

# Reasons behind providing care for older persons

Akehsan Dahlan, PhD<sup>1</sup>, Nadirah Mohamad Dzaki, BSc<sup>2</sup>, Izzati Syazwani Adeli, BSc<sup>3</sup>, Ninik Nurhidayah, PhD<sup>4</sup>

<sup>1</sup>Faculty of Health Sciences, Universiti Teknologi MARA, Selangor Campus, Selangor, Malaysia, <sup>2</sup>Bright Future Learning Centre, Petaling Jaya, Selangor, Malaysia, <sup>3</sup>Klinik Kesihatan Seksyen 19, Shah Alam, Selangor, Malaysia, <sup>4</sup>Department of Occupational Therapy, School of Health Polytechnics, Surakarta, Indonesia

## ABSTRACT

**Introduction:** There is a global increase in the ageing population, and Malaysia is expected to become an ageing country. As elderly individuals experience deterioration in physical and cognitive functions, they often require long-term care from caregivers. This study aims to investigate the reasons why caregivers provide care for older adults at home.

**Materials and Methods:** A qualitative phenomenological approach was employed, and semi-structured face-to-face interviews were conducted with 12 caregivers. Thematic analysis was used to identify patterns and themes in the data.

**Results:** Four master themes emerged from the analysis of the reasons for providing care to the older person by caregivers: personal factors needed by the elderly, personal factors of the caregivers, support from family members and friends, and environmental factors. Caregivers were motivated by the medical conditions of the older person, caregivers' sense of duty, and the desire to repay their elderly for their past care. Additionally, religious beliefs also played a role in motivating caregivers. Financial stability, knowledge and experience in caregiving, and the absence of other suitable caregivers were additional factors influencing caregiving decisions. Caregivers received support from family members, friends and sometimes hired help.

**Conclusion:** Cultural values, religious beliefs, and gender roles influence caregiving attitudes, emphasising the need for comprehensive understanding. Invaluable findings highlight the pressing need to comprehend the intricate dynamics, informing the development of tailored support systems. The study reveals that caregiving at home for the elderly is shaped by personal, social and environmental factors. Insight into these dynamics is crucial for robust support systems. By addressing the dimensions of caregiving, policymakers, healthcare professionals and society can better support caregivers in their essential role.

## KEYWORDS:

*Caring, older person, reason, phenomenology*

## INTRODUCTION

The global trend of the ageing population needs attention from all authorities. This trend is expected to continue in the coming decades, and Malaysia, in particular, is moving

towards an ageing country. With ageing comes a range of challenges, including physical, psychological and cognitive decline, eventually leading to a dependency on others for daily activities. For instance, frailty and cognitive deterioration among the older person often result in falls, causing significant worry and requiring constant supervision from caregivers.<sup>1</sup> Consequently, the need for long-term care and support from caregivers becomes essential. A caregiver can be anyone: one who looks after a family member, partner or friend in need of assistance due to illness, frailty, disability or psychological issues and who cannot manage without their support.<sup>2</sup> Traditionally, the older person's care has been the responsibility of family members, as the extended family system has been deeply rooted in many societies for years.<sup>3</sup> As we move toward a community-based healthcare system, it is expected that a substantial portion of care for older adults will be provided within the home setting.<sup>4</sup> The World Health Organization emphasises the significance of home as a place of emotional and physical associations, memories, and comfort, reinforcing the importance of caring for older individuals in their own homes.<sup>5</sup> Caring involves taking on the well-being of another person and offering dedicated attention and support.<sup>6</sup>

Preliminary studies have identified various reasons why people choose to care for older individuals. Often, caregiving begins when the older person develops an illness or disability that impacts their ability to function independently. Long-term illness, disability or simply the challenges associated with ageing can significantly affect the lives of older individuals, making it difficult for them to manage daily tasks independently.<sup>7</sup> Some studies have found that caregivers are motivated by a desire to repay their parents for the care they received when they were young.

Caregivers recognise the sacrifices their parents made throughout their lives to provide them with the best possible care, and this acts as a strong driving force.<sup>8</sup> Taking care of ageing parents when they are sick and in need gives children a sense of fulfilment and serves as a way to express gratitude for their parents' selfless dedication.<sup>9</sup> Additionally, the emotions of care, the sense of duty and the interdependency between family members are common factors contributing to caring for older individuals.<sup>10,11</sup>

The need for providing holistic care plays a significant role in inspiring caregivers to provide support.<sup>12-14</sup> Participants in Northern California expressed their willingness to take on the role of a caregiver due to their deep commitment to holistic

This article was accepted: 16 March 2024

Corresponding Author: Akehsan Dahlan

Email: akehsan@uitm.edu.my

care for the person in need.<sup>13</sup> The profound sense of a holistic caregiving approach motivates caregivers and families to provide comprehensive support for their ageing loved ones. Caregivers often feel a strong responsibility since they understand the needs of their relatives better than anyone else.<sup>15</sup> It becomes their duty to pay attention to and care for the needs of their ageing parents. As parents age, the responsibility naturally falls on their children to ensure their well-being.<sup>16</sup>

However, some caregivers may find themselves lacking support, forcing them to shoulder the responsibility of caring for an older person alone. As the disease progresses, caregivers often find themselves in the position of providing care without significant assistance from other family members.<sup>17</sup> Despite their best intentions, other family members may struggle to offer help due to their own commitments.<sup>18</sup> It is commonly expected that unmarried individuals will take on caregiving responsibilities since they usually may have fewer responsibilities of their own. However, even married caregivers face the challenge of balancing their own family obligations while caring for their ageing parents. Caregivers may receive support from others during the caregiving journey. Even when the primary caregiver takes on the majority of the responsibilities, other close family members are often willing to lend a helping hand. Spouses or children within the same household typically provide the most assistance, but siblings, cousins and other relatives from different households also step in to provide support.<sup>17</sup>

Beyond family, caregivers may also find support from their friends.<sup>17</sup> Having someone to talk to about their caregiving experiences, whether it's a close friend or a fellow member of a support group, can be most valuable for caregivers.<sup>17</sup> Sons who care for parents with dementia, for example, demonstrate a willingness to take on the caregiving role and provide support to their parents.<sup>17,18</sup> In families where the husband is the head, the wife often takes on the caregiving responsibilities due to the other obligations of the husband. Furthermore, in cultures like Myanmar, caregiving is perceived as a duty primarily assigned to daughters, and elderly parents expect help and support from their daughters.<sup>19</sup> This cultural perception is widespread across many cultures worldwide, including Asian Indian contexts. Culture, encompassing a person's way of life and traditions, plays a significant role in shaping attitudes toward caregiving.

For instance, a qualitative study conducted in Kuala Lumpur, Malaysia, among 12 caregivers to patients with moderate to severe dementia, shed light on the cultural significance of caregiving among Chinese caregivers and its connection to the concept of filial piety.<sup>20</sup> The findings showed that Chinese caregivers perceive caregiving as a profound sense of duty or reciprocity deeply rooted in their cultural beliefs.<sup>20</sup> Similarly, Borrayo et al.,<sup>21</sup> explored the caregiving dynamics among 33 Spanish-speaking Latino caregivers in three states in the United States of America, namely Florida, Colorado, and Minnesota, and found that ethnicity and culture also influence caregiving structure in Latino communities.

Thus, the reasons behind caring for older individuals are diverse and complex. They encompass a sense of duty, reciprocity, the need to provide a holistic care and cultural expectations. Understanding these factors is crucial for developing effective support systems and interventions to assist caregivers in their vital role. As the global population continues to age, it becomes increasingly important to recognise and address the challenges faced by caregivers and provide them with the necessary resources and support to ensure the well-being of both the caregivers and the older individuals under their care.

## MATERIALS AND METHODS

This research employed a qualitative phenomenological approach to gain insights into the reasons for caring for an older person at home. A total of 12 respondents meeting specific inclusion criteria, were purposively sampled for face-to-face semi-structured interviews. The study was conducted among four carers residing in Selangor, Melaka, and Johor. The inclusion criteria for the participants were as follows:

- Caregivers who provided support for elderly individuals aged 60 years and above in at least one Activity of Daily Living (ADL).
- Caregivers who provided care to the elderly at home for at least three months.
- Caregivers who could understand Bahasa Malaysia and English.

Thematic analysis was applied as the data analysis approach, which is a qualitative tool for identifying patterns or themes. This method is commonly used to recognise people's opinions, judgments, understandings, experiences, and values. According to Kiger and Varpio, there are six steps to follow when conducting a thematic analysis.<sup>22</sup>

- Step 1: Familiarising yourself with the data
- Step 2: Generating initial codes
- Step 3: Searching for themes
- Step 4: Reviewing themes
- Step 5: Defining and naming themes
- Step 6: Producing the manuscript.

The forward translation method was used to translate the quotes and themes from Bahasa Melayu to English. To protect their identity, participants were given pseudonyms when presenting the findings.

## FINDINGS

Twelve Malay family caregivers participated in this study. Their ages ranged from 23 to 69 years, with two participants aged 60 years and above. The majority of the participants were females, and only one was male. Nine of the participants were still employed. The reasons for caring for an older person were analysed in this study and are presented in Table I. Four master themes of caregivers' reasons for providing care were identified: the personal factor of the elderly, the personal factor of the caregiver, the support of others and the environmental factor. This study found that the older people had at least one illness that could affect their ability to manage daily life, particularly if it impacted their

Table I: Summary of master themes, themes and subthemes (n=12)

Master themes	Themes	Subthemes
1. Personal factors of elderly	1. Personal health status 2. Self-care management	<ul style="list-style-type: none"> <li>• Medical illness</li> <li>• Physical, mental and psychological</li> <li>• Follow up</li> <li>• Safety</li> <li>• Inability to be independent</li> <li>• Pension</li> <li>• 'I want to care and repay.'</li> </ul>
2. Personal factor of caregiver	1. Own wish 2. Financial 3. Knowledge and experience 4. No choice	<ul style="list-style-type: none"> <li>• Responsibility</li> <li>• Role model</li> <li>• Belief in religion</li> <li>• Afford to provide</li> <li>• Received help</li> <li>• 'I have knowledge...'</li> <li>• Caring experience</li> <li>• Stigma</li> <li>• No one wants to care</li> </ul>
3. Support from others	1. Close person	<ul style="list-style-type: none"> <li>• Personal status</li> <li>• Siblings and relatives</li> <li>• Spouse and children</li> </ul>
4. Environment factor	2. Significant others 1. Home	<ul style="list-style-type: none"> <li>• Maid and friend</li> <li>• Convenient house</li> <li>• Distance</li> </ul>

physical, mental or psychological health. As a result, many older individuals became dependent on caregivers to continue their daily activities.

#### Master Theme 1: Personal Factors of the Elderly

Older individuals with illnesses that impair their physical, mental or psychological abilities may require a caregiver to assist them. This is often indicated by changes in behaviour and personality that resemble those of small children, demonstrating the need for additional care from a caregiver. These individuals may lose their ability to function independently, requiring assistance with daily tasks. All the participants in this study were caring for an older person who had an illness, and they observed changes in their loved one's behaviour and capabilities after the diagnosis of a medical condition that had the potential to impact their quality of life.

"... My husband was diagnosed with Parkinson's disease, and after a few years, he began to experience difficulty urinating. It was sudden and unexpected, and it required immediate medical attention."

"... My mother has memory problems and often forgets what she has done. For instance, she might forget that she has already eaten or taken a bath, and sometimes she forgets if she has already prayed. Additionally, she has trouble remembering the day and time, which can be challenging for her and those around her."

Realising the limitations caused by illness, many things that the older person is unable to do anymore. Their performance regresses, and they need a lot of help and assistance daily. The moment illness affects older people, they lose the ability to perform daily activities. This is the beginning of dependency on caregivers, especially in managing themselves in daily life, such as feeding, dressing, personal hygiene, and mobility. This situation causes them to need extra care and supervision, especially to maintain their health and safety in every setting.

"... I had to go up and down to attend follow-up health clinics. Despite the challenge, I made sure to attend all the appointments to ensure proper care and treatment for him."

"... While taking a shower, we place my father on a seat next to his wheelchair and then carefully wheel him into the bathroom. Once inside, we assist him with the shower and ensure his safety and comfort throughout the process."

The care recipients in this study were dependent on the caregiver in managing themselves. Caregivers needed to help and assist them every day at home, and this became a routine and responsibility for the caregivers.

#### Master Theme 2: Personal Factors of Caregivers

Caregivers may choose to care for older persons for various reasons. Some may do it out of a sense of financial security, while others may feel they have the knowledge and experience to provide the best possible care. Conversely, some caregivers may feel compelled to provide care despite having no desire to do so. The majority of caregivers in this study chose to care for their elderly loved ones out of a sense of personal motivation. They felt a responsibility to care for the older person given the close relationship they shared, such as parent-child or spouse. The participants in the study were primarily Malays and Muslims, and their religion emphasises the importance of showing devotion to parents. Hence, caregivers in the study saw caregiving as a way to reciprocate the kindness and services provided by their elderly loved ones. The strong bond and relationship between caregiver and care recipient often lead to a sense of duty and responsibility to care for the older person. Religion also plays a significant role in motivating caregivers, instilling an obligation to care for parents. Thus, caregiving can be seen as a way to repay the kindness and services received from elderly loved ones and fulfil religious obligations.

"... I have always wished to work near Lipis so that I can be close to my parents and take care of them. Being able to support and care for them is a top priority for me."

" ... As children, it's our responsibility to take care of our parents, and it's a driving factor for me. I want to repay my mother for everything she has done for me by taking care of her in her old age. It's a small way of showing my love and gratitude towards her."

Caregivers believe that by caring for the older person, they are being responsible to them and able to repay the care recipients by returning the same actions as previously done by the care recipients.

Financial support could be one of the reasons caregivers are able to provide caregiving. The caregivers in this study can afford to provide caregiving for the older person, and they have no financial issues to support them. This is because the caregivers in this study are mostly employed, which allows them to earn money from their jobs and receive financial support from others in caregiving. The financial support usually comes from close family members.

" ... I feel fortunate that I have a job that enables me to support my mother financially without any difficulties."

" ... We are willing to buy any necessary medical equipment, such as beds, blood pressure monitors, and any required medicines. We also invest in high-quality medical-grade bed pads to ensure comfort and hygiene for our loved ones."

Family caregivers who have good financial support are able to provide the care recipients' essentials and meet their needs for care at home. Some families are able to provide medical equipment for the older person to ensure their comfort when caring at home.

#### *Knowledge and Experience*

Interestingly, a few of the caregivers had good knowledge of caring for older people. They gained this knowledge through their experiences at work and previous caregiving experiences, which makes them the most suitable individuals to perform caregiving.

" ... Based on my current job and expertise in healthcare, I believe I am the most suitable person to provide care for my loved ones. Despite having five sisters, I believe the most qualified individuals should take up the responsibility, given their knowledge and skills in terms of care and prevention. Moreover, as the only one residing in Lipis, I feel it's my duty to take care of my loved ones in need."

" ... The experience that taught us about caregiving was not while looking after our father but rather when our aunt took care of our late mother. Her approach and methods provided us with valuable insights and learnings, which we can apply while taking care of our loved ones in the future."

Caregivers believe that with the knowledge and experiences they have, they are capable of managing the health and well-being of the sick and elderly. Most caregivers who have knowledge and caregiving experience apply that knowledge when caring for other older individuals.

#### *No Choice in Caregiving*

This concept refers to situations in which caregivers perceive that they have no other option but to provide care for an older person. This may occur when no one else is willing or

able to take on the caregiving role. Additionally, social stigma and personal status can play a role, as society often views individuals who refuse to care for the older person negatively. Unmarried or unemployed individuals may be assumed to have fewer commitments, and this perception can influence them to assume caregiving responsibilities despite their own preferences or circumstances.

In some cases, caregivers may feel that they have no choice due to the death of a potential caregiver, leaving them as the only available option. These factors can create a sense of obligation that may affect the quality of care or the caregiver's well-being.

" ... My aunt fell ill, and unfortunately, she passed away. After her demise, there was no one left who was willing to take care of my grandmother in the village."

" ... Sadly, there is nobody who is willing to take care of my grandmother, and we are not keen on sending her to an old folks' home. Despite her age, she still has many other family members who love her and care for her deeply."

Even though caregivers feel they have no choice, they still provide caregiving for the older person. This is because they still feel responsible for the older person, and most of them do not have the intention to put the older person in a nursing home. Hence, they provide caregiving even though they must do it.

#### *Master Theme 3:*

##### *Support from Others*

Realising that support from others, including close family members and significant others, may help the caregivers in caregiving. The support comes in different ways. Others usually support by providing care assistance for the older person and also moral support. Caregivers receive support from siblings, relatives, husbands, and children. Each of them helps the caregivers when in need, especially when running errands, to ease the caregivers in the caregiving process.

" ... If any of my siblings are unable to provide care, we may seek assistance from our nieces or nephews to help take care of our loved ones."

" ... When I am at work, my husband will take care of my grandmother in our house. He will ensure that she is safe and comfortable while I am away, providing the necessary support and care that she needs."

##### *Significant Others*

Caregivers in this study not only receive support from close family members but also from outside individuals such as maids and friends who assist and support them in caregiving. In another view, the help from others actually helps calm the hearts of the caregivers.

" ... When my aunt goes to work, she requires an assistant to manage the tasks efficiently. The assistant must feed and take care of him. If we are busy working during that time, the assistant also needs to handle his urinary and bowel movements."

*"Our group comprises supportive and caring friends who always have each other's backs. Whenever any one of us faces a challenging situation, we encourage and uplift each other by saying, 'It's okay, you don't need to worry about it. I'll take care of it. You can focus on other things.' Although these actions may seem small, they significantly reduce our stress levels and help us overcome our challenges with ease."*

Colleagues not only help in work but also serve as important people whom caregivers can talk to when needed, especially to share the situation of handling the older person at home. Even though they are not family members, their help is able to reduce the caregiving burden that the caregivers feel.

#### Master Theme 4:

##### Environmental Factors

The environment is an important factor when providing caregiving for an older person, especially the home, which is the setting for caregiving. This can help ease their tasks in managing the older person at home. A convenient house that suits the care recipient is important because they live there, while the proximity to facilities and other family houses may be a factor for the caregiver to provide the caregiving. They feel that it is convenient for caregiving.

*"... My house is conveniently located for my mother's care since some of her children reside in the nearby apartment complex. This makes it easier for us to coordinate and provide care for her."*

*"... I am grateful that my house is equipped with some disability-friendly features, which make it more accessible for my loved ones who have mobility challenges."*

The home environment plays a crucial role in facilitating caregiving for older individuals. A suitable and accessible home environment can significantly contribute to the well-being and comfort of the care recipient, making it easier for caregivers to provide the necessary care and support.

## DISCUSSION

The findings of this study shed light on the multifaceted nature of caregiving for older individuals and the factors that influence the caregiving experience. This study revealed four main themes that contribute to caregivers' decision to care for an older person living at home: personal factors of the elderly, personal factors of the caregiver, support from others, and environmental factors. These themes align with previous research that highlights the impact of health conditions and disabilities on the older person, the strong desire of caregivers to care for their loved ones, the sense of responsibility and reciprocity, and the importance of support networks in caregiving.<sup>7,14-16</sup>

The personal factors of the older person, including medical illness and functional limitations, significantly influence the need for caregiving. The study participants observed that the older person often exhibited child-like behaviours and personalities, despite their advanced age and physical decline. This finding echoes the challenges faced by seniors in managing daily tasks and self-care due to long-term illness or disability<sup>4,7</sup>. Caregivers recognised the need to ensure the

maintenance of the elderly's self-care and relied on their presence and assistance to fulfil this role. Furthermore, the personal factors of the caregiver played a crucial role in their decision to provide care. The close relationship between caregivers and the care recipient, especially in parent-child dynamics, generated a strong motivation to reciprocate the care received during childhood.<sup>15,16,18</sup> Caregivers felt a sense of responsibility and fulfilment in their role, driven by their desire to give back to their parents.<sup>12,16,20</sup> Religious beliefs also influenced caregiving decisions, with caregivers perceiving their role as an act of obedience and devotion to their faith. The role model of a father who practised religious teachings further reinforced the caregiver's commitment to caring for the older person.<sup>15,20</sup>

Financial stability and the ability to meet the needs of the care recipient emerged as important factors for caregivers. Some caregivers had the financial means to provide daily essentials, healthcare management, and assistance aids, which enhanced the comfort and well-being of the older person. In some cases, caregivers received financial assistance and aid from external sources, supporting their ability to fulfil the caregiving role. The caregivers' knowledge and experience in managing the older person's care also contributed to their confidence and belief that they were qualified for the caregiving task.

However, the study also highlighted situations where caregivers felt compelled to provide care due to limited alternatives. The stigma associated with not providing care and the absence of other available caregivers influenced their decision-making process. In some cases, the death of a previous caregiver or the lack of commitment from other family members necessitated the caregiver to assume the caregiving responsibility.<sup>16,23,24</sup> The marital status of the caregiver also played a role, with single caregivers potentially having fewer responsibilities compared to their married counterparts.<sup>19</sup> Gender also appeared to influence the distribution of caregiving roles, as women were more commonly involved in caring for the elderly.<sup>24</sup>

Caregivers received support from various sources, including siblings, family, spouses, children, maids and friends. The assistance provided by family members and relatives, both in terms of caregiving support and moral encouragement, was vital in facilitating the caregiving process. Even when care was not shared, other family members were often willing to help.<sup>23</sup> Additionally, assistance from maids eased the caregiving burden, particularly for working caregivers. Support from understanding friends or colleagues also played a significant role, providing caregivers with opportunities for conversation, support, and shared experiences.<sup>25</sup>

Lastly, the caregiving experience is significantly influenced by environmental factors. Caregivers identified the importance of a convenient and disability-friendly home environment, as it eased the caregiving tasks and improved the overall quality of care. Accessibility to necessary facilities and proximity to relatives' houses also played a role in facilitating caregiving, providing caregivers with readily available support and assistance when needed.

## CONCLUSION

Research findings revealed that caregiving for an older person living at home is bound by the need to provide a holistic care, influenced by a complex interplay of personal, social, and environmental factors. These invaluable insights shed light on the reasons caregivers choose to provide care, emphasizing the importance of understanding these factors in developing robust support systems. By acknowledging and addressing the personal, social, and environmental aspects of caregiving, policymakers, healthcare professionals, and society as a whole can better support caregivers in their crucial and deeply compassionate role of caring for the older person.

## ACKNOWLEDGEMENTS

We would like to express our gratitude to all the respondents in this study.

## ETHICS APPROVAL AND INFORMED CONSENT

This study was approved by the Research Ethics Committee (REC) UiTM. Ref. number: REC/06/2021 (MR/465) and the informed consent was obtained from all the participants.

## CONFLICT OF INTEREST

None.

## REFERENCES

- Nazmi NA, Dahlan A, Sahid MH. Fall concerns among carers of an older person. *Environ Behav Proc J* 2022; 7(20): 185-91.
- Figueiredo MD, Gutierrez DM, Darder JJ, Silva RF, Carvalho ML. Formal caregivers of dependent elderly people in the home: challenges experienced. *Ciência Saúde Coletiva* 2021; 26: 37-46.
- Grundy E, Henretta JC. Between elderly parents and adult children: a new look at the intergenerational care provided by the 'sandwich generation. *Ageing Soc* 2006; 26(5): 707-22.
- Tu J, Liao J. Primary care providers' perceptions and experiences of family-centered care for older adults: a qualitative study of community-based diabetes management in China. *BMC Geriatr* 2021; 21(1): 438.
- World Health Organization. Ageing: healthy ageing and functional ability 2020 [cited June 2023]. Available from: <https://www.who.int/westernpacific/news/q-a-detail/ageing-healthy-ageing-and-functionalability>
- Ris I, Schnepf W, Mahrer Imhof R. An integrative review on family caregivers' involvement in care of home-dwelling elderly. *Health Soc Care Community* 2019; 27(3): e95-111.
- Arulanandem K, Jayawickramaraja PT, Hettige S, Ramanayake RP, Kisokanth G. The burden experienced by elders and family caregivers in caring for the elderly in Batticaloa District. *Sri Lank Fam Physic* 2019; 35: 7-11.
- Yeh KH, Yi CC, Tsao WC, Wan PS. Filial piety in contemporary Chinese societies: a comparative study of Taiwan, Hong Kong, and China. *Inter Sociol* 2013; 28(3): 277-96.
- Stuifbergen MC, Van Delden JJ. Filial obligations to elderly parents: a duty to care? *Med Health Care Philos* 2011; 14: 63-71.
- Mutalib AS, Dahlan A, Danis A, Masuri MG. Interdependency and quality of life amongst Malay Older people in the community: an interpretative phenomenological analysis. *Procedia Soc Behav Sci* 2016; 234: 90-7.
- Makhtar TA, Dahlan A, Masuri MG, Danis A. Interdependence in Malay older people who live in the institutions: an interpretative phenomenological analysis. *Procedia Soc Behav Sci* 2016; 234: 98-105.
- McDonnell E, Ryan AA. The experience of sons caring for a parent with dementia. *Dementia* 2014; 13(6): 788-802.
- Meyer OL, Nguyen KH, Dao TN, Vu P, Arean P, Hinton L. The sociocultural context of caregiving experiences for Vietnamese dementia family caregivers. *Asian Am J Psychol* 2015; 6(3): 263.
- Myhre J, Bjørnstad Tonga J, Ulstein ID, Høye S, Kvaal K. The coping experiences of spouses of persons with dementia. *J Clin Nurs* 2018; 27(3 4): e495-502.
- Andersson M, Ekwall AK, Hallberg IR, Edberg AK. The experience of being next of kin to an older person in the last phase of life. *Palliat Support Care* 2010; 8(1): 17-26.
- Ali SB, Aziz RA. Penjagaan tidak formal warga tua: Antara tanggungjawab dan beban. *e-BANGI* 2018; 13(3): 183-95.
- Schoenmakers B, Buntinx F, Delepeleire J. Factors determining the impact of caregiving on caregivers of elderly patients with dementia. A systematic literature review. *Maturitas* 2010; 66(2): 191-200.
- Wenger GC, Scott A, Seddon D. The experience of caring for older people with dementia in a rural area: using services. *Ageing Ment Health* 2002; 6(1): 30-8.
- Naing MZ, May SY, Aung MH. Caregiver burden from caring for dependent elderly in Yangon, The Republic of the Union of Myanmar. *Makara J Health Res* 2020; 24(1): 3.
- AM ZI, Noorlaili MT, Rosdinom R, Azlin B, Iryani T. Caring for moderate to severe dementia patients-Malaysian family caregivers experience. *IIUM Med J Malays* 2018; 17(1): 93-102.
- Borrayo EA, Goldwaser G, Vacha-Haase T, Hepburn KW. An inquiry into Latino caregivers' experience caring for older adults with Alzheimer's disease and related dementias. *J App Gerontol* 2007; 26(5): 486-505.
- Kiger ME, Varpio L. Thematic analysis of qualitative data: AMEE Guide No. 131. *MedTeach* 2020; 42(8): 846-54.
- Wenger GC, Scott A, Seddon D. The experience of caring for older people with dementia in a rural area: using services. *Ageing Ment Health* 2002; 6(1): 30-8.
- Alavi K, Sail RM. Peranan wanita Melayu dalam proses penjagaan ibu bapa tua: dilema dan cabaran dalam era globalisasi. *Kaji Malays* 2010; 28(2).
- Quinn C, Clare L, Pearce A, Van Dijkhuizen M. The experience of providing care in the early stages of dementia: An interpretative phenomenological analysis. *Ageing Men Health* 2008; 12(6): 769-78.