family caregiving. This question indicated that this study seeked to investigate the challenges that arise in family caregiving including qualitative, quatitative, and mixed method studies.

The steps carried out in this study were started by formulating a research question. The research question was then used as the basis for the search for relevant articles. The article search process was carried out through Web of Science, Scopus, Google Scholar, and accessed to EZ University Putra Malaysia (UPM) to find all articles related to family care in Malaysia. The keywords used in this research are "burden", "finance", and "stress". After the articles were found, a screening was carried out to determine whether the data found are relevant. All selected articles were considered relevant to the study if it consisted of the keywords and took place in Malaysia. These results were analyzed and synthesized before it was presented into table for categorization.

**Findings**

Seventeen relevant articles were selected for the final review after the comprehensive screening. Then, these seventeen article papers were used for systematic review. By employing PRISMA guidelines, our research findings were categorized into four groups: mental health status, impact, quality of life, and burden towards family caregiving in Malaysia (see Table 1.).

**Tabel 1. The list of reviewed articles**

No	Title of the article	Authors	Findings	Category
1	Mental health status and its associated factors among caregivers of psychiatric patients in Kuching, Sarawak	(Vun et al., 2019)	Anxiety and depression are prevalent among caregivers of psychiatric patients.	Mental health status
2	Caregivers' strain when nursing palliative care patients in North East of Peninsular Malaysia	(Taib et al., 2020)	As many as 39.3 percent of the 122 caregivers were found to be under significant stress.	
3	Factors associated with high strain in caregivers of Alzheimer's disease (AD) in Malaysia	(E. W. L. Chan et al., 2019)	As many as 77.7 percent of caregivers had a high level of stress.	

4	'I am still able to contribute to someone less fortunate': A phenomenological analysis of young adults' process of personal healing from major depression	(Siaw Leng Chan et al., 2020)	Caring for a family member with mental health issues presents numerous challenges, but contributes to personal healing.	
5	The mentally ill and their impact on family caregivers: A qualitative case study	(Azman et al., 2019)	The negative consequences are financial burdens, social, psychological, and physical health issues.	Impact
6	Impact of pediatric acute otitis media on child and parental quality of life and associated productivity loss in Malaysia: A prospective observational study	(Crawford et al., 2017)	Acute otitis media has a negative impact on parental quality of life and a significant economic impact on both the patient and societal levels.	
7	Impact of internet addiction on health anxiety in Malaysian youth during Covid-19 pandemic	(Khodabakhsh et al., 2021)	High internet usage has an impact on the mental health of people caring during the Covid-19 pandemic.	
8	Work-family conflict among working parents of children with autism in Malaysia	(Sitimin et al., 2017)	Balancing work roles and family roles is very challenging for parents of autistic children.	
9	Schizophrenia in Malaysian families: A study on factors associated with quality of life of primary family caregivers	(ZamZam et al., 2011)	Caregivers who are well educated, physically fit, and treat minor illnesses have a significantly higher quality of life in various aspects.	Quality of life
10	Health-related quality of life in Malaysian gastrointestinal cancer patients and their family caregivers—A comparison study	(Abdullah et al., 2020)	Caregivers had better the health-related quality of life than cancer patients'.	
11	Quality of life amongst family caregivers of older persons with terminal illnesses	(Ghani et al., 2016)	Caregivers' perceptions of the benefits of their caregiving experiences have positively influenced their quality of life.	
12	The financial burden of colorectal cancer treatment among patients and their families in a middle-income country	(Azzani et al., 2016)	A large financial burden on the patient	Burden towards family caregiving
13	Behavioural and psychological symptoms of dementia, cognitive impairment and caregiver burden in patients with dementia	(Rosdino et al., 2013)	Caregiver burden was more experienced among caregivers with better education.	
14	Burden in caregivers of adults with epilepsy in Asian families	(Lai et al., 2019)	The burden of caregivers is strongly linked to the family system.	
15	Burden of care among caregivers of patients with Parkinson disease: A cross-sectional study	(Razali et al., 2011)	The burden of care is significantly higher in Parkinson's disease patients with advanced age and stage of illness.	
16	Burden of stroke caregivers: Evidence from a qualitative study in Sarawak, Malaysia	(Rahman et al., 2018)	Caregivers burden is exacerbated by financial problems, multiple responsibilities, behavioral changes in stroke survivors, and lack of social support.	
17	Caregiver burden among caregivers of individuals with severe mental illness: Testing the moderation and mediation models of resilience	(Mulud & McCarthy, 2017)	Female caregivers felt more burdened.	

## Discussion

### Mental Health Status

Patients have mental health disorders, but there is also a risk for the caregivers. Assessing the mental health status of caregivers of psychiatric patients in Kuching, Sarawak, the researchers found that anxiety and depression are shared among the caregivers until this group of people requires a

screening (Vun et al., 2019). The male respondents, composed of 46% of overall participants (n=198), have been found to have depression with a probability of as high as twice that compared the female respondents since they are the breadwinners of the family and lack knowledge in caregiving. The factors that lead to anxiety are age and finances; meanwhile, lack of expertise to handle the stress is the factor for depression among the caregivers. The other factor that causes both anxiety and depression is the thought of patients as being dependent.

In Kelantan, 122 caregivers responded to the Malay version of the Caregivers Strain Index to identify the strains among the caregivers nursing palliative care patients at YOKUK@Sayang Home Care (Taib et al., 2020). The study showed that 39.3% of caregivers have significant stress. The score was high in physical, routine, anxiety, and financial strain, whereby the anxiety issue was commonly found among caregivers with more than 50 percent.

The study to determine caregiver strain index (CSI) and resilience (RES) levels among 230 caregivers of Alzheimer's disease patients in Malaysia resulted in caregivers having a group of stress (E. W. L. Chan et al., 2019). The correlation between CSI and RES has been found as significantly negatively correlated. The care recipients' physical function is related to CSI level, and caregivers' gender and employment status do not directly influence CSI but relate to the caregivers' RES level. The duration of caregiving is associated with an increase in CSI.

In a study of personal healing from major depression by Chan, Lau, and Wong, taking care of family members with mental health issues created a lot of challenges (Siaw Leng Chan et al., 2020). However, the study highlighted that caring for others was perceived as one of the healing contributors to personal healing experiences.

## Impact

A study in Kedah had been participated by fiveteen family caregivers to identify how their lives had been affected as they were taking care of family members who had a mental illness by combining the method of semi-structured interview and questionnaire (Azman et al., 2019). The study showed that the family caregivers experienced a negative impact categorized into a financial and social burden and psychological and physical health.

Acute otitis media (AOM) is a disease found in children below five years old. This disease is also the cause for children to visit clinics or hospitals and obtain their antibiotic prescriptions. Using the Quality of Life questionnaire, which includes questions regarding work or productivity loss and financial cost, a study has been conducted to identify the impact of the disease on the quality of life of children and their parents (Crawford et al., 2017). As many as one hundred ten children and caregivers joined the study from three different settings. The participants were recruited from the University of Malaya, the National University of Malaysia hospitals, and Sultanah Bahiyah Hospital, with most respondents being mothers of the patients. The study shows that AOM negatively influences the quality of life of the caregivers in terms of emotion and daily disturbance. Still, the most significant negative impact was on the children. Besides, AOM has a substantial effect on the economy of patients and society.

As the world is affected by the COVID-19 pandemic, most people were instructed to stay at home for the first two years before the vaccination program. Work and learning are conducted online, creating another issue: internet addiction to health anxiety. In the recent study by Khodabakhsh et al., four hundred and forty-eight young adults were surveyed (Khodabakhsh et al., 2021). The study showed that high internet use is associated with health anxiety. This impacted the mental health of people taking care of their families and families who are not staying together due to the influx of information about the virus, symptoms, and statistics (number of death and infection).

Twelve respondents who were the working parents of children with Autism in Malaysia participated using a semi-instructed interview to analyze the conflict between work and family roles (Sitimin et al., 2017). It is reported that working parents have challenges balancing their work roles and family roles simultaneously. The nursery, which accepts Autism children and support from their employer, is crucial to lessen the working parents' work-family conflict.

### Quarter of Life

Using the quality of life questionnaire (WHOQOL-BREF) and Brief Psychiatric Rating Scale, a study was conducted to examine how socio-demographic, clinical, and psychosocial factors correlated to primary family caregivers' quality of life with family members suffering from Schizophrenia (ZamZam et al., 2011). The findings of the study show that caregivers with a high educational level background, not associated with any medical problems and requiring less social readjustment, have become predictive to acquire a higher quality of life in one or more domains among the caregivers. The factors for patients to have a higher quality of life score in one or more parts have been identified as having a high level of education, not attending a daycare program, shorter duration, later onset of illness, and lower Brief Psychiatric Rating Scale scores. Meanwhile, findings of the study of 323 dyads of gastrointestinal cancer patients and their family caregivers using the Medical Outcomes Study 12-item Short-Form revealed that the caregivers had a better health-related quality of life than the patients (Abdullah et al., 2020).

As most of the research showed how family caregiving could negatively affect caregivers, the study by Ghani, Ainudin and Dahlan showed different responses (Ghani et al., 2016). Ten caregivers in Selangor participated in a semi-structured interview to determine the quality of life among family caregivers taking care of older persons with terminal illnesses. The study emerged two themes: strengthening family bonds and improving sense of self-worth. The respondents explained that doing the caregiving task allows them to develop a strong bonding between the caregiver and the patient, strengthen family relationships, and establish a value of responsibility among family members. Regarding the improvement of the sense of self-worth, the respondents perceive that caregiving can help them become patient people, better understand other people's problems, and create the feeling of becoming a better person.

### Burden

Patients and their families feel the burden in the financial aspect, although the government offers subsidization in public hospitals (Azzani et al., 2016). It is reported from the study partaken by 138 patients who undergo colorectal cancer treatment from all four stages of cancer. The study's findings showed that as the stage of the cancer increases, it could influence the cost of treatment too. The coping strategy used by the patients and their families to overcome the financial burden is combining the current income and savings.

The severity of a patient's cognitive impairment was not firmly connected to the caregiver burden (Rosdinom et al., 2013). The caregiver burden affects dementia patients' behavioral and psychological symptoms of dementia and male patients. The study also finds that caregiver with better education has the most significant commitment, but the authors suggested that all caregivers should be periodically screened to ensure their well-being. This study involved 65 elderlies diagnosed with dementia and their caregivers at University Kebangsaan Malaysia Medical Centre and Hospital Kuala Lumpur.

Factors that have been related to the caregiver burden for caring for adults with epilepsy are family system, demographic, psychosocial, and clinical characteristics (Lai et al., 2019). The study was survey-based; 111 caregivers participated in responding to questionnaires that asked about the perceived burden, quality of life, psychological distress, family functioning, and

perceived social support. Poorer family functioning, lack of support, and lack of caregivers are associated with the caregiver burden. In the aspect of demography, a female caregiver is the one that feels a high load compared to male caregivers. Meanwhile, Indians had a higher mean score burden than Chinese and Malay ethnicity's. The caregiver feels more burdened when the severity of the illness is high and needs additional care. Meanwhile, findings from Razali et al. supported previous studies where Parkinson's disease patient's age, stage, and severity of illness were correlated with the burden in the caregiving; meanwhile, and caregivers' burden does not relate to their gender, social status, kinship, or the duration of caregiving (Razali et al., 2011).

A cross-sectional study of 18 caregivers of stroke patients in Kuching, Sarawak, resulted in five themes to determine the caregivers' burden and challenges (Rahman et al., 2018). The semi-structured interview shows that caregivers experience physical, social, financial, employment, and time burdens. Caregivers encounter sleep disturbance, forgetfulness, and being emotionally irritated. They also reported that they lack time with friends and cannot attend a family functions. The caregivers were having financial challenges with nutritional needs, education, and transport. Multiple responsibilities and no time for self have become a burden on the caregivers' time; meanwhile, lack of concentration at the workplace is associated with the themes of employment.

The research on the burden among caregivers of patients with severe mental illness in Klang Valley, Selangor, resulted in long caregiving duration, perceived lack of support, and experiencing patients' behavioral disturbance were the stressors related to caregiving (Mulud & McCarthy, 2017). The findings of the study also mentioned that caregiver gender was related to caregiver burden mediated by resilience. It was found that female caregivers felt more burdened.

Most of the studies that we found focused on the impact, burden, quality of life, and mental health status of the caregivers in Malaysia. All these studies are essential to identify the factors associated with the load or stressor among caregivers and to better understand their challenges while doing their caregiving tasks. Individuals suffering from any illness were not the only ones who experienced a life turning event because this event may directly or indirectly impact caregivers' lives.

Most caregivers face a financial, social, psychological, and physical burden, based on the studies. The patients and their families are concerned about paying for the treatment since the stage of illness can influence the cost (Azzani et al., 2016). The more severe the disease, the higher the cost of treatment. In the social aspect, the caregivers were found to reduce focus on their job because they were worried about the patients they took care of, and there was no time to socialize with their friends or attend family events (Rahman et al., 2018).

Anxiety and depression are commonly experienced by the caregivers, which are also related to high-stress levels (Taib et al., 2020; Vun et al., 2019). Male caregivers have a probability of having depression twice as higher as female caregivers, which is caused by the lack of knowledge in caregiving (Vun et al., 2019). The caregivers also were stressed due to behavioral disturbance shown by patients (Mulud & McCarthy, 2017; Rosdinom et al., 2013).

Taking care of individuals with illness can impact the physical of the caregivers as they have sleep disturbance, forgetfulness, and emotional irritability (Rahman et al., 2018). Although caregivers with a high level of education do not affect the quality of life (ZamZam et al., 2011), they are the ones that feel more burdened due to demanding jobs and responsibilities (Rosdinom et al., 2013). In addition, female caregivers feel more burdened than male caregivers (Lai et al., 2019; Mulud & McCarthy, 2017). Out of seventeen studies that mainly mentioned the negative influence of caregiving on the life of caregivers, one study conducted in Selangor showed a more positive perspective where caregiving tasks were perceived as an opportunity for them to strengthen the family bond and help the caregivers to improve the sense of self-worth (Ghani et

al., 2016). This study is also in accordance with previous research set in Iran which describes the challenges of caregivers which are almost the same (Akbari et al., 2018)

## Conclusion

Based on the analysis and synthesis of the selected articles, there are four interesting themes found in this study. The first theme relates to caregivers' mental health status, which shows the same pattern in the articles analyzed. Some caregivers experienced significant stress while caring for a person with an illness. The second theme is the impact of the analysis showing that parenting has a negative impact on caregivers because of financial, social, psychological, and physical health burdens. Meanwhile, the third theme discusses the caregivers' quality of life, which indicates exciting results because the lack of parenting experience had a positive impact on the quality of life of caregivers with positive perceptions. Finally, the caregiver's burden theme presents that the burdens borne by caregivers included financial problems, multiple responsibilities, behavioral changes in stroke survivors, and lack of social support.

In general, the challenges faced by caregivers are very diverse, even gender, educational background, and perceptions of caregiving are identified as having an influence on mental health conditions and quality of life. Given the significant impact on the mental state of caregivers, this study recommends that related parties and mental health professionals provide training or knowledge on how to manage stress and burden during caregiving (Bertuzzi et al., 2021). Support group activities can be an alternative in the midst of the lack of social support for those who take care of people with illnesses, especially in Malaysia.

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