Understanding Challenges Faced by Caregivers of Chronically III Older Adults in Determining Interventions for their Wellbeing: A Qualitative Analysis

### Santos Bukarak<sup>1\*</sup> & Masarah Mohamad Yusof<sup>2</sup>

<sup>1,2</sup>Department of Social Work, School of Social Sciences, Universiti Sains Malaysia

\*Corresponding Author: santos@ism.gov.my

## Abstract

The problems that caregivers of older adults with chronic illnesses deal with can have a range of repercussions. This study aims to evaluate the challenges experienced by those who care for older adults with chronic illnesses. The two main objectives of this research are to examine the challenges experienced by caregivers of older adults with chronic illnesses and to identify the caregivers' needs to improve their functionality. In-depth interviews were conducted with 15 caregivers of older adults with chronic illnesses who received financial assistance from the Social Welfare Department of Penang to collect qualitative data. This study uses thematic analysis to highlight some of the challenges caregivers face, including increased costs for care, financial unrest, limitations of care elements, and a lack of social support. The study suggested several social work interventions to enhance the provision of social services based on the needs of the target population. All levels of government must act together, including the Social Welfare Department, which not only works with older adults but also supports those who care for them. The growing older adult population today has ushered in a new period of societal transition.

Keywords: Caregivers, older adults, chronically ill, social work intervention, wellbeing



### 9

## Introduction

The number of senior citizens is increasing everywhere, and according to Noor Ani et al. (2018), the pace of population ageing is increasing considerably more quickly in developing nations than in industrialised nations. According to *Jabatan Kebajikan Masyarakat* (2017) and World Health Organisation (2011), older people are 60 or older. In addition to family structures and intergenerational links, the labour and financial markets and the demand for products and services like housing, transportation, and social protection will undergo unprecedented social transformations due to the ageing population (United Nations, 2017). Malaysia is one of the countries that will age the fastest, with the proportion of older people expected to be 15.3 percent of the total population in 2030 (National Population and Family Development Board Malaysia, 2017). Advances in medical technology, better socioeconomic conditions, a drop in fertility, and women's participation in higher education and the workforce were among the factors contributing to Malaysia's rapidly ageing population growth (National Population and Family Development Board Malaysia, 2017).

One of the primary departments tasked to oversee the welfare of older adults in Malaysia is Jabatan Kebajikan Masyarakat (JKM) under the Kementerian Pembangunan Wanita, Keluarga dan Masyarakat (KPWKM). JKM had a programme called Bantuan Penjagaan Terlantar (BPT) that provided financial assistance for the caregivers of chronically ill elderly. The BPT financial aid programmes aim to lessen the burden on families and caregivers and motivate them to care for loved ones with disabilities or chronic illnesses (Jabatan Kebajikan Masyarakat, 2019).

Common diseases like Alzheimer's and dementia disease, heart failure, cancer, chronic obstructive pulmonary disease (COPD), chronic kidney disease, diabetes, and coronary heart cause chronic illness in older adults (National Aging Team, 2017; Joyce et al., 2005). These illnesses can be challenging to manage, impairing an aged person's capacity to carry out daily tasks. As a result, providing long-term care and supervision for senior people with severe chronic illnesses is necessary (Safwan Hamdy & Md Yusuf, 2018). Caring for older adults needs a complete commitment and much time, and it also shows how burdening the caregivers' occupations are (Suridah & Rahimah, 2018). According to Suridah and Rahimah (2018), Riekkola Carabante et al. (2018), Peetoom et al. (2016), and De Oliveira-Monteiro et al. (2018), this is related to several issues for the caregiver in terms of social function, psychological wellbeing, and financial concerns, as well as the problems facing chronically ill older adults.

## **Theoretical Framework**

As shown in Figure 1, this study utilises three theories to understand the stress among the caregivers of chronically ill elderly. These theories are Caregiver Stress Theory, Maslow's Hierarchy Needs Theory, and System Theory.



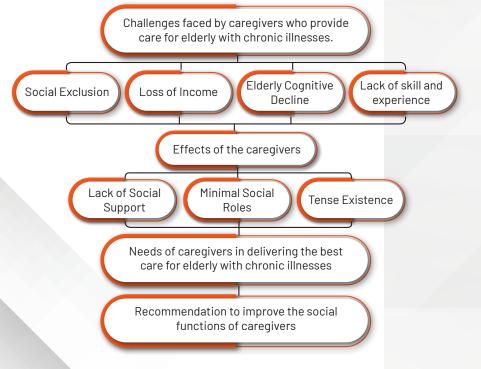
# Methodology Research design

This study attempts to highlight the difficulties faced by caregivers of older adults who have chronic illnesses, as well as the need to improve their social functionality. Exploratory qualitative methods offer a deeper understanding of the concerns and problems faced by the caregivers who look after chronically ill older adults, making them the optimal design strategy for this research. The participants were contacted by phone for the qualitative interviews. Additionally, the study uses a phenomenological methodology to characterise the participants' ordinary human experiences, including anger, loneliness, and melancholy (Lewis, 2015).

## Population, sampling, and data collection technique

The study target population is the caregivers of Penang's chronically ill older adults. These caregivers who participated in the BPT scheme in all of Penang's JKM districts – JKM Timur Laut, JKM Barat Daya, JKM Seberang Perai Utara, JKM Seberang Perai Tengah, and JKM Seberang Perai Selatan make up the study sample. The number of participants for this research study was between 10 and 15, consistent with the justification for qualitative research – small sample size in a qualitative framework improves the reliability of fine-grained data, provides intimate contact between the researcher and the participants, and enables in-depth research in naturalistic situations (Crouch & McKenzie, 2006).

Figure 1 Conceptual Model of the Study.



10

Non-probability sampling, the purposive sampling technique, was used in this study. The researcher conducted an individual, semi-structured interview over the phone with the respondent during the data-gathering process. The COVID-19 epidemic is the rationale for adopting the telephone technique because it is the best way to prevent direct interaction between the respondents and the researcher.

INTERNATIONAL

**OF SOCIAL POLICY AND SOCIE** 

VOLUME 20/2024

### **Data analysis**

Thematic analysis was used to analyse this research investigation. Braun and Clark (2006) state that thematic analysis is a qualitative analytic technique that looks for patterns or themes relating to various epistemological and ontological views. The transcript of all the data obtained from the interviews was divided according to the linked themes and sub-themes and the research goals. The researcher used this approach to collect coded phrases to describe the participant's emotions or ideas. According to Alhojailan and Ibrahim (2012), one benefit of thematic analysis for the researcher is that it might allow them to go beyond simply calculating clear-cut terms or sentences or conveying their views. Using thematic analysis helps this study examine the topics related to the needs and challenges faced by caregivers who care for older adults with chronic illnesses.

## Results

### Increase in the caregiver's costs

The provision of necessities for senior people with chronic illnesses is crucial since it is a requirement that they use daily. According to Maslow's hierarchy of requirements, this problem can be solved. McLeod (2018) states that basic needs must be satisfied before additional requirements. The essential requirements for seniors with chronic illnesses include diapers, milk, food, powder, and many more. However, since the cost of necessities rises each year, carers find it most difficult for them. Since they are committed to providing care for the chronically ill elderly, caregivers have difficulty making money because they cannot work. The requirements of the chronically ill elderly must be met every day by the caretaker, but as the cost of those demands rises annually, so does their ability to do so. As a result of this study's findings, both the fundamental necessities and the need for medicines have increased in price for senior people.

According to the research, there is no price regulation on pharmaceuticals in pharmacies throughout Malaysia, and market forces are allowed to promote competition (Babar, 2015). This assertion is consistent with that report. Having a monthly obligation to pay for utilities and loan debt is another difficulty these carers face. One of the findings discovered that a caregiver had purchased a home while employed and had sufficient income to cover their loan obligations. However, the caretaker is liable for paying the loan obligation if one of them gets ill and becomes bedridden. The caregiver must find additional sources of income in addition to providing care for the elderly who suffer from chronic illnesses, making it extremely difficult for them to pay the instalments.

Additionally, they have no alternative option for housing. Therefore, they are unable to sell the house when the need arises. A house and money are two additional crucial fundamental wants, according to McLeod (2018), and they are placed under physiological needs in Maslow's extended theory of needs.

### **Financial unrest**

VOI UME 20/2024

One of the main difficulties experienced by caregivers is financial uncertainty. The results of this study demonstrate that there are specific circumstances, such as job loss or, in more severe cases, the loss of a primary source of income, that put carers taking care of chronically ill older adults in a difficult financial position. A few carers struggled to care for their elderly relatives who suffered from chronic illnesses until they decided to resign from their positions. It ensures they can fulfil their obligations to provide excellent attention and care to the patient.

This study discovered that choosing to stop working is the best course of action because most participants had no social support system to help them care for the chronically ill elderly if they were working. This action is due to how difficult and impossible it is to simultaneously perform the two tasks of being a caretaker and an employee. According to Arksey (2002), most caregivers had decided to give up their jobs entirely to focus only on providing care. Caregiver financial hardships are a result of this circumstance. According to Suridah and Rahimah (2018), caregivers' financial situation is a strain because they have to support themselves and meet the demands of ill elderly patients. According to Ahmad's (2012) study, many caregivers frequently experience financial difficulties due to caring for older adults.

The study's findings revealed the difficulties these carers face while dealing with unstable income. Four caregivers experienced this difficulty because some had to work a part-time job, such as selling *nasi lemak*, setting up stalls in front of the house, giving tuition, or hanging banners. Part-time employment, however, cannot assist caretakers in making a consistent income because it is only available if there is a demand from the general public or businesses. For instance, a caregiver selling *nasi lemak* needs help making sales when only a few people go out to buy it because of the COVID-19 pandemic restrictions. The execution of the Mobility Control Order (MCO) in Malaysia to address the COVID-19 pandemic issue has severely impacted small enterprises, according to a report by Fabeil et al. (2020). This finding is consistent with a caregiver's assertion that their daily sales are declining.

## Limitation of care elements

Another conclusion from the study's first purpose, which was to learn about the difficulty caregivers encounter when providing care for older adults with chronic illnesses, is the limitation of care elements. During the interview, the researcher

discovered six factors related to limited care, including age, illness, not receiving proper care knowledge, taking care of more than one chronically ill person, and assistance needed from their immediate family members. All of the carers who were interviewed acknowledged that caring for older people with chronic illnesses presented the same difficulties.

**OF SOCIAL POLICY AND SOCIE** 

VOLUME 20/2024

Older adults with chronic illnesses present unique challenges for caregivers because their health is deteriorating, and they are unable to perform daily tasks like eating, bathing, using the restroom, and communicating with the person providing care. This issue has forced caretakers to assist people in performing and meeting everyday demands like lifting, washing, cleaning faces and peeing, changing diapers, eating, and more due to ageing. The findings are supported by a study by Shilpa Amarya (2018), which discovered that ageing is a natural process throughout life. It is uncontrollable and results in increased dependency as humans age. Physical impairment and functional disability are observed, and they include changes to the nervous system, declining cognitive function, musculoskeletal system, and changes in body composition (Shilpa Amarya, 2018).

The ability of caregivers to care for older adults with chronic illnesses presents a difficulty because they are sixty years of age or older. The ability of several caregivers in this study who have achieved seniority to care for patients is decreasing as they grow older and worse. It is due to their deteriorating level of immunisation and because being a caregiver at this age might be dangerous for them. Shilpa Amarya (2018) asserts that physical degeneration and functional incapacity worsen over time, leading to increased dependency as people age.

In addition, the fact that they are ill makes it difficult for caregivers to provide care for older patients with chronic illnesses. Nine of the carers who participated in the interviews said they were unwell. Five caregivers admitted to being unwell when they started taking care of elderly with chronic illnesses. Meanwhile, two caregivers told the researcher that they developed illnesses as a result of the stress they underwent after beginning to provide care for older adults with chronic illnesses. Several different sorts of discomfort, including back pain, leg pain, hand pain, vein pain, fever, and slipped disc, were noted during the interview.

The findings of this study are consistent with those of studies looking at the workload of caregivers for the elderly. Peetoom et al. (2016) reported that some caregivers experience difficulties providing informal care as a result of health issues like joint pain, back pain, exhaustion, and mental health. In addition, it was shown that the majority of caretakers had illnesses including high blood pressure, diabetes, heart problems, high cholesterol, and others (Suridah & Rahimah, 2018).

In addition, because they never go through the required training or courses about the proper care for the chronically ill elderly, caregivers also struggle with not having the correct information. They only provide care based on their personal experiences, what they believe to be the best decisions, observation of hospital nurses providing care, and lessons learnt through looking after their sick, INTERNATIONAL JOURNAL OF SOCIAL POLICY AND SOCIETY VOLUME 20/2024

bedridden neighbours. Bahagian Pembangunan Kesihatan Keluarga (2008) asserts that knowledge of the physical and psychological changes associated with ageing, including diminished brain cells, personality, mind, and emotions, is crucial for caregivers to have in order to be better prepared for the older adult's declining health.

In addition, the knowledge needed to manage this chronically ill person can be applied more methodically by the health department's guidelines, which calls for the overall care of both the elderly patient and the caregiver (Bahagian Pembangunan Kesihatan Keluarga, 2008). Unfortunately, this study discovered that the majority of caregivers did not receive formal training from any connected organisations, which can be harmful to both the caregiver and the elderly with a chronic illness. A theoretical systems approach can be used to understand this problem. The systems theory approach to this type of integration treatment, according to Greene and Blundo (1999), is created to incorporate seniors and their families to lessen the pressures because family systems are perceived as interconnected and interdependent. However, the stability may be jeopardised by older persons' decreasing function and rising care needs (Greene & Blundo, 1999). The caregiver's inexperience will make it more challenging to care for an aged person with complete dependence, especially if they have a chronic illness.

This study also discovered that some carers experience difficulties while trying to provide care for older people who have chronic illnesses in their families. The findings of this study highlighted the physical and psychological strain that carers of chronically ill patients must endure. According to Faronbi et al. (2019), caring for chronic patients causes carers to suffer from various illnesses, including headaches, stomach aches, upper respiratory infections, weight loss or weight gain. Stress experienced by caregivers, leading to exhaustion and negative health impacts, may be more common among those who provide care for older people with chronic illnesses (Ahmad, 2012).

The findings of this study indicated that similar outcomes were caused by the stress of providing care for multiple patients. The majority of caregivers also faced health issues as a result of their caregiving duties. This data demonstrates how difficult it is for caregivers to provide care for one older person who has a chronic illness, let alone if they are also providing care for two or three other chronic patients who require intense care and are in poor health. Burnout and abuse among the patients being cared for are both possibilities when the caregiver's situation is out of control. Stress among caregivers, which results from having to fulfil a variety of duties, can lead to caregivers abusing sick seniors verbally or physically (Janetta Ananias, 2014; Pillemer & Finkelhor, 1989).



## Social supports

Social support is crucial for caregivers to give the elderly with chronic illnesses the best care possible. However, this study's findings revealed that the caregivers' most significant problem is a lack of social support, particularly from their families, siblings, and children. This outcome is comparable to Nur Saadah and Siti Hajar's (2011) study, which found that only a few fortunate carers had adequate assistance from their extended families, friends, neighbours, communities, and social service organisations. If the caregiver's family is asked to help, they may present a variety of excuses, sometimes to avoid doing so. The fact that their children are in school, they have financial difficulties, that their husbands are employed full-time, that they live elsewhere or beyond the neighbourhood, and other factors are frequently cited (Peetoom et al., 2016; Nurul Hudani et al., 2018).

The family is an integral part of the caregiving system and social support. According to Nurul Hudani et al. (2018), the family is crucial in many ways, including offering emotional, psychological, and financial support. As a result of the caregiver's family role in the system not functioning well, the challenge of caring for the elderly who have chronic illnesses will become increasingly onerous.

In addition, carers for older people with chronic illnesses often face difficulties due to a lack of social support from both local elected officials and government organisations. Nur Saadah and Siti Hajar (2011) claim that only a tiny percentage of those who were fortunate enough to be caring for others were given the proper support in the form of social, emotional, and monetary aid from their neighbours' families, communities, and governmental organisations like JKM, Zakat, health clinics, and NGOs in their areas. This claim demonstrates that more caregivers are still stressed out and overworked and need the comprehensive aid that the community and governmental organisations should give them. It also entails the responsibility of elected officials to assist the elderly and caregivers who need long-term care in the local community. Unfortunately, this survey also discovered that most caregivers still needed assistance from relevant organisations, the local community, or government officials.

Additionally, according to Nur Saadah and Siti Hajar (2011), caregivers require acknowledgement of their contributions, services that are tailored to their particular needs, opportunities for relaxation, practical assistance, a person with whom they can open up about their own emotional needs, information on benefits and services as well as details on the health of the chronic patients they are caring for, income that covers the cost of care, and other things. Therefore, the roles of government agencies and elected representatives are crucial in enhancing caregiver self-confidence. However, this study found that the needs of a caregiver from government agencies and elected representatives still need to be met, thus indirectly adding pressure on them.

INTERNATIONAL JOURNAL OF SOCIAL POLICY AND SOCIE VOLUME 20/2024

## **Discussion and Recommendation**

## Intervention through social work approach

It is advised that JKM develop interventions using a social work approach to aid in addressing the difficulties faced by caregivers who care for older people with chronic illnesses. A problem-solving model will be applied in the suggested intervention. This model is a method in social work that is connected to help clients solve problems through particular stages like engagement, assessment, intervention, evaluation, and termination. According to Demiris et al. (2010), problem-solving intervention is an organised, cognitive-behavioural intervention that can teach people problem-solving coping skills to help them deal with significant unpleasant life events and daily changes.

Social workers can employ a variety of theories, including system theory, ecological theory, psychodynamic theory, and others, to better understand the issues carers face during the evaluation stage. Social workers can employ a variety of theories during the intervention stage, including the coping theory, resilient theory, and crisis theory, among others, to create plans of action based on the needs of their clients. Social work intervention for individuals is a way to help caregivers who care for the chronically ill elderly deal with the challenges they face.

According to M.Si (2015), when a person is facing a problem, they need someone to help them deal with it, so social workers can play influential roles in solving the main problems using methods and related techniques. The intervention is divided into several phases, namely the preparation phase, the initial phase, the intermediate phase, and the final phase (M.Si, 2015). Each stage assists the caregiver in concentrating on the client's needs holistically, such as their emotional, social, physical, and spiritual requirements. Through these individualised interventions, carers will also be assisted in understanding their difficulties, how those difficulties affect them personally, and the needs they desire. With the help of this intervention programme, it is intended that caregivers gain a better awareness of their predicament and how to handle their difficulties with the advantages they already possess.

According to the new universal definition of social work, social workers' interventions are highly timely because they have training in academic fields and professions that are practice-based. According to Ornellas et al. (2018), the new worldwide definition of social work reads as follows: Social work is a practice-based profession and an academic subject that promotes social change and development, social cohesiveness, and the empowerment and emancipation of people. Social work involves people and structures to address life difficulties and improve welfare. It is underpinned by theories from the social sciences, humanities, and indigenous knowledge (Ornellas et al., 2018).

In addition, group work can be used to perform social work treatments that concentrate on recovery, prevention, and caregiver development. As change

agents for caregiver groups experiencing difficulties in caring for older patients with chronic illnesses, social workers play a range of responsibilities. Demiris et al. (2010) found that the caregiver's intervention can encourage them to employ more problem-focused and social support coping mechanisms. Social workers can use empowerment theory as a unifying framework, as it presents an integrative, holistic approach to meeting the client's needs. This aligns with the role of social workers who practice empowerment approaches that aim to see and access the challenges a client faces (Lee & Hudson, 2017).

**OF SOCIAL POLICY AND SOCIET** 

VOLUME 20/2024

Additionally, Lee Hudson's (2017) research demonstrated that competent social workers' empowerment strategies are founded on values, principles, procedures, and expertise incorporated into conceptual frameworks. Caregivers of these chronically ill older adults can benefit from several advantages through group intervention. In other words, individuals can understand that their difficulties are shared by other group members, which motivates them to share. Additionally, people can discuss their experiences dealing with the effects of difficulties that are common to them. As an intermediary within the group during the intervention process, social workers might assist group members in slipping into their current roles. Social workers serve as partners, counsellors, advocates, risk or need assessors, care managers, and agents of social control in issue-solving (Asquith et al., 2005).

#### Increased financial assistance from JKM for caregivers

According to the respondents, the welfare department should consider the caregiver himself as being vulnerable in terms of having enough money for daily needs in order to provide extended welfare help to caregivers. The current formal aid system, such as JKM, could be improved with the help of this approach. The majority of caregivers face several difficulties, including financial difficulties, severe health issues that require ongoing care, ageing into their 60s, living alone without family support, and JKM assistance that is limited to the costs associated with caring for elderly patients who are chronically ill. As a result, the caregivers need to extend assistance from the welfare department.

The United States government's "Medicaid" programme is one of the best examples of enhancing the overall assistance system and offering direct benefits to caregivers as well as chronically sick senior people (Coe et al., 2019; Kaye & Teshale, 2020; Ingram-french, 2020). This Medicaid programme, entirely funded by the US federal government, emphasises, and strengthens the role of family caregivers in managing older individuals who require long-term care. The benefit of this programme is that it can offer several advantages in some states in the United States, including the waiver of laws requiring family caregivers who provide skilled healthcare services to be paid, the provision of behavioural health services for family caregivers as a value-added service, the establishment of a mechanism to identify and provide family caregivers with individualised training based on data gathered during the care coordination process, and the ability to conduct formal caregiver assessments and plan to meet needs identified in the assessment (Kaye & Teshale, 2020).

According to Coe et al. (2019), their research demonstrates that the Medicaid programme that prioritises family-based care is less likely to experience several adverse outcomes throughout a nine-month trial, such as a lower prevalence of infections, shortness of breath, and bedsores as a result of better health outcomes. One of the best examples of a programme that benefits caregivers and older people with chronic illnesses is the Medicaid programme. The Malaysian government should learn more about this initiative and adapt it to fit our country's circumstances, culture, and public perceptions to improve services to this target population.

#### JKM's cooperation with other governmental organisations

One of the suggestions for interventions that the JKM can implement is to make the financial assistance programme for those who look after chronically ill older people more robust and inclusive. JKM should broaden this programme by shifting its emphasis away from the aid component. The best way to strengthen this intervention is to work with diverse public and private organisations involved in the care of chronically ill older adults, such as health departments, religious departments, and district offices in each district.

Social workers at the JKM can create a comprehensive programme where each department can fulfil its specific tasks by its jurisdiction by working together across these departments. For instance, the health department can help JKM with health issues, including ongoing training for caregivers on adequately caring for older people with chronic illnesses. The health department can include topics such as safe lifting, bathing, feeding, dressing, and recreation for seniors with chronic illnesses. In addition to standard check-ups for chronically ill older patients, the health department can offer supplementary programmes that teach patients how to observe their conditions, make medications, repair wounds, and other things. This health department's programme also includes information for caregivers, such as how to deal with stress, sadness, and the challenges of caring for chronically ill seniors.

Additionally, the Department of Health must regularly monitor and care for caregivers. This JKM support programme also allows for the inclusion of health department courses. Promoting such a programme will make it possible to indirectly contribute to caregivers' and patients' overall social well-being in higher-quality care.

Given how difficult it can be to provide the finest care for older people who have chronic illnesses, the function of the religion department is crucial in assisting caregivers in living a life full of obstacles and stresses. The strength of religion is

VOI UME 20/2024

**OF SOCIAL POLICY AND SOCIE** 

VOLUME 20/2024

In addition, the religion department can offer courses that are pertinent to the idea of caring for chronically ill elders. Through the religious division, they can request cooperation from other religious bodies to assist carers practising religions other than Islam. Christianity, Buddhism, Hinduism, and Sikhism are a few religions that can coexist in this curriculum. This is because, according to the findings of the researchers' interviews, these caregivers are not just focused on one race or religion. However, instead, they recognise that all races and religions share the same problems and that, to overcome the difficulties of providing care, they need the support of their religions.

Social workers play a crucial role in analysing caregivers' strengths during the evaluation stage of intervention as an empowering technique, tearing down all of their assets that might be used to create a coping mechanism. Based on this study's findings, using, and strengthening religious beliefs is an excellent way to help carers deal with the difficulties of taking care of older people with chronic illnesses. Therefore, collaborating with religious organisations would be a wise move.

As a critical facilitator for executing programmes at the district level, the JKM office is one of the many government organisations that play a significant role. As a mediator between clients and departments, communities, and NGOs, the JKM's position in the district office is comparable to that of a social worker. All government departments use the district office as a resource when communicating with the local population on a district-level basis so that initiatives from public and private organisations can be directed to carers with the JKM district office's assistance. For instance, carers or the elderly who are chronically ill can receive basic equipment help directly from any agency or private company. Besides, the district office could help with any donations, support, or classes that might benefit the caregiver. Because of this, the JKM office in the district has a crucial function as a mediator in managing resources to meet client's needs, including carers and older people with chronic illnesses.

### Increasing senior citizen benefits

Being able to meet the fundamental needs of older adults who are chronically ill is one of the most challenging issues caretakers confront because the cost of essential products for these senior people, like special milk, diapers, food tubes, powders, and medications, increases annually. When the primary focus is on providing care for older adults with chronic illnesses, this issue becomes more urgent when the caregiver lacks a stable job or is entirely disabled. INTERNATIONAL JOURNAL OF SOCIAL POLICY AND SOCIETY VOLUME 20/2024

In addition, the COVID-19 epidemic, one of the difficulties for caregivers to work full- or part-time, makes the situation much worse. The financial assistance provided by *Jabatan Kebajikan Masyarakat* (JKM), which has been increased from RM350.00 to RM500.00 at this time, could assist in reducing the impact of the rising cost of necessities for chronically ill older people in Malaysia (Department of Social Welfare Malaysia, 2020). However, in the long run, the basic demands of senior people with chronic illnesses will continue to rise year after year. Eventually, more than financial assistance will be needed to meet the costs. Therefore, extending privileges is the most excellent strategy to address the rising cost of necessities for chronically ill older adults in order to prevent the caregiver from being directly impacted by the price increase.

Regarding this circumstance, the Philippines government is one of the countries that implemented this through the "Expanded Senior Citizen's Act" of 1992, enacted under Republic Act 9994 (Inabangan et al., 2019). The objectives of Republic Act 9994, according to Inabangan et al. (2019), are to improve the well-being of the elderly and to provide more significant benefits, such as a discount on medicine, treatments, professional fees, and essential goods. Moreover, the Act also gives a 20 per cent discount to transportation, restaurants, hotels, recreational centres, and leisure places, and a 5 per cent discount on necessities, prime commodities, and public utilities such as water and electricity bills (Inabangan et al., 2019). To achieve the well-being of the elderly, the Malaysian government can study Republic Act 9994 further to implement in this country because it can give many benefits, especially to the chronically ill elderly in Malaysia, and indirectly help the caregivers absorb the expenses. The idea of this intervention is in line with the role of social workers as agents of change at the macro level.

In order for the government to pay attention to social issues in society and work toward bringing about a change that is beneficial to the entire society, changes at the macro level are crucial. The intervention will be based on social policy that meets the needs of the target population and our current cultural context. If the government worries about the challenges carers and chronically sick senior citizens encounter, this notion may be considered and improved in our nation. A bottom-up model might be connected to developing new policies in response to the challenges at the grassroots level. A higherlevel solution is sought for problems seen from a lower-level perspective. The primary issue for carers of older adults with chronic illnesses, according to the study's findings, is meeting their fundamental needs. Therefore, the government should evaluate, assess, and plan before executing a plan, considering the needs of senior people with chronic illnesses. According to Bentur and Sternberg (2019), the bottomup model refers to initiatives for positive change born out of grassroots experiences and elevated, promoted, and transformed into expert ideas.



#### Improve JKM's home help programme

JKM launched an excellent programme for home help services. The Department of Social Welfare Malaysia (2020) describes this programme as a social assistance service given by JKM volunteers to elderly and disabled individuals (OKU) who live alone or with less capable and loving relatives. Providing food and drink, personal cleaning, chit-chatting with friends, leisure activities, organising, cleaning, washing, and many more are included in the activities performed by the Department of Social Welfare Malaysia (2020).

The implementation of this programme is based on the guidelines for the implementation of the JKM programme for home assistance services, where the frequency of visits is based on the needs and comfort of the clients and families assisted and the duration of the visit to the client's home is at least one hour with a frequency of once per week(Department of Social Welfare Malaysia, 2020). There are several improvements to the Home Help programme that the JKM should consider since they could assist the elderly with chronic illnesses and their caregivers more. Perhaps JKM can include the programme's client on the list of older adults who are chronically ill receiving financial aid. In addition to meeting the needs of older people with chronic illnesses, this concept can also benefit caretakers.

Additionally, the psychosocial impact of the caregivers can be diminished by allowing them to communicate their problems with volunteers and receive assistance from them in providing care for older adults who have chronic illnesses. Extending this home help service programme to carers is a two-pronged approach where volunteers can reach out to caregivers by offering supportive assistance to them in order to continue care in addition to assisting the chronically ill elderly. This approach is consistent with the profession's objectives, which centre on promoting people's rights, self-determination, empowerment, and growth (International Federation of Social Workers, 2010). Based on their knowledge, particularly with caregiver difficulties, social workers must take a crucial leadership role in the programme to ensure its effectiveness. Social workers must keep track of, access, and assess volunteer home visits.

Second, with the cooperation of numerous government departments and private businesses, including the healthcare department, the religion department, counsellors, other religious faith bodies, and Non-Governmental Organisations (NGOs), this programme can be more successful and comprehensive. Particularly for the caregivers who practice different religions like Christianity, Buddhism, Hinduism, or the Sikh faith, the functions of religious faith bodies are crucial. Many findings from the researcher's interviews with respondents can be related to the role of religious faith as one method for easing caregiver stress when they are dealing with so many difficulties when caring for the chronically ill elderly. Mahdavi et al. (2017) claim that spirituality helps lessen sadness, anxiety, and substance misuse while also enhancing mental and physical health, well-being, and healthy behaviour. In addition, the functions of the healthcare department are essential to the caregivers because they could support the activities by enhancing the abilities of the caregivers and their knowledge of how to interact with senior patients who are chronically ill. By their respective areas of expertise and jurisdiction, social workers can play crucial roles as a bridge to bring together or create a network of cooperation between various organisations, including those in the public and private sectors, non-profits, and religious bodies, in order to meet the actual needs of the clients, the elderly or caregivers in particular. This collaboration may also be centred on one or more aspects of the target group's recovery, prevention, or development toward well-being. This collaboration aims to enhance the standard of services provided by the organisations where social workers are employed.

## Conclusion

This study gathered some critical topics from a researcher's interview with 15 participants, followed by related sub-themes in which they appeared directly and indirectly throughout the interview. The data analysis outcomes revealed that the goals emphasize in this study had been accomplished. Based on these findings, the intervention model was expanded in several ways, and it was suggested explicitly to JKM by government organisations to make existing programmes more comprehensive. Hopefully, this study will be prioritised to benefit carers and olderadults with chronic illnesses. The Medicaid programme that the United States and the Philippines both implemented and examples from other nations are used to illustrate this intervention paradigm. If appropriate, the programmes launched by these nations can directly benefit caregivers and the elderly with chronic illnesses. They can be researched in greater detail. However, before it can be put into action, this concept needs to be more thoroughly examined and tailored to the circumstances and culture of our nation.

## References

- Ahmad, K. (2012). Informal Caregiving to Chronically III Older Family Members: Caregivers' Experiences and Problems. South Asian Studies A Research Journal of South Asian Studies, 27(1), 101–120. https://pdfs.semanticscholar. org/d07f/1b7055b4c7e76dedf5fe9a74a99e47bda7f9.
- Alhojailan, M. I., & Ibrahim, M. (2012). Thematic Analysis : A Critical Review of Its Process and Evaluation. WEI International European AcademicConference Proceedings, 1(2011), 8-21.
- Arksey, H. (2002). Combining informal care and work: Supporting carers in the workplace. *Health and Social Care in the Community*, *10*(3), 151–161. https://doi.org/10.1046/j.1365-2524.2002.00353.x

Asquith, S., Clark, C., & Waterhouse, L. (2005). The Role of the Social Worker in the Twenty First Century: a Literature Review. 47. http://www.scotland.gov.uk/ Resource/Doc/47121/0020821.pdf

**OF SOCIAL POLICY AND S** 

OLUME 20/2024

- Babar, Z. U. D. (2015). Pharmaceutical pricing in Malaysia. *Pharmaceutical Prices in the 21st Century, November*, 1–411. https://doi.org/10.1007/978-3-319-12169-7
- Bahagian Pembangunan Kesihatan Keluarga. (2008). Panduan untuk penjaga warga emas. In *Kementerian Kesihatan Malaysia*.
- Bentur, N., & Sternberg, S. A. (2019). Dementia care in Israel : Top down and bottom up processes. 4–9.
- Braun, V. & Clark, V. (2006). Using Thematic Analysis in Psychology. *Taylor & Francis*, 41. https://doi.org/10.1017/CB09781107415324.004
- Coe, N. B., Guo, J., Konetzka, R. T., & Van Houtven, C. H. (2019). What is the marginal benefit of payment-induced family care? Impact on Medicaid spending and health of care recipients. *Health Economics (United Kingdom)*, 28(5), 678–692. https://doi.org/10.1002/hec.3873
- Crouch, M., & McKenzie, H. (2006). The logic of small samples in interview-based qualitative research. *Social Science Information*, 45(4), 483–499. https://doi. org/10.1177/0539018406069584
- De Oliveira-Monteiro, N. R., Camargo Novelli, M. M. P., & Silva Ribeiro, J. V. (2018). Psychological Conditions in Caregivers of the elderly with Dementia: Brazilian Cases. *MOJ Gerontology & Geriatrics*, 3(April 2018). https://doi.org/10.15406/ mojgg.2018.03.00112
- Demiris, G., Parker, Oliver, D., Washington, K., Fruehling, L. T., Haggarty-Robbins, D., Doorenbos, A., Wechkin, H., & Berry, D. (2010). A problem solving intervention for hospice caregivers: A pilot study. *Journal of Palliative Medicine*, 13(8), 1005–1011. https://doi.org/10.1089/jpm.2010.0022
- Department of Social Welfare Malaysia. (2020). Portal Rasmi Jabatan Kebajikan Masyarakat. In Jabatan Kebajikan Masyarakat Malaysia. http://www.jkm.gov.my/jkm/index.php?r=portal/ left&id=NzFHMnJLSWxoQytmM3RscmUvMVdWZzO9%OAhttp:// w w w . j k m . g o v . m y / j k m / i n d e x . p h p ? r = p o r t a l / left&id=NGZibOVqSXVIVHZsZjNBVmRpaHBpUT09



- Fabeil, N. F., Pazim, K. H., & Langga, J. (2020). Survivability of Micro-enterprises during the Pandemic Crisis. Asian Journal of Entrepreneurship, 1(4), 144–152. http://myjms.mohe.gov.my/index.php/aje/article/view/11666.
- Faronbi, J. O., Faronbi, G. O., Ayamolowo, S. J., & Olaogun, A. A. (2019). Caring for the seniors with chronic illness: The lived experience of caregivers of older adults. Archives of Gerontology and Geriatrics, 82, 8–14. https://doi.org/10.1016/j. archger.2019.01.013
- Greene, R. R., & Blundo, R. G. (1999). Postmodern Critique of Systems Theory in Social Work with the Aged and Their Families. *Journal of Gerontological Social Work*, *31*(3–4), 87–100. https://doi.org/10.1300/J083v31n03\_06
- Inabangan, A. K., Garcia, L., & Abocejo, F. (2019). Evaluation of the Philippine Expanded Senior Citizens Act(RA 9994) on Mandated Privileges for the Elderly. European Academic Research, 6(10), 6112–6138. https://www.researchgate. net/publication/331166618\_Evaluation\_of\_the\_Philippine\_Expanded\_Senior\_ Citizens\_Act\_RA\_9994\_on\_Mandated\_Privileges\_for\_the\_Elderly
- Ingram-french, M. (2020). "Pacing "Ourselves: Saving Medicaid through Programs of All- Inclusive Care for the Elderly. 124(3). https://www.payingforseniorcare. com/longtermcare/paying-spousal-caregivers.html%0Afile:///Users/ freitagc/Zotero/storage/MX57NM2T/paying-spousal-caregivers.html
- International Federation of Social Workers. (2010). International Federation of Social Workers Consultation Paper : Health and Illness.
- Jabatan Kebajikan Masyarakat. (2017). Jabatan Kebajikan Masyarakat. In *Jabatan Kebajikan Masyarakat* (pp. 8–10). http://www.jkm.gov.my/jkm/index.php
- Jabatan Kebajikan Masyarakat. (2019). Financial Assistance for Carers of Bed-Ridden Disable and Chronic. Official Portal Department of Social Department. http:// www.jkm.gov.my/jkm/index.php
- Janetta Ananias, H. S. (2014). Factor Contributing to Elder Abuse and Neglect in the Informal Caregiving Setting. *Aggression and Violent Behavior*, 50((2)), 268–285. https://doi.org/10.1002/9781118320655.ch15
- Joyce, G. F., Keeler, E. B., Shang, B., & Goldman, D. P. (2005). The lifetime burden of chronic disease among the elderly. *Health Affairs (Project Hope)*, 24 Suppl 2(Suppl 2). https://doi.org/10.1377/hlthaff.w5.r18

Judith A. B. Lee and Rhonda E. Hudson. (2017). *Empowerment Approach to Social Work Treatment* (F. J. Turner (ed.); Six Editio). Oxford University Press.

**OF SOCIAL POLICY AND S** 

OLUME 20/2024

- Kaye, N., & Teshale, S. (2020). Medicaid Supports for Family Caregivers. National Academy for State Health Policy, October, 1–26. https://www.nashp.org/ medicaid-supports-for-family-caregivers/#toggle-id-8
- Lewis, S. (2015). Qualitative Inquiry and Research Design: Choosing Among Five Approaches. In *Health Promotion Practice*, 16 (4). https://doi. org/10.1177/1524839915580941
- M.Si, D. P. (2015). Metode Intervensi Pekerjaan Sosial dengan Individu dan Keluarga (M. P. Dr. Endah Nur Tjendani (ed.)). UPT Percetakan & Penerbitan Universitas Jember.
- Mahdavi, B., Fallahi-Khoshknab, M., Mohammadi, F., Hosseini, M. A., & Haghi, M. (2017). Effects of Spiritual Group Therapy on Caregiver Strain in Home Caregivers of the Elderly with Alzheimer's Disease. Archives of Psychiatric Nursing, 31(3), 269–273. https://doi.org/10.1016/j.apnu.2016.12.003
- McLeod, S. (2018). Maslow's Hierarchy of Needs. *Business*, 3–5. http://www.simplypsychology.org/maslow.html
- National Aging Team. (2017). 10 Most Common Chronic Diseases [Infographic] -Healthy Aging Blog | NCOA. NCOA Blog Healthy Living. https://www.ncoa.org/ blog/10-common-chronic-diseases-prevention-tips/
- National Population and Family Development Board Malaysia. (2017). Ageing Phenomenon: Malaysia Towards 2030. PopInfo Malaysia. http:// familyrepository.lppkn.gov.my/708/1/POP INFO JUN-DEC2017\_Final.pdf
- Noor Ani, A., Rajini, S., Balkish, M. N., Noraida, M. K., Maria, A., Fadhli, M. Y., Jabrullah, A. H., & Tahir, A. (2018). Morbidity patterns and healthcare utilisation among older people in Malaysia: 1996–2015. *Public Health*, *163*, 105–112.
- Nur Saadah, M. ., & Siti Hajar, A. (2011). Informal Caregivers and Their Coping Styles : A Preliminary Report. *International Journal of Public Health Research*, 1(1), 23– 30.
- Nurul Hudani Md Nawi, Getrude Cosmas, Puteri Hayati Megat Ahmad, Dahlan A. Malek, Habibie Ibrahim, & Peter Voo. (2018). Hubungan Intergenerasi, Sokongan Psikologi dan Sokongan Sosial dalam Penjagaan Warga Tua. *Jurnal Kinabalu*. https://jurcon.ums.edu.my/ojums/index.php/ejk/article/view/1670



- Ornellas, A., Spolander, G., & Engelbrecht, L. K. (2018). The global social work definition: Ontology, implications and challenges. *Journal of Social Work*, *18*(2), 222–240. https://doi.org/10.1177/1468017316654606
- Peetoom, K. K. B., Lexis, M. A. S., Joore, M., Dirksen, C. D., & De Witte, L. P. (2016). The perceived burden of informal caregivers of independently living elderly and their ideas about possible solutions. A mixed methods approach. *Technology* and Disability, 28(1–2), 19–29. https://doi.org/10.3233/TAD-160441
- Pillemer, K., & Finkelhor, D. (1989). Causes of elder abuse: Caregiver Stress Versus Problem Relatives. American Journal of Orthopsychiatry, 59(2), 179–187. https://doi.org/10.1111/j.1939-0025.1989.tb01649.x
- Riekkola Carabante, J., Rutberg, S., Lilja, M., & Isaksson, G. (2018). Spousal caregivers' experiences of participation in everyday life when living in shifting contexts. *Scandinavian Journal of Occupational Therapy*, 25(6), 457–465.
- Safwan Hamdy, M., & Md Yusuf, M. (2018). Review on Public Long-Term Care Services for Older People in Malaysia. *MJoSHT*, *2*, 2601–2604.
- Shilpa Amarya, K. S. and M. S. (2018). Ageing Process and Physiological Changes. IntechOpen, 23. https://doi.org/10.1016/j.colsurfa.2011.12.014
- Suridah Ali & Rahimah Abdul Aziz. (2018). Penjagaan tidak formal warga tua: Antara tanggungjawab dan beban (Informal Care of Old Folks: Between Responsibility and Burden). Journal of Social Sciences and Humanities, 13(3), 183–195.
- United Nations. (2017). Global Health and Aging. In National Institute on Aging. https://doi.org/10.1016/B978-0-12-375000-6.00006-9
- World Health Organisation. (2011). Definition of an older or elderly person: Proposed Working Definition of an Older Person in Africa for the MDS Project. WHO. http:// www.who.int/healthinfo/survey/ageingdefnolder/en/index.html accessed August 11, 2011