

**PSYCHOLOGICAL DISTRESS AND ITS  
ASSOCIATED FACTORS AMONG CAREGIVERS  
OF GERIATRIC PATIENTS IN HOSPITAL  
UNIVERSITI SAINS MALAYSIA (HOSPITAL USM)**

**By**

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## **LIST OF ABBREVIATIONS**

ZBI –Zarit Burden Interview

SCB- Screen for Caregiver Burden

CCI- Kosberg and Cairl's Cost of Care Index (CCI)

CBI- Caregiver Burden Inventory

WHO- World Health Organisation

# **GANGGUAN PSIKOLOGI DAN FAKTOR-FAKTOR YANG BERKAITAN DENGANNYA DALAM KALANGAN PENJAGA PESAKIT GERIATRIK DI HOSPITAL USM**

## **ABSTRAK**

Gangguan psikologi dalam kalangan penjaga pesakit geriatrik mewujudkan kesan negatif kepada pesakit geriatrik dan pesakit yang menerima penjagaan yang tidak berkualiti daripada penjaga mereka. Satu keratan, tinjauan deskriptif silang dijalankan untuk menilai gangguan psikologi dan faktor-faktor yang berkaitan dengannya dalam kalangan penjaga pesakit geriatrik di Hospital USM. Sebanyak 212 soal selidik telah berjaya diedarkan kepada penjaga pesakit geriatrik di Hospital USM. Pilihan ini dipilih secara rawak yang memenuhi kriteria. Data telah dianalisis menggunakan pakej perisian SPSS versi 22.0. Statistik ketara dianggap nilai  $p < 0.05$ . Majoriti subjek mempunyai gangguan psikologi yang rendah ialah (60.4%) dan gangguan psikologi yang tinggi ialah (39.6%). Terdapat kaitan umur  $p < 0.001$ , status perkahwinan  $p = 0.007$  dan tahap pendidikan  $p = < 0.001$  dengan gangguan psikologi antara penjaga pesakit geriatrik di Hospital USM. Jantina  $p = 0.049$  dan status ekonomi  $p = 0.12$  tiada kaitan dengan gangguan psikologi penjaga pesakit geriatrik di Hospital USM. Selain itu, penyelidik juga mendapati terdapat kaitan yang signifikan antara umur dan faktor-faktor terpilih mengurangkan tekanan pada penjaga (kesihatan fizikal).

# **PSYCHOLOGICAL DISTRESS AND ITS ASSOCIATED FACTORS AMONG CAREGIVERS OF GERIATRIC PATIENTS IN HOSPITAL USM**

## **ABSTRACT**

Psychological distress among caregivers of geriatric patients will create negative consequence to geriatric patients and patient will receive poor quality care from their caregivers. A cross sectional, descriptive survey was carried out to determine the Psychological distress and its associated factors among caregivers of geriatric patients in Hospital USM. In total 212 caregivers were successfully approaches at Hospital USM. Subjects was randomly selected that fits with inclusion criteria. Data was statistically analysed using SPSS software version 22.0. Statistical significant was considered at p value  $< 0.05$ . Majority of the subjects have low psychological distress (60.4 %) and remaining is the high psychological distress (39.6%). There were significant associations between age  $p < 0.001$ , marital status  $p = 0.007$  and level of education  $p = < 0.001$  with psychological distress among caregiver of geriatric patients in Hospital USM. Gender  $p = 0.049$  and economic status  $p = 0.12$  were no significant association with psychological distress among caregiver of geriatric patients in Hospital USM. Moreover, researcher also found that there were significant association between age and the selected factors of stressor to the caregivers (physical health).



# CHAPTER 1

## INTRODUCTION

### 1.1 Background of the Study

Psychological distress was commonly faced by caregivers who provide long-term care of geriatric patients. The caregiver's task resulting in additional responsibilities on the caregivers' daily life, and occupies the caregivers' time, energy, and attention (Yıkılkan, Aypak, & Gorpelioglu, 2014). Besides that, as caregivers, they were required to meet a diversity of needs by monitoring treatment-related symptoms, providing emotional support, social support, spiritual support, and assisting with personal, financial and instrumental tasks. Usually caregiving was often assumed by women like spouses and daughters who were provide a great assistance with several tasks, including personal care, household, transportation, financial and emotional support (Garcia-Alberca, Cruz, Lara, Garrido, Gris, et al., 2012) . Then, by providing caregiving it may be disturb the caregiver's daily routine, and social and personal life. These disruptions can be viewed as secondary stressors that increase the burden of caregiving (Goldzweig, Merims, Ganon, Peretz, & Baider, 2012).

According to the study of Goldzweig, Merims, Ganon, Peretz, & Baider (2012) caregivers experienced emotional difficulties through feelings of fear, uncertainty, hopelessness, powerlessness, and mood disturbances. Moreover, previous studies found that caregivers who were providing care often experienced burden and strain, and had a 63% higher risk of mortality than non-caregivers. Then, studies has consistently reported that increased caregiver burden is associated with a decline of well-being and quality of life among caregiver of geriatric patient (Yıkılkan, Aypak, & Gorpelioglu, 2014).

Furthermore, growing in the number of geriatric patients with chronic health conditions and, increasing life expectancy require caregiving service by family members. In addition, numerous of studies showed significantly higher levels of psychological distress among caregivers of geriatric patients with chronic diseases problem compared with the general population or non-caregiving controls. It was also found that caregivers' appraisal of the caregiving situation is an indication of their levels of psychological distress (Goldzweig et al., 2012).

According to a Pew Research Center survey, population of people ages 65 years old and older was expected to triple to 1.5 billion by mid-century which is in 2010 is 531 million to year 2050 is 1.5 billion. In the U.S., the population of older person is expected to slightly more than double, which is from 41 to 86 million. In year 2050, the majority of people in Japan, South Korea and Germany are expected to be older than 50 years old. Some Latin American countries, which are now younger than the U.S., will likely be older than the U.S. by 2050. Most countries, including the U.S. was estimated to see the share of their population that is 65 years old and older exceed the share that is younger than 15 years old by mid-century (Pew Research Global Attitude Project, 2014).

In East Asia, public concern with the growing number of older people, where nearly nine over ten Japanese, eight over ten South Koreans and seven over ten Chinese describe aging as a major problem for their country. In Japan and South Korea, most of the populations were expected to be older than 50 by 2050. Besides that, China is one of the most rapidly aging countries in the world. Then, in Indonesia, the proportion of older people in the population was relatively moderate and is expected to remain so in the future (Pew Research Global Attitude Project, 2014).

Apart from that, there were also increase in the geriatric population in the countries of East and Southeast Asia. Singapore is the most rapidly aging country in the Asia Pacific region after Japan. Individuals aged 65 and older made up 14% of Japan's total population in 1995. As a result of improved healthcare and a continuous decline in fertility during the past 25 years, the Singaporean population will undergo rapid aging in the next 30 years.

Older persons which aged 65 years and above consist of 4.7% of the population in 1980. But in 1999 this number had increased to 7.3% and is estimated to increase to 18.9% by the year 2030. The fastest growing age group in the 1990–2000 decade was the oldest old which is people aged 85 years and above (Mehta, 2005).

In Malaysia the population was increased from 23.49 million people in 2000 to 29.34 million in 2012. The total population is about 7.76 million people which are 26.4% below the age of 15 years. 20.03 million or 68.3% is in the economically-productive age group of 15-64 year. 1.56 million people or 5.3% are elderly people aged 65 years and above. Malaysia population of older persons in the year 2012 was 8.2% from the total population of the country which is, 2.4 million people out of 29.34 million people. With declining fertility and longer life expectancy, Malaysia aging population is ageing was increasing over a year. By 2030, Malaysia will be in the category of ageing nations with older persons constituting more than 15% of the population. In Malaysia, average life expectancy is 72.3 years for male and 77.2 for female (Zawawi, 2014).

## **1.2 Problem Statements**

The purpose of this study is to assess the psychological stress among caregiver of geriatric patient and its associated factors in Hospital USM. With the number of geriatrics patient with various type of disease is growing at Hospital USM, the number of caregiver in Hospital USM to provide care to the geriatric patient also continue to increase. Usually responsibility of caring for the geriatric patient in Hospital USM very often falls on close family members. Caregiving responsibilities linked to a number of adverse health conditions, including stress depression, poor wellbeing, and sleep disturbance. Previous studies state that caregivers those with higher caregiving strain have been shown to have increased risk of mortality (Chan, Malhotra, Malhotra, Rush, & Ostbye, 2013).



Apart from that, increasing population of geriatric population with chronic disease problem may cause increasing psychological distress among caregiver. It is also occur in Hospital USM. This is because patient with chronic disease problem may require additional monitoring and household modifications on the part of the caregiver. Moreover, spending time with a geriatric patient as a care recipient may suffer from depression. Moreover, by providing caregiving with chronic disease patient have also been shown to be distressing for caregivers. Due to a lot of difficulty maintenance of caregivers' responsibility then may lead to caregiver stress, and continue to create a negative physical and mental health consequences including loss or reduction in employment and decreased quality in childcare and marital relationships (Do, Cohen, & Brown, 2014).

Based on previous study a lot of caregiver for geriatric patient especially with Alzheimer shows the highest stress level and has significant negative consequences, such as anxiety and depression (Garcia-Alberca et al., 2012). Difficulty in providing caregiving for the geriatric patient with cognitive problem tend to create the symptom of psychological distress among caregiver are included depression , anxiety , agitation, lost appetite, sleep deprivation and loss of control are the negative impact from overload work in management of geriatric patient (Rote, Angel, & Markides, 2014).

Besides that, caregiving for geriatric patient with a chronic disease in Hospital USM was shown to negatively impact the caregiver, and was associated with psychological distress. Usually, the caregiver will face negative impact including physical, social, and emotional well-being. Then, caregiving for geriatric patient is particularly difficult due to the physical, cognitive, and behavioral and emotional problems presented by the geriatric patient. The features of behavior of geriatric patient have been linked to numerous negative outcomes in caregivers, including psychological disturbances such as anger, burden, anxiety, depression, guilt, and worry (Arango Lasprilla, Moreno, Rogers, & Francis, 2009).

According to Arango Lasprilla, Moreno, Rogers, & Francis (2009) also, problem of psychological distress tend to create physical health problems such as a decrease in immune system functioning, hypertension, cardiovascular disease, symptoms of fatigue, and sleep problems. Providing caregiving will also affect social activity restrictions, relationship changes, feelings of isolation and inadequate social support. Then, resulting caring for a geriatric patient is related to poor quality of life and financial problems (Arango Lasprilla, Moreno, Rogers, & Francis, 2009).

Furthermore, with an increasing life expectancy of geriatric also will created problem in providing care to geriatric population. This problem also has been faced by Hospital USM because the number of geriatric population growing each year will increase number of caregiver to provide care to them. Because of that, the geriatric persons was require health and instrumental care during later life stages then will increase the cost of caregiving to prove care and treatment to them. Apart from that, the cost of treatment need to support by caregiver is also one big issue in Hospital USM because a lot caregiver ask for charity to support the all the cost.

Besides that, in Hospital USM old age caregiver also took care of her or his spouse. Usually, caregivers with old age are not suitable to take responsibilities in providing caregiving because of their physical weakness and poor health. According to Haley (2003) old age caregivers of geriatrics patients may be more expose to the negative effects of caregiving, such as fatigue and sleep disruption, because of their own old age, poor health, and willingness to suffer to care for their partner. Additionally, many caregivers report they do not have the necessary skills and knowledge to provide sustained care for a geriatric patient, so they lack confidence and feel unprepared. Caregivers say they receive little guidance from nurses or doctors in Hospital USM. Then, they do not know how to assume the caregiver role, that they are not familiar with the type and amount of care needed, and that they do not know how to access and utilize resources (Given, Sherwood, & Given, 2008).

In addition, in Hospital USM many caregivers have limited finances and a lack of transportation to go to the hospital. Lack of support from other family members can be a major source of distress for primary caregivers. But, by distribution of responsibility and role in caregiving within the family member will influences family members to adapt their roles to maintain daily household functioning (Haley, 2003).

In Malaysia there are not many studies concentrating on the psychological distress among caregivers of geriatric patients that relate to age and selected factors of stressor to caregivers (physical health). In Malaysia, most studies only focus in the burden factors that related to demographic data. The caregivers burden problems depend on different age, gender, and educational achievement, (Rosdinom, Norzarina, Zanariah, & Ruzanna, 2011). Apart from that, the awareness of the need to identify psychosocial distress among caregivers geriatrics is growing and has affected the development of screening instruments. For example when caregivers have depression during provide caregiving, it can affect the quality of life of geriatric patients. The aims are to reduce the problems related to emotional and distress and to improve the quality of life of geriatric patients.



### **1.3 Research Objectives**

#### **1.3.1 General Objectives**

- To determine psychological distress among caregivers of geriatric patient in Hospital Universiti Sains Malaysia (Hospital USM).

#### **1.3.2 Specific Objective**

- To determine the level of psychological distress among caregivers of geriatric patients in Hospital USM.
- To determine the association between selected demographic data (age, gender, marital status, level of education, and economic status) with psychological distress among caregivers of geriatric patients in Hospital USM.
- To determine the association between age with the selected factors of stressor to the caregivers (physical health).

### **1.4 Research Questions**

- What is the level of psychological distress among caregivers of geriatric patients in Hospital USM?
- Is there any association between selected demographic data (age, gender, marital status, level of education, economic status) with psychological distress among caregivers of geriatric patients in Hospital USM?
- Is there any association between age with the selected factors of stressor to the caregivers (physical health).

## **1.5 Hypothesis**

1. Ho 1 = There is no significant association between demographic data (age, gender, marital status, level of education, and economic status) and psychological distress among caregivers of geriatric patients in Hospital USM.

HA 1 = There is a significant association between demographic data (age, gender, marital status, level of education, and economic status) and psychological distress among caregivers of geriatric patients in Hospital USM.

2. HO 2 = There is no significant association between age and the selected factors of stressor to the caregivers (physical health).

HA 2 = There is a significant association between age and the selected factors of stressor to the caregivers (physical health).

## **1.6 Definition of Terms (Conceptual/Operational)**

There are a few important concepts involved in this study. They were explained below:

### **1.6.1 Psychological Distress**

Psychological distress was defined as a state of emotional suffering (Drapeau, Marchand, & Beaulieu-prévost, 2007). According to Ridner (2004) The term 'distress' was describe as individual discomfort related to signs and symptoms of acute or chronic illness. Besides that, psychological distress more often explains within the context of strain, stress, and distress.

In this study was determined level of psychological distress by selected demographic data (age, gender, marital status, level of education, and economic status). This is because In Malaysia, the study only focus in the burden factors that related to demographic data including age, gender, and educational achievement, (Rosdinom, Norzarina, Zanariah, & Ruzanna, 2011) but not include economic status, and marital status. So, in this study the researcher wants to add several demographic data (economic status, and marital status) with psychological distress among geriatric patients in Hospital USM. In addition, in this study the researcher wants to determine the factor of stressor of caregiver (physical health) this is because, previous study stated that the factors of physical health (Schulz & Sherwood, 2009) of caregiver of geriatric patient able to create psychological distress to the caregivers.

#### **1.6.2 Associated Factors**

Associated factors of stressor to caregiver was found by researcher is physical health. Physical health was defined as an essential part of overall health of an individual, which includes everything from physical fitness to overall wellbeing. Health was defined as a state of complete well-being and physical health as a state of physical well-being in which an individual is mechanically fit to perform their daily activities and duties without any problem (Cheshireast,2014). This study was focused on physical health because previous study found that psychological distress associated with caregiving is negatively affect the caregiver's physical health (Schulz & Sherwood, 2009). According study of Son et al., (2007) state that by providing caregiving to geriatric patient will create negative physical health to the caregivers.

### 1.6.3 Caregiver

Caregiver was defined as a caring for a friend, family member or neighbor who because of sickness, frailty or disability, cannot manage everyday living without help or support (Goodhead & McDonald, 2007). According to Rosdinom et al., (2011) caregivers were someone who attends to the patient for at least 12 hours a day, almost everyday. Caregivers were also defined as those who were taking care of the patient, such as assistance with activities of daily living, managing finances, administering medication, and providing emotional support (Rosdinom et al., 2011). Besides that, caregivers were also involve in the management of personal care household, financial support, administrative tasks, assistance with mobility, providing emotional support and companionship. Caregiving may also include nursing care, their role will be different with the age and nature of the impairment of the geriatric patient, but is likely to involve the caregivers taking responsibility to ensure the well-being of that person that caregivers cared for. Usually this were include continuously monitoring geriatric patient condition, deal with formal care systems, and alert with any deficit that are not provided by paid health care workers (Goodhead & McDonald, 2007).

In this study include all caregivers like children, spouse, and relatives. This is because according Rosdinom et al., (2011) indicate that a closer kinship to the patient imposed heavier burden of caregiving. Besides that, in this study also was including caregiver in 18 years old and above. According to Haley (2003) old age caregivers of geriatrics patients may be more expose to the negative effects of caregiving. Then, in this study also involved caregivers who were attended to the patient for at least 12 hours a day, almost everyday (Rosdinom et al., 2011). This is because much time caregiver spends time with geriatric patient will create more distress to them. Then, in this study also was included both male and female caregiver. This is because female caregivers tend to report higher level of burden compared to male caregivers (Rosdinom et al., 2011).



Apart from that, this study includes marital status (married, unmarried, divorce/separated, widowed). In previous study caregivers who were married are less strain than unmarried caregivers (Prince et al., 2012). Besides that, according to the studies by Schoenmakers et al., (2010) spouses were significantly often show higher level of depressed than non-spouse. Then, divorce or separate and widowed felt less stress. Level of education (university/college, secondary school, primary school, or others) was also included. According to Given, Sherwood, & Given (2008) many caregivers said they do not have the necessary skills and knowledge to deliver care for geriatric patient, so it will create depression to them. Moreover, this study also was included economic status (below RM 1 000 per month, RM 1 100-2 000 per month, RM 2 100-3 000 per month, or above RM 3 100). Caregiver was limited finances, was related to poor caregiving (Haley, 2003).

#### **1.6.4 Geriatric Patient**

Geriatric is known as an elderly or older person. According to the World Health Organization (2014), most developed countries defined of 'elderly' or older person as 65 years and above. In Africa, a definition of old age person is 50 to 65 years. It was difficult in establishing a definition in Africa because of the unknown the actual birth dates due to many individuals in Africa do not have an official record of their birth date. There is no United Nations standard numerical criterion, but the United Nation agreed to cutoff 60 years above to refer to the older population (World Health Organization, 2014).

According to World Health Organization (2014) also in western area such as in Britain, the definition of old age is after 50. But pension schemes mostly used age 60 or 65 years for requirement. The United State has not used a standard criterion, but usually 60 years and above refer to the old age population. However, based on developed world 60 and 65 years are often used for statutory and occupational retirement pensions. Based on study by Mehta, (2005) , the average age of the geriatric patients was 75 years. According to study by Cocco, Gatti, de Mendonça Lima, & Camus, (2003) population being over 65 years of age. After that, based on study by Scazufca, Menezes, & Almeida, (2002) was used geriatric patients aged 60 and above.

In this study, geriatric patients were include all age 60 years old and above in medical ward (7 Utara, 7 Selatan, 8 Selatan), surgical ward (2 Intan, 3 Utara, 2 Zamrud, 2 Utara, 4 Timur belakang), gynecology ward ( 1 Utara). Developed country used cutoff is 60 years old and above to refer to the older population. This study also was including male and female geriatric patient with different race (Malay, Chinese, Indian or others) and religion (Islam, Hindu, Buddha or others).

### **1.7 Significance of the Study**

Increasing geriatric population in the world as well as Malaysia, attention now focused on the impact and burden of long-term care by caregiver. So, majority of caregiver of geriatric patient like children would prefer to place their parent to high cost of formal long-term care services, children and other family members usually expect a large responsibility of caring for their parents. Hence, caregiver of geriatric patient felt burden when multiple demands of overload work such as assistance with personal care tasks such as bathing, dressing, and eating, cooking and cleaning (Rote et al., 2014). Usually, caregivers of geriatrics patient will have higher risk of depression was greater than that of non-caregivers of geriatrics patient, especially those caring for chronic disease patients (Rote et al., 2014).

Studies by Gallagher-Thompson et al.,( 2003) family caregiving among geriatric patients was associated with depression, anxiety, anger, and poor self-reported health. This negative impact is likely to be greater for caregivers of chronic disease. Moreover, thought this study, the nurses was able to determine the level of stress of caregiver in taking care of geriatric patient. For nursing practice, this study will help the nurses in understanding what the problems that causes psychological distress among caregiver of geriatric patient by assessing mental health status. It also will help the nurses to plan their nursing care plan and able to create nursing diagnosis related to family caregiver.

In addition, when the nurses are able to identify the nursing diagnosis related to family caregiver that causes psychological distress among them, the nurses will be able to plan the nursing care to settle the problem. Besides that, this study aimed to explore the process of psychological distress of caregiver associated with the care of a geriatric patient, the perception of the relationship with the geriatric patient, the image of the caregiver role, and the contextual aspects of coping and social support relationships (McCarty & Cs, 1996).

## **CHAPTER 2**

### **LITERATURE REVIEW**

#### **2.1 Introduction**

In this chapter, the literature reviews consists of psychological distress, caregiver, geriatric patient and instruments.

#### **2.2 Review of Literature**

##### **2.2.1 Psychological Distress**

Previous research shows that psychological distress is more often among caregiver than non-caregiver. This is because caregivers perceive their workload as heavier, in poor health and were taking more medication than others. Moreover, caregivers report feeling isolated and experiencing pressure on their socio-economic life (Schoenmakers et al., 2010). Besides that, caregiver depressive symptoms were significantly associated with four types of caregiving efforts which are physical, mental, emotional, and time-related. Over time, some families eventually need to institutionalize their parents. However, placing their parents in a nursing home does not end the caregiving role. The families caregiver still need to provide care similar to when their elderly family member lived at home, because they need to communicate frequently with nursing home staff for details of residents' needs (Tsai & Tsai, 2013) .

Tsai & Tsai (2013) study stated that the distress among Western caregivers has been shown to remain the same and still increase after geriatric family members were institutionalized. After geriatric patient admitting to a nursing home, Western family members still experienced emotional distress such as guilt, sadness, loss, and depression (Tsai & Tsai, 2013).



Furthermore, demographic factor as one of the factor associated with psychological distress of caregiver of geriatric patient. Most study discussed about relationship between age, gender ,marital status, level of education, economic status (Piercy et al., 2013). Several of researches said old caregiver experience higher distress than younger one. According to Di Mattei et al., (2008) also caregivers over 70 years of age are more likely to experience stress than younger ones. This is because old person as a vulnerable person who are have difficulties in physical and psychological problem. According to Schoenmakers, Buntinx, & Delepeleire (2010) older caregivers are also more often depressed than their younger one. This is because, for older caregivers the burden of care is often heavier due to their own physical limitations and the fear to leave their relative behind when they die. Younger caregivers become depressed because of the combination of their social position such as job, family, and friends (Schoenmakers et al., 2010).

In the contexts of gender, although both men and women are involved in caregiving, women are predominant caregiving. Caregivers who stay with their parent commonly involve a heavier caregiving commitment than those caregivers who live separately from their parent. Apart from that, based on previous study, women are important caregiving compared to men. Then, lack of knowledge regarding men compared to women as a caregiver make women more trusted as a caregiver. Majorities of study on depression and burden in caregiving noted that the level of stress in female population is higher compared to male population. This is due because women tend to spend more time with their parent compare to men (Di Mattei et al., 2008). According to the studies by Schoenmakers et al., (2010) female caregivers are more often depressed than men caregiver. Instead, the extra household burden for female caregivers is usually heavier than that of their male caregiver.

In addition, in previous study caregiver who are married reported less strain than non-married (Prince et al., 2012). Apart from that, according to the studies by Schoenmakers et al., (2010) spouses are significantly more often depressed than other caregivers. This is can cause isolation from their spouse. Then It is also will cause disruption of family relationships due to lack of time to spend time together especially between married caregivers (Goodhead & McDonald, 2007).

Apart from that, based on previous study, the low level of education among caregiver was associated with higher depression and increases psychological distress compared to person in higher level of education. Good level of education and knowledge about management of older person make them feel more confident to deliver nursing care. They also know how to handle stress by stress coping technique. According to Given, Sherwood, & Given (2008) many caregivers said they do not have the necessary skills and knowledge to deliver care for geriatric patient, so they lack confidence and feel unprepared to do the nursing care although they already received some guide line from nurses. Caregivers also said they are not familiar with the type and amount of care needed, and that they do not know how to access and utilize resources. Their feelings of uncertainty contribute to their distress. According to Given, Sherwood, & Given (2008) also, family caregivers with both knowledge and skill to provide care have reduce distress.

Furthermore, financial consequences of providing informal care include disruptions in regular employment, having to take time off from work, interfering with work schedules, missed training opportunities, and need to leave employment due to caregiving's role (Kusano et al., 2011). According to study of Rote, Angel, & Markides (2014) lower financial support of caregivers will increase depressive symptom scores. High financial support of caregivers will be support medication and treatment of geriatric patient. In addition, according to Liu, Guo, & Bern-Klug (2013) financial stress is one of the primary hardships among Chinese caregivers especially in oldest old Chinese, particularly women and rural elders have limited financial resources to live independently due to a lack of pension and medical insurance. Due to lower financial support of caregiver experience high level of distress.



### **2.2.2 Associated Factors**

The associated factors that will be reviewed in this study are physical health. In previous study was found caregiving is commonly associated with health impacts (Neri et al., 2012). According to study by Neri et al.,(2012) caregiving is widely acknowledged to be a source of physical health. These depressions have negative effects on several aspects of caregivers' wellbeing, such as their physical, family, marital roles and daily activities. Then, that study also showed physical health of caregivers is worse than the health of non-caregivers, as indicated by subjective measures of health and by objective measures such as stress hormones, antibodies and medication use (Neri et al., 2012) . Besides that, factors linked to caregiver's physical health include the care recipient's behavior problems, cognitive impairment, functional disabilities, duration and amount of care provided vigilance demands such as constantly having to watch a person with Alzheimer's disease to prevent self-harm (Schulz & Sherwood, 2009).

According to study by Son et al., (2007) most of the caregivers of geriatric patient are poorer in health context. It is showed only one half of caregivers reported their health as good or excellent, as opposed to three fourths of elders in general. That study also showed that caregivers experienced a one-third increase in negative health symptoms after assuming caregiving responsibilities. Then, spouse caregivers reported more days of illness because of infectious disease, primarily upper respiratory tract infections than non-caregivers . Then, caregivers also used more prescription medications than non-caregivers. Besides that, According to study by Son et al., (2007) prolonged exposure to the chronic stress of caregiving can lead to changes in sympathetic arousal and cardiovascular reactivity, predisposing caregivers to hypertension and cardiovascular disease. So, it is not surprising that caregivers have a greater risk of mortality than non-caregivers. In addition, the study found that people who were providing care for a spouse and experiencing strain had mortality risks that were 63% higher than those whose spouse was not disabled (Son et al., 2007). According to Chan et al., (2013) caregivers of older adults will be more depressed, have poorer self-rated health, and utilize more health services compared to non-caregivers.

Apart from that, according to Goodhead & McDonald, (2007) state that the health impacts on caregivers are common. Usually the caregivers often ignore or diminish the importance of maintaining their own health. For example, the disruption to sleep leads to caregiver fatigue. In addition, caregivers had poorer antibody production, a higher incidence of sleep problems, less adequate diets and more sedentary behavior. The health impacts were greater for older caregivers. Chronic stress and distress may lead to elevated stress hormones, primarily through the hypothalamic-pituitary and adrenal axis, causing repeated arousal and inefficient control of physiological responses. Moreover, distress may trigger risky health behaviors such as poor diet, sedentary behavior and substance abuse. Negative feelings were more likely when the caregiver did not have anybody to help them regularly or when caregiving conflicted with work and other activities (Goodhead & McDonald, 2007).

### **2.2.3 Caregiver**

Caregiver of family member is “unpaid” caregiver. They faced adverse health conditions, including stress depression poor wellbeing sleep disturbance (Chan et al., 2013). Studies said that some unpaid caregiver or informal caregivers experience physical, mental, social, and financial stresses that negatively impact their physical and mental health. Essential task and role of caregiver has a marked impact on the life of the caregiver (Goodhead & McDonald, 2007). Responsibility of caring for the geriatric patient very often falls on close family members like their children. Besides that, caregivers report a variety of burdens or strains associated with providing care, which are varied and differ by type of care provided. Providing care has been shown to affect family and social relationships, availability of leisure time, and employment and finances (Kusano et al., 2011). Moreover, study by Arango Lasprilla, Moreno, Rogers, & Francis (2009) stated that the patient problems also tend to cause the most distress in caregivers. For example, patient condition like cognitive problems including loss of memory or disorientation, psychological problems including depression, lack of interest, and physical problems like motor malfunctions. These are problems of patients with dementia that most commonly reported by caregivers.



According to Goodhead & McDonald (2007) caregivers showed negative impact like a worse physical health. They tend to take more medications than non-caregivers. This research recognized a nine per cent greater risk of health problems in caregivers and a 23 per cent higher rate of stress hormones than for non-caregivers. Other finding showed caregivers had poorer antibody production, a higher incidence of sleep problems, less adequate diets and more sedentary behavior. The health impacts were greater for older caregivers (Goodhead & McDonald, 2007).

In addition, financial status will be a negative impact for informal caregivers. Usually caregivers need to incur the cost of medication and treatments of their parent. Due to financial constraints around caregiving will be cause financial pressure adds to stress. According Goodhead & McDonald, (2007) there are additional expenses arising from medical appointments, transport and parking, and home modifications. The main financial impact is the loss of earnings, there are a number of other expenses commonly incurred. These include incontinence products, medical expenses and medication, transport, house adaptations, extra clothing or bedding, mobility aids, and special dietary requirements (Goodhead & McDonald, 2007).

Besides that, effect from caregiving is sleep disturbance. It was also identified as one of the sign and symptom of health problems among family caregiver. Besides that, sleep disturbance in family caregiver often report feeling depressed among them. Moreover, depression symptoms in caregiver including fatigue, and sleep disturbance. These symptoms may interfere with caregiver' ability to assume and fulfill the caregiving role. In addition, caregiver existing symptoms may worsen during the course of their caregiving activities. Because of that, negative symptoms in caregivers may affect their health and quality of life. Besides that, sleep disturbance among caregiver of geriatric patient has been associated with caregiver depressive symptoms. Previous study showed that higher levels of fatigue were correlated with higher levels of depression among caregiver. Then, in another study, caregivers of patient with chronic disease reported higher levels of physical fatigue than non-caregiver (Chiu et al., 2014).

#### **2.2.4 Geriatric Patient**

Geriatric patient is elderly or old person who are age 60 years old and above. They have health, cognitive, and behavior problems that need caregiver to take care of them. Moreover, previous study showed association between the psychological symptoms with geriatric patient behavior creating negative effect to their caregivers. In this situation, it will increase caregiver burden, stress, and depressive symptom. Behavior problem of geriatric patient such as physical aggression, agitation, psychotic symptoms such as hallucinations and delusions, sleep disturbances, depression, oppositional behavior, and wandering are reported to be more stressful for caregivers than cognitive and functional problems in the patient, perhaps due to the capricious nature of geriatric patient (Ornstein & Gaugler, 2012).

Besides that, due to the physical, cognitive, and behavioral emotional problems presented by the geriatric patient with chronic disease make caregiver feel distress. The behavior of geriatric patient may lead the caregivers faces psychological disturbances such as anger, burden, anxiety, depression, guilt, and worry. Then, with increase psychological distress also will create physical health problems to caregiver such as a decrease in immune system functioning, hypertension, cardiovascular disease symptoms of fatigue, and sleep problems (Arango Lasprilla et al., 2009).

Besides that, a number of studies indicated that providing care for a geriatric patient may create a stressful environment because it requires a lot of time, resources, and emotion work. Previous research distinguished among primary stressors and secondary stressor. Primary stressor is those that are associated with caregiving experience such as relationship of caregiver to care recipient and socioeconomic resources. Then, secondary stressor is those which influence other role obligations such as work or parenting, subjective assessments of stress or burden. The health and functioning of the geriatric caregiver and geriatric patient as a care recipient can be seen as a primary stressor that influences caregivers' subjective assessments of stress. For example, when geriatric patient as a care recipient refuse to accept care, it increases caregiver psychological distress through increasing feelings of role overload, lack of control, and lack of adequate resources to cope with the demands of care tasks (Rote et al., 2014).

## **2.3 Instruments**

### **2.3.1 Zarit Burden Interview (ZBI)**

Zarit Burden Interview is unidimensional measure of caregiving burden. It is a self-administered questionnaire. Zarit Burden Interview (ZBI) scale will be rate as (0 = never, 1 = rarely, 2 = sometimes, 3 = quite frequently and 4 = nearly always and the total of item is 22 items. The four-point Likert scale will be use in this questionnaire. Each question has scale 0 to 4 points, with 88 total points possible. A higher score correlates with a higher level of distress. 0 to 20 points indicates little or no distress, 21 to 40 points reflects mild-to-moderate distress, 41 to 60 points indicates moderate-to-severe distress, and 60 to 88 points reflects severe levels of distress (Arango Lasprilla et al., 2009). This questionnaire takes about 20 to 25 minutes to administer (Chou, Chu, Tseng, & Lu, 2003).

### **2.3.2 Montgomery's Burden Scale**

This questionnaire is to measure the relationship between the caregiving experience with the subjective and objective burden. It is self-administered questionnaire. It contains two parts which are Measurement of Objective Burden and Measurement of Subjective Burden. Objective burden is defined as the extent of disruptions or changes in various aspects of the caregivers' life and household. While, subjective burden is defined as the caregivers' attitudes toward or emotional reactions to the caregiving experience. This questionnaire has 5-point Likert scale. It ranges from 1-5 score, 1 is "a lot more", and 5 is a "lot less". Responses of objective burden range from 9 to 45, where higher scores are showed of greater objective burden. The Measurement of Subjective Burden consists of a 13-item scale with a 5-point Likert rating. Scale scores for subjective burden ranges from 13 to 65. Higher scores showed greater subjective burden. This questionnaire takes approximately 15 to 20 minutes to administer (Chou et al., 2003).



### **2.3.3 Screen for Caregiver Burden (SCB)**

SCB is a self-administered questionnaire. This questionnaire is a 25- item measure designed to identify distressing caregiver experiences rapidly, specifically for spouse caregivers of Alzheimer's care recipients. This questionnaire indicate the degrees of distress in each item. Each item is scored 0 (no occurrence or occurrence, no distress) 1 (mild distress) 2 (moderate distress) and 3 (severe distress). Then, the scores of the 25 items are summed. Total scores are from 0 to 75. The higher the score, the greater the assessed subjective burden. This tool is simple and easy to administer and takes about 15 minutes for a caregiver to complete all the questions (Chou et al., 2003).

### **2.3.4 Kosberg and Cairl's Cost of Care Index (CCI)**

CCI is a self-administered questionnaire. It is multidimensional measure of caregiving burden. It was developed by Kosberg and Cairl then initially explored with caregivers who were caring for impaired elderly relatives. This tool assists professionals in family assessments and to identify actual or perceived problem areas of families in the care of geriatric relatives. This tool has 20-items which are 4- point likert scale ranging from "Strongly Agree" to "Strongly Disagree". A high score on each subscale indicates a higher burden ranging from 20 to 80. Higher score indicates a higher burden. The instrument takes 15 to 20 minutes to administer (Chou et al., 2003).

### **2.3.5 Caregiver Burden Inventory (CBI)**

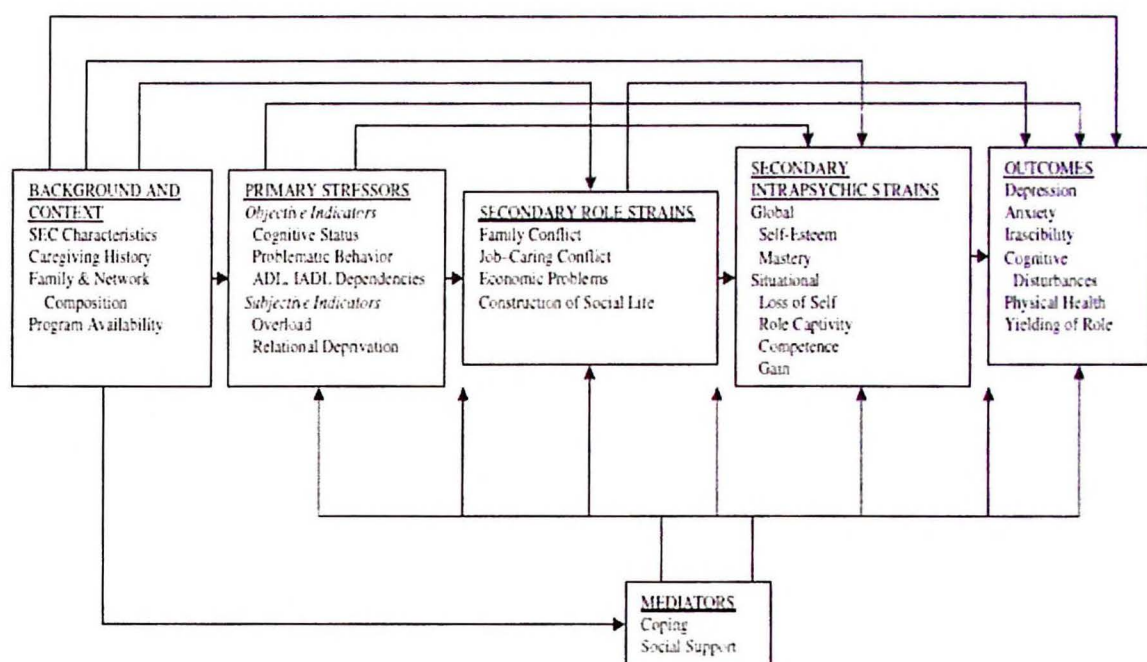
The research instrument in this study is used Caregiver Burden Inventory (CBI) questionnaire. CBI was conducted by Novak & Guest (1989). It is multidimensional instrument and measured the impact of burden on caregivers. The total burden score for all scales can range from 0 to 96. A higher score indicates a higher burden. Five interpretable factors resulted from a factor analysis which is time-dependence burden, developmental burden, physical burden, social burden, and emotional burden. It will take approximately 15 to 20 minutes to complete all the 24 items in the questionnaire (Chou, Chu, Tseng, & Lu,



2003). This study is used this CBI instrument because this instrument is multidimensional instrument. CBI able to measure the level of psychological distress among caregiver of geriatric patient. Then, it able gives a sensitive reading of caregivers' feelings and a sophisticated picture of caregivers' response to the demands of care. In addition, it is provides a unique set of subscales designed to assess the factor of stressor to caregiver of geriatric patient. Besides that, it shows adequate internal consistency reliability, moderate intercorrelations of subscales, and high factor loadings. However, the CBI overcomes this problem and each subscale can be used to generate a caregiver psychological distress profile. The CBI also offers a short and comprehensive measure of psychological distress that makes it a practical tool for assessing and responding to caregiver psychological distress (Chou, Chu, Tseng, & Lu, 2003).

## **2.4 Conceptual / Theoretical Framework**

Figure 2.1 shows extended stress-coping model by Pearlin and associates' (Pearlin, Mullan, Semple, & Skaff, 1990), which is the original Pearlin theoretical model of stress of caregiver. This model indicates that those caring for geriatric patients with greater impairment will report more depressive symptoms. The existing model evaluates four major domains as key to understanding the experience of psychological distress among caregiver. There are background and contextual factors, which are the primary and secondary stressor, mediating factors, and outcomes of psychological distress. Each domain consist of several components and there are multiple linkage and lines of impact among the domains (McCarron & McCallion, 2005).



**Figure 2.1:** Stress-coping Model Original Pearlin model (Pearlin et al., 1990).

Apart from that, use of Pearlin's model helped identify variables to be measured and encouraged the adaptation of an existing caregiving measure which is the caregiving assessment scale. The success of this effort encouraged a similar approach to staff appraisals of that caregiving in which the caregiving Hassles Scale was adapted for use with staff of caring geriatric patient. From this model, data arise on the increases of duration spent by the caregivers in care of geriatric patient. However, these efforts pointed out to the authors that there may be some differences in the variables and in the weights to be assigned to the variables in a coping and stress model that guides staff caregiver research. Based on the result and the existing literature, it was decided to explore how the Pearlin model might be augmented and revised to be a more helpful and complete framework (McCarron & McCallion, 2005).