SELF-PERCEIVED DEPRESSION, ANXIETY AND STRESS AMONG CAREGIVERS OF CANCER PATIENTS IN INSTITUT KANSER NEGARA, PUTRAJAYA DURING COVID-19 PANDEMIC

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By

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LIST OF SYMBOLS

%	Percentage
=	Equal to
Z	Z score
Δ	Precision of estimation
P	Population’s proportion
n	Number of subjects
m	Ratio between two groups
α	Alpha
<	Less than
≥	More than or equal to
>	More than
&	And
β	Beta

LIST OF ABBREVIATIONS

Adj OR	Adjusted Odds Ratio
AUC	Area Under the ROC Curve
CI	Confidence Intervals
CMCO	Conditional Movement Control Order
DASS-21	Depression Anxiety Stress Scales and 21 specific items
ECOG PS	Eastern Cooperative Oncology Group Performance Status
GDP	Gross Domestic Product
IKN	Institut Kanser Negara
JEPeM	Human Research Ethics Committee of Universiti Sains Malaysia
MNCRR	Malaysia National Cancer Registry Report
MREC	Medical Review and Ethics Committee
NMRR	National Medical Research Register
OR	Odds Ratio
RTO	Radiotherapy and Oncology
ROC	Receiver Operating Characteristic
SE	Standard Error

SPSS	Statistical Package for the Social Sciences
VIF	Variance Inflation Factor
WHO	World Health Organization

ABSTRAK

KEMURUNGAN, KERISAUAN DAN TEKANAN YANG DIRASAKAN SENDIRI DALAM KALANGAN PENJAGA PESAKIT KANSER DI INSTITUT KANSER NEGARA, PUTRAJAYA SEMASA PANDEMIK COVID-19

Latar Belakang: Kejadian kanser terus meningkat di Malaysia, dan kesan kanser sangat ketara terhadap aspek fizikal, emosi dan praktikal penjaga. Di samping itu, peningkatan penyakit COVID-19 yang pesat telah menyebabkan banyak cabaran bagi penjaga kerana mereka perlu memberikan penjagaan yang lebih sama ada dengan sedikit atau tanpa bantuan daripada petugas kesihatan atau perkhidmatan penjagaan di rumah. Oleh itu, penjaga cenderung untuk mendapat gejala kesihatan mental yang buruk.

Objektif: Kajian ini bertujuan untuk menentukan prevalen dan faktor berkaitan dengan kemurungan, kerisauan dan tekanan dalam kalangan penjaga pesakit kanser di Institut Kanser Negara (IKN), Putrajaya semasa pandemik COVID-19.

Metodologi: Kajian keratan rentas menggunakan kaedah persampelan rawak dilakukan dengan melibatkan sejumlah 437 penjaga yang menghadiri Jabatan Radioterapi dan Onkologi dan Jabatan Paliatif, IKN. Manifestasi psikologi diukur menggunakan *Depression, Anxiety Stress Scale and 21 specific items* (DASS-21), yang telah diterjemah dan disahkan. Regresi logistik mudah dan regresi logistik berganda digunakan untuk menjawab persoalan penyelidikan.

Keputusan: Manifestasi psikologi yang paling kerap berlaku dalam kalangan penjaga adalah kerisauan 178 (41.4%) diikuti dengan kemurungan 125 (29.1%) dan tekanan 116 (27.0%). Modal pelbagai pembolehubah menunjukkan bahawa kerisauan dalam kalangan penjaga dikaitkan dengan jantina perempuan, *adjusted odds ratio* (Adj OR) = 1.69 (95% CI : 1.13, 2.54; *p*-value <0.05) manakala penjaga kepada pesakit yang lebih tua adalah kurang cenderung untuk kemurungan, Adj OR = 0.97 (95% CI : 0.96, 0.99; *p*-value <0.05). Penjaga yang mempunyai hubungan pasangan suami isteri merupakan faktor perlindung untuk mengalami tekanan, Adj OR = 0.54 (95% CI : 0.32, 0.93; *p*-value <0.05). Di samping itu, etnik bukan Melayu mempunyai risiko kemurungan, Adj OR = 2.20 (95% CI : 1.34, 3.63; *p*-value <0.05) dan kerisauan, Adj OR = 1.82 (95% CI : 1.16, 2.87; *p*-value <0.05) yang lebih tinggi berbanding dengan etnik Melayu. Akhirnya, menjaga pesakit yang mempunyai status keupayaan yang lemah adalah lebih cenderung untuk meletakkan diri mereka dalam hasil kesihatan psikologi yang teruk seperti kemurungan, Adj OR = 2.24 (95% CI : 1.10, 4.56; *p*-value <0.05), kerisauan, Adj OR = 3.97 (95% CI : 1.87, 8.42; *p*-value <0.001) dan tekanan, Adj OR = 3.91 (95% CI : 1.94, 7.90; *p*-value <0.001).

Kesimpulan: Hasil kajian menunjukkan prevalen kemurungan, kerisauan dan tekanan yang tinggi dalam kalangan penjaga pesakit kanser yang menghadiri IKN, Putrajaya, semasa pandemik COVID-19. Penjaga yang merupakan perempuan, bukan Melayu, menjaga pesakit muda dan pesakit yang mempunyai status prestasi yang buruk, adalah berisiko untuk mendapat hasil kesihatan psikologi yang negatif. Usaha penjaga tidak ternilai semasa pandemik ini, dan mereka adalah pekerja barisan hadapan yang luar biasa namun tidak kelihatan. Oleh itu, adalah penting bahawa penggubal dasar mengiktiraf sumbangan berharga mereka dan dimasukkan dalam pembetukkan polisi setempat. Usaha penyelidikan untuk masa depan harus ditekankan pada pembinaan kaedah intervensi yang baru untuk mengurangkan faktor risiko psikologi bagi penjaga semasa era COVID-19.

KATA KUNCI: penjaga, kanser, kemurungan, kerisauan, tekanan

ABSTRACT

SELF-PERCEIVED DEPRESSION, ANXIETY AND STRESS AMONG CAREGIVERS OF CANCER PATIENTS IN INSTITUT KANSER NEGARA, PUTRAJAYA DURING COVID-19 PANDEMIC

Background: Cancer incidence continues to rise in Malaysia, and the effect of cancer is profound on the caregivers' physical, emotional and practical aspects. In addition, the rapid rise of COVID-19 disease has caused many challenges for caregivers as they need to provide immense care with little or no support from healthcare providers nor home care services. As a result, caregivers are likely to exacerbate the symptoms of poor mental health.

Objectives: This study aims to determine the prevalence and associated factors of depression, anxiety and stress among caregivers of cancer patients in Institut Kanser Negara (IKN), Putrajaya, during the COVID-19 pandemic.

Methodology: A cross-sectional study design using a random sampling method was adopted involving a total of 437 caregivers attending the Radiotherapy and Oncology Department and Palliative Department, IKN. The psychological manifestations were measured using Depression Anxiety Stress Scales and 21 specific items (DASS-21) questionnaires, previously translated and verified. Simple logistic regression and multiple logistic regression analyses were used to address the research question.

Results: The most common psychological manifestation among caregivers is anxiety 178 (41.4%), followed by depression 125 (29.1%) and stress 116 (27.0%). The multivariable model indicated that the prevalence of anxiety among caregivers was associated with being female, adjusted odds ratio (Adj OR) = 1.69 (95% CI : 1.13, 2.54; p-value <0.05) while caregivers of the older patients were less likely to be depressed, Adj OR = 0.97 (95% CI : 0.96, 0.99; p-value <0.05). Spousal caregivers were a protective factor for stress, Adj OR = 0.54 (95% CI : 0.32, 0.93; p-value <0.05). Additionally, non-Malay ethnicity were more likely to experience depression, Adj OR = 2.20 (95% CI : 1.34, 3.63; p-value <0.05) and anxiety, Adj OR = 1.82 (95% CI : 1.16, 2.87; p-value <0.05) compared to Malay ethnicity. Finally, caring for patients with poor functional status were more likely to placed them in a considerable poor psychological health outcome of depression, Adj OR = 2.24 (95% CI : 1.10, 4.56; p-value <0.05), anxiety, Adj OR = 3.97 (95% CI : 1.87, 8.42; p-value <0.001) and stress, Adj OR = 3.91 (95% CI : 1.94, 7.90; p-value <0.001).

Conclusion: The current study indicates a high prevalence of depression, anxiety and stress among caregivers of cancer patients attending IKN, Putrajaya, during the COVID-19 pandemic. Caregivers who are female, non-Malay ethnicity, caregiving for young and poor performance status patients are at risk of negative psychological health outcomes. Caregivers' efforts have been invaluable during this pandemic, and they are incredible yet invisible frontline workers. Thus, it is imperative that policymakers acknowledge their valuable contributions and be factored in developing local policies. Future research efforts should focus on developing new intervention methods to reduce psychological risk factors for caregivers during the COVID-19 era.

KEYWORDS: caregiver, cancer, depression, anxiety, stress

CHAPTER 1

INTRODUCTION

1.1 Background

Cancer is the most feared and dreaded disease (K. Park *et al.*, 2020). According to Global Cancer Statistics 2020, the number of new cancer cases was estimated as 19.3 million, while 10 million cancer-related mortalities were reported globally. An estimated 28.4 million new cancer cases are predicted for 2040, an increase of 47 per cent from 2020, based on demographic changes and unchanged cancer incidence rates (Sung *et al.*, 2021). The prevalence of cancer is rising due to immense population growth, increased life expectancy, increased early detection, advanced treatment and improved survivorship care.

From 2007 to 2011, a total of 103,507 new cases of cancer were reported, while 115,238 cases occurred between 2012 and 2016 based on the available data from Malaysia National Cancer Registry Report (MNCRR) 2012-2016. Thus, in the space of four years, the incidence of cancer increased by 11.3 per cent. The increased number of cancer cases are being detected at the third and fourth stages of cancer, from 58.7 per cent from 2007 to 2011 to 63.7 per cent from 2012 to 2016 (National Cancer Registry, 2019). In Malaysia, cancer is the main cause of mortality, accounting for about 29,000 fatalities in 2020 (World Health Organization International Agency for Research on Cancer (IARC), 2020). It is an alarming finding despite significant efforts by the Ministry of Health in cancer control strategy.

Cancer affects the social environment of cancer patients, which has a significant impact beyond cancer patients. The effect of cancer is profound on the family members' physical, emotional and practical aspects, leading to a greater risk of psychiatric morbidity related to stressful events (Palos *et al.*, 2011). The diagnosis of cancer is a traumatic event upon the patient and their family members as they are the ones who are being forced to make changes in their lives, taking on a new role as a caregiver and responsibilities with little preparation or training (Fujinami *et al.*, 2015; Wagner *et al.*, 2011). Meanwhile, the advancement of diagnosis and treatment has led to an increase in the survival rates of cancer patients. Outpatient cancer care has shifted from the hospital to the community in recent years, with caregivers being asked to undertake complex medical procedures at home and carry multiple responsibilities for their patients. This includes taking care of the patient's symptoms, treatments, side effects, and other practicalities such as assisting with household activities, providing financial and transportation assistance, and supporting the patient's emotions (van Ryn *et al.*, 2011). Thus, a caregiver plays a vital role in the care and recovery of a patient, starting from diagnosis through treatment and often towards the death of the patient.

The capability to perform caregiving tasks varies amongst individuals. High stress is common when the duties or responsibilities of a caregiver outweighs the capacity to deliver. Under such condition, caregiving demands would negatively affect the caregivers' psychological outcome, and if it is unresolved, it can have negative consequences on their physical well-being (Kim *et al.*, 2016; van Ryn *et al.*, 2011). These consequences are also embedded in the psychological domain and manifested as anxiety, helplessness and loss of control, depression, heightened emotional imbalance, and failure to manage or perform caregiving duties (Northouse *et al.*, 2012). These events have adverse effects on the quality of the caregiver’s life. Caregivers sacrifice a lot to deliver care services; therefore, any aberration that affects their mental health is considered a significant public health issue.

1.2 Problem statement

COVID-19 is a novel viral respiratory disease that was initially discovered in Wuhan, China, in December 2019 (Holshue *et al.*, 2020; Wang *et al.*, 2020). The disease is caused by SARS-CoV-2 and has spread rapidly out of control since its first outbreak (World Health Organization, 2020). Currently, COVID-19 has infected more than 170 million individuals and resulted in more than 3 million deaths in at least 220 countries (Worldometer, 2021).

The COVID-19 pandemic causes an unprecedented event in our lifetime from schools and business closures, physical distancing measures, widely implemented nation lockdown, quarantine, and social isolation, all public health preventive measures to control the COVID-19 transmission. As a result, COVID-19 has put significant pressure on the global economy, and in most countries, life-saving supplies and hospital beds are already scarce. According to the Department of Statistics Malaysia, Malaysia’s gross domestic product (GDP) performance was the lowest recorded since 1998, with GDP contracting by 17.1 per cent in the second quarter of 2020 with the uncertainty of unemployment rates (Department of Statistics Malaysia, 2020).

Malaysia has announced its first Movement Control Order or known as “lockdown”, on 18th March 2020. The sudden announcement may put pressure on the caregivers as they may lack preparation to learn from the healthcare workers, resulting in low confidence in their caregiving ability. Moreover, the caregivers need to maintain low-risk transmission of COVID-19 infection while caring for their loved ones. Before the diagnosis of cancer, most patients and their families would seek cancer treatment for options, however during the COVID-19 pandemic, delaying treatment should be considered as cancer patients are more susceptible to COVID-19 than individuals without cancer, and they have poorer outcomes when being infected (Liang *et al.*, 2020). In contrast, some view that cancer might be worsening if it is not treated accordingly, or a patient might be at greater risk of contracting the infection and dying from it should the patient come to the health facilities (Burki, 2020). Therefore, the uncertain future of the cancer patients may cause added stress to the caregivers.

1.3 Rationale of the study

With the restriction of movement, caregivers provide increased levels of care with little or no support from health care professionals nor home care services. Concurrently, employed caregivers need to balance both worlds of paid work and caregiving roles (Phillips *et al.*, 2020). Thus, caregivers are genuinely the unrecognised frontliners in our society. To the author’s knowledge, there is limited literature that addresses the psychological health among caregivers of cancer patients, particularly in Malaysia during the COVID-19 pandemic. Therefore, the caregivers at a higher risk of developing negative caregiving outcomes during this pandemic could be identified by investigating the associated factors for depression, anxiety, and stress. With the unpredictability of the future, the result from this study can be helpful in guiding healthcare professionals and policymakers to care for the caregivers’ welfare who are continuously providing care.

1.4 Research questions

1. What is the prevalence of depression, anxiety and stress among caregivers of cancer patients in Institut Kanser Negara, Putrajaya, during the COVID-19 pandemic?
2. What factors are associated with depression, anxiety and stress among caregivers of cancer patients in Institut Kanser Negara, Putrajaya, during the COVID-19 pandemic?

1.5 Objectives

1.5.1 General Objective

To determine the prevalence and associated factors of depression, anxiety and stress among caregivers of cancer patients in Institut Kanser Negara, Putrajaya, during the COVID-19 pandemic.

1.5.2 Specific Objectives

1. To determine the prevalence of depression, anxiety and stress among caregivers of cancer patients attending Institut Kanser Negara, Putrajaya, during the COVID-19 pandemic.

2. To determine the factors associated with the prevalence of depression, anxiety and stress among caregivers of cancer patients attending Institut Kanser Negara, Putrajaya, during the COVID-19 pandemic.

1.6 Research hypothesis

There are significant associations between depression, anxiety and stress with sociodemographic characteristics of caregivers and patients’ characteristics.

CHAPTER 2

LITERATURE REVIEW

This chapter contains the various literature regarding the prevalence of depression, anxiety and stress, as well as their associated factors among caregivers of cancer patients. Several search engines, including Google Scholar, PubMed and Scopus, were used to obtain the literature. Also, different search methods were used, such as Boolean operators, “AND”, “OR” and “NOT”, whereas the keywords were “caregiver”, “cancer”, “depression”, “anxiety”, and “stress”.

2.1 Epidemiology of cancer

Cancer is a major burden of disease in Malaysia. Many contributing factors increase the risk of cancer, such as lifestyle changes, population ageing, and a declining fertility rate. The number of cancer cases increased exponentially with age, with the highest age at diagnosis was within the age group of 60 – 64 years old in males and 55 – 59 years old in females. Chinese ethnicity had the highest incidence in males and females (National Cancer Registry, 2019). Family members usually play the role of caregivers for cancer patients within the family. In several ways, caring for someone with cancer differs from caring for someone with other illnesses, a major factor being the acute nature of most cancerous diseases.

In contrast to chronic diseases such as dementia, cancer can rapidly deteriorate the patient’s health which may initiate higher stress levels for caregivers (Kent *et al.*, 2016). Irrespective of the cited figure, there is a proportional relationship between present caregivers for cancer patients and the number of individuals affected with the disease or condition. Moreover, these numbers are expected to increase over time (Palos *et al.*, 2011). Since outpatient and home settings are the main means for cancer care, it is expected that the demands for caregivers would increase in line with the projected growth.

2.2 Prevalence of depression, anxiety and stress among caregivers

There are several ways in which cancer impacts the quality of life immensely, but psychological well-being takes a major blow (Northouse *et al.*, 2012; Yang *et al.*, 2012). However, events such as depression, anxiety and stress, which are typical of psychological symptoms among caregivers of cancer patients, are yet to receive the needed attention. These specific psychological symptoms have been reported to vary significantly in previous studies, but the overall prevalence remains unclear. This variation can be due to differences in illness trajectory, diagnosis, and different population groups studied concerning various attributing factors.

A study on caregivers of end-stage cancer patients indicates that 52.0% of caregivers develop depression symptoms, and 61.0% of caregivers develop anxiety symptoms (Saria *et al.*, 2017). Meanwhile, the prevalence of anxiety and depression was 42.2% and 16.4%, respectively, among caregivers of incurable lung and non-colorectal gastrointestinal cancer patients in Boston (Nipp *et al.*, 2016). Likewise, about 1 in 4 (24.6%) caregivers of breast cancer patients receiving treatment were found to be under stress (Mahadevan *et al.*, 2013). There is also a disparity in the prevalence of anxiety and depression between countries. A study in Korea reported that more than 80% of caregivers suffer from depression, and approximately 40.0% experience anxiety symptoms (B. Park *et al.*, 2013). Although a similar proportion (45.0%) of caregivers experienced anxiety in Uganda, a lower prevalence of depression (26.0%) was observed (Katende and Nakimera, 2017). Accumulated evidence from several studies continues to highlight higher odds of depression and anxiety in caregivers compared to the general population (Finocchiaro *et al.*, 2012; Friðriksdóttir *et al.*, 2011; B. Park *et al.*, 2013; Price *et al.*, 2010). Likewise, a study based in the United States of America reported that the majority of caregivers of cancer patients experienced elevated stress (69.2%). The high prevalence of stress was significantly associated with caregivers' perceptions of a lack of choice in delivering care (Longacre *et al.*, 2014). Thus, these findings indicate that caregivers represent a vulnerable population group at a high risk of mental health.

2.3 Associated factors of depression, anxiety and stress among caregivers

Although psychological effects following the diagnosis of cancer impact negatively on the quality of caregiver's life, it is not sufficient to determine the prevalence of depression, anxiety, and stress in caregivers of cancer patients. Instead, different sociodemographic characteristics of caregivers and clinical variables of the patients have been considered to play a role in developing depression, anxiety, and stress in caregivers of cancer patients.

2.4 Sociodemographic characteristics of caregivers

A study conducted in Iceland found that females were significantly associated with worse caregiver anxiety than men (Friðriksdóttir *et al.*, 2011). Highlights from the study reinstated that caregivers of cancer patients have numerous needs, and most of them are not readily met. One of the common factors associated with poor mental health among caregivers was the low capacity to keep up with their psychological needs. The result from this study showed that unmet needs were higher in women and younger caregivers. Specifically, patient care, honest and reliable information were the most crucial needs, whereas the personal health of caregivers was the least important (Friðriksdóttir *et al.*, 2011). A study conducted in Greece showed a similar result, wherein anxiety was more common in women compared to men. This might be attributed to the dual role performed by Greek women by taking care of the patient and household or domestic duties (Mystakidou *et al.*, 2013). Conversely, no association was reported between sex of caregivers and psychological factors (i.e. anxiety, depression, and stress) (Din *et al.*, 2017; Mahadevan *et al.*, 2013; B. Park *et al.*, 2013; Y. Park *et al.*, 2018; Song *et al.*, 2011).

Other studies have focused on exploring the relationship between the age of caregivers and possible outcomes of caregiving. In Australia, caregivers belonging to the younger age group experienced a high level of burden, which was associated with an increased risk of anxiety (Price *et al.*, 2010). Similar findings were seen in another study conducted in the United States of America (Nipp *et al.*, 2016). On the other hand, researchers viewed older caregivers as more traditional people and are more ready to take on the responsibility of caregiving. Although their health condition is decelerating with the increased age, they would not perceive the caregiving burden as being heavy (Chang *et al*., 2010). Therefore, they have a lower risk compared to younger age group caregivers of having mental health problems.

Several studies have reported positive associations between cohabitation status and the caregivers' readiness in delivering palliative care. On that note, caregivers separated from the patients felt less prepared compared to the ones cohabitating with the patients. The mental state of preparedness is pertinent and affects the caregiver's reaction under stressful conditions when taking care of critically ill patients. Caregivers with low preparedness are less hopeful and more likely to experience anxiety when caring for their patients and vice versa for those who are well prepared (Henriksson and Årestedt, 2013). Overall, the perception of caregivers regarding their ability to carry out various caregiving functions culminates in their preparedness. Examples of these roles include providing physical care, supporting the patient emotionally, preparing domestic support services, and handling the stress of caregiving (Fujinami *et al.*, 2015). However, another study revealed the highest anxiety scores among those who cohabitate with their patients. Given the caregiver's unlimited and constant care and availability, cohabiting is associated with more demanding duties, resulting in lost personal time and sleep deprivations (Govina *et al.*, 2019; Mystakidou *et al.*, 2013). It was also found that spouses whose cohabitating partners were diagnosed during the early stages of cancer had a significantly high mortality rate (Nakaya *et al.*, 2019).

In an attempt to perform numerous tasks relating to the caregiving role, caregivers are exposed to the adverse effects of stress and burden. Past studies found that employed caregivers are more likely to have work productivity loss and work interferences (Reid *et al*., 2010; Mazanec *et al.*, 2011). Moreover, low income is identified to be associated with depression in caregivers. Families of low-income patients were often faced with the high cost of cancer treatment, resulting in catastrophic health expenditures (B. Park *et al.*, 2013). In some cases, caregivers had to quit their work to provide full-time care for the patient. Thus, this increases financial hardship and places more burden upon caregivers, which subsequently lead them to develop depressive symptoms (Yang *et al.*, 2012).

Caregivers with medical illnesses had a significantly higher probability of anxiety (Karabekiroğlu *et al.*, 2018). The tendency to prioritise the patient's care while neglecting their own psychological and physical health causes the caregiver's mental health to deteriorate (Yang *et al.*, 2012). In terms of the association with the patient, symptoms of depression were more pronounced among spousal caregivers in comparison to those of other familial associations with the patient. Spousal caregivers consider caregiving repayment to their spouses and feel a heightened emotional burden than do other caregivers. Additionally, patients generally share their feelings and thoughts with spouses, which may exacerbate depressive symptoms (Yang *et al.*, 2012). The decisions regarding caregiving roles for a patient are fundamental. A spousal caregiver is often actively involved in the decisions regarding caregiving roles for their patient. In addition, the commitments to care for a cancer patient and handling cancer-related impact on the family may heighten the levels of anxiety, stress and diminish the sense of well-being, especially in a critically diseased state. These adverse effects of illness are more expressed by female spouses (Mystakidou *et al.*, 2013; Penning and Wu, 2016).

Caring for a family member who is ill often requires teamwork, especially among family members. Although caregiving can be a satisfaction, it also can be challenging work. In addition, caregiving responsibilities may need to be changed over time, depending on different situations, patient's needs, and caregiver's own abilities and limitations. Thus, sharing caregiving responsibilities is a significant source of social support for the caregivers and remains protective towards the caregivers' psychological well-being (Din *et al.*, 2017; Price *et al.*, 2010). Support could be in many ways, including practical care, communication, financial, and emotional supports. Numerous studies have observed that lack of social support is associated with the caregiver's burden level, both psychologically and physically (Karabekiroğlu *et al.*, 2018; Mahadevan *et al.*, 2013). However, frequent hospital visits and interaction with medical staff assist caregivers in overcoming the burden associated with poor social support (Williams *et al.*, 2013).

The caregiving burden with long-duration of caregiving can also lead to adverse health outcomes such as an increase in heart rate, which in the future can lead to atherosclerosis and cardiovascular morbidity (Corà *et al.*, 2012). Likewise, those who spent hours per day caring for the patients may affect their quality of life and psychological health (Mahadevan *et al.*, 2013; B. Park *et al.*, 2013).

2.5 Characteristics of patients

Caregivers who cared for male cancer patients have higher depression and anxiety than those who cared for female patients. This is because women are generally assumed to be more competent in managing themselves and are independent in handling their own needs. On the other hand, male patients require more help in personal care, which may impact their caregivers' depression and anxiety levels (Karabekiroğlu *et al.*, 2018). Caregivers caring for elderly patients, on the other hand, are less likely to be stressed (Mahadevan *et al.*, 2013).

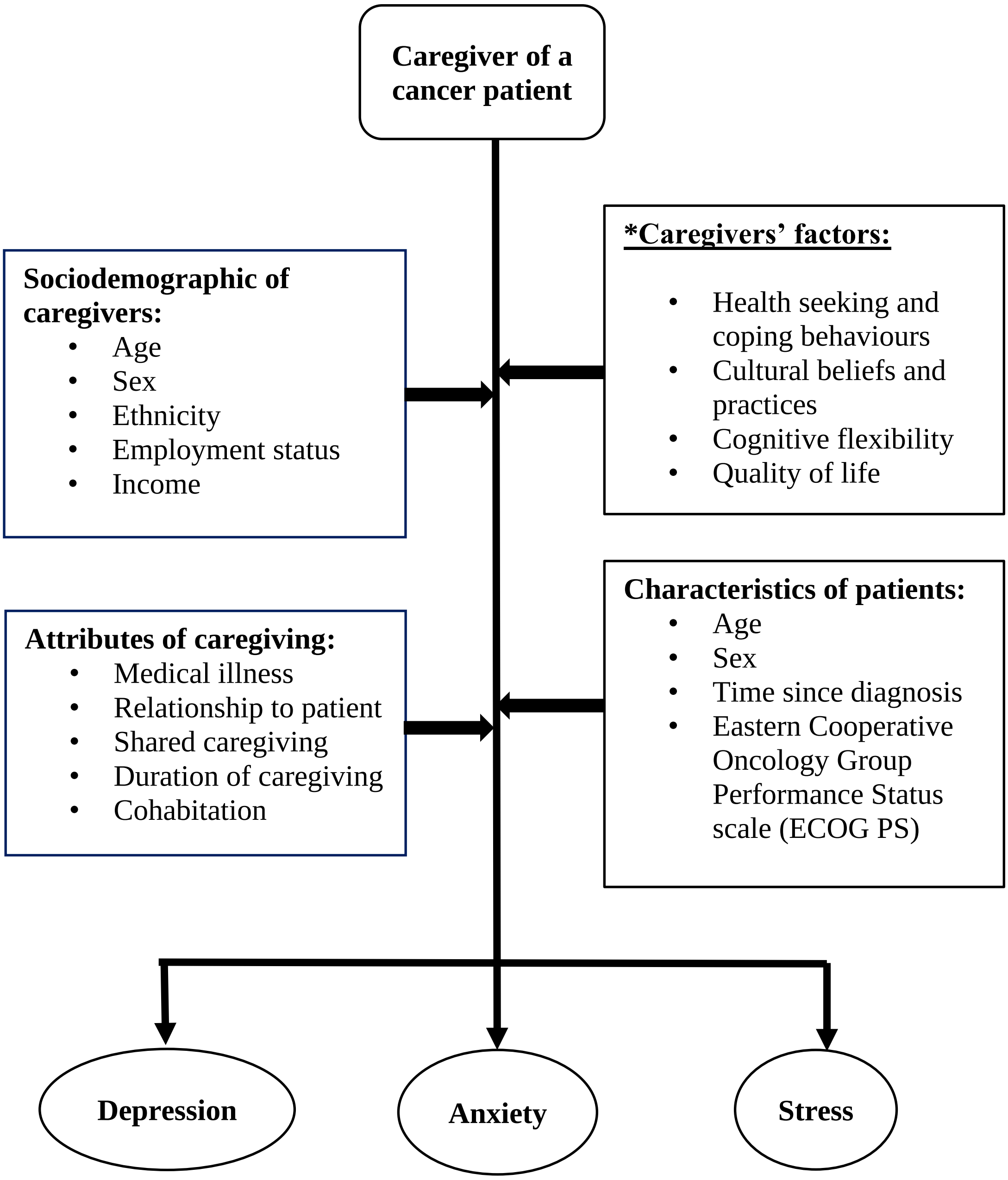
Friðriksdóttir *et al.*, (2011) reported that the manifestation of symptoms of depression and anxiety among caregivers varied with the period of diagnosis. Specifically, the likelihood of expressing anxiety and depression among caregivers of cancer patients is higher from the second to the fifth year of diagnosis. This period is characterised by important events regarding the caregiving role, such as the concluding aspect of treatment, progression or recurrence of the underlining cancer disease. Furthermore, the initial or first treatment often commences within the first year, whereas recurrence or progression is common after five years of care management.

Caregivers may experience a higher level of stress relating to the patient's worsening performance status and medical conditions. As the disease progresses, associated symptoms may become more apparent and require greater aid with symptoms management and physical assistance. These events may aggravate the caregiver's mental state, thus increasing the likelihood of experiencing tiredness, distress and frustration (Mahadevan *et al.*, 2013; Woźniak and Iżycki, 2014). Executing the caregiving role for a terminally ill cancer patient is not only challenging but equally traumatic. To mention a few, it involves complexity in supporting the patient physically and medically, management of finances, complex decision making and harmonising all-encompassing care (Given *et al.*, 2012). In an attempt to reduce their emotional fears, the majority of caregivers experience devastating anxiety probably associated with future concerns, adapting with the present circumstances, fear of loss, and loneliness (Corà *et al.*, 2012; Mystakidou *et al.*, 2013; Y. Park *et al.*, 2018).

2.6 Conceptual framework

Error! Reference source not found. depicts the conceptual framework for this research. Three main categories were identified for the associated factors for anxiety, depression and stress among caregivers of cancer patients. The categories were sociodemographic, attributes of caregiving and patients' characteristics. Sociodemographic of caregivers that impact their psychological health are age, sex, ethnicity, employment status, and income. The attribute of caregiving includes medical illness, relationship to the patient, shared caregiving, duration of caregiving, and cohabitation. Additionally, the psychological health of caregivers is influenced by patients' characteristics, including sex, age, time since diagnosis, and functional status. Variables such as age, sex, and time of diagnosis are collected directly through surveys, whereas a measuring tool known as the Eastern Cooperative Oncology Group performance status (ECOG PS) scale is used in quantifying the functional status.

Other caregivers' factors, including health-seeking and coping behaviours, cultural beliefs and practices, cognitive flexibility and quality of life, are excluded to minimise the time required for caregivers to participate in this study. The outcomes of interest are depression, anxiety, and stress of caregivers.



Note: *Variables not included in the study

Figure 2.1: Conceptual framework of the study

CHAPTER 3

METHODOLOGY

3.1 Study area

This study area was Institut Kanser Negara (IKN), a government tertiary hospital located in Putrajaya, Malaysia. IKN is one of the recommended centres that specialises in cancer therapy. The hospital is recognised for significant patient visits and exemplifies the diverse races in Malaysia. The Radiotherapy and Oncology (RTO) Department and Palliative Department comprises in-patient wards, day-care, and outpatient clinics.

3.2 Study design

A cross-sectional study design was adopted to assess the self-perceived anxiety, depression and stress among caregivers of cancer patients in IKN during the COVID-19 pandemic.

3.3 Study period

The study was carried out between January 2021 and June 2021.

3.4 Reference population

Caregivers of cancer patients who attended IKN.

3.5 Source population

Caregivers of cancer patients who attended RTO Department and Palliative Department in IKN.

3.6 Sampling frame

Caregivers of cancer patients who attended RTO Department and Palliative Department in IKN that fulfilled the study criteria.

3.7 Inclusion criteria

Caregivers were enrolled in this study if they fulfil the following criteria (i) plays the primary caregiving role, (ii) both patients and caregivers are 18 years old and above, (iii) the caregiver is a member of the patient’s family and (iv) sufficient understanding of English or Malay language.

3.8 Exclusion criteria

Caregivers were excluded from the study if they (i) are illiterate caregivers and (ii) caregivers undergoing psychiatric treatment at the time of the study.

3.9 Sampling method

The researcher approached each caregiver at different times in the RTO Department and Palliative Department. Random sampling was applied by evaluating the number of admissions and follow-ups in a day at the specific study locations (i.e. outpatient clinics, in-patient wards, and day-care). Patients were then randomly selected, and those who were not accompanied by their caregivers were taken out of the selection and replaced with another.

3.10 Sample size calculation

The calculation of the sample size was performed for each of the study objectives. The study used both manual and online questionnaires, and the sample size was increased to 15% drop out.

Objective 1: To determine the prevalence of depression, anxiety and stress among caregivers of cancer patients in IKN, Putrajaya, during the COVID-19 pandemic.

Sample size calculation by using a single proportion formula:

$$\boldsymbol{n} = \left(\frac{\boldsymbol{Z}}{\Delta}\right)^{\mathbf{2}} \boldsymbol{P}(\mathbf{1} - \boldsymbol{P})$$

Table 3.1: Value of the proportion of depression, anxiety and stress among caregivers of cancer patients

Domain	**Z**	**Δ**	**P**	**Literature Review**	**n**	**$\boldsymbol{n}$ + 15%**
Depression	1.96	0.05	26.0%	Katende and Nakimera, (2017)	296	341
Depression	1.96	0.05	42.3%	Geng *et al.*, (2018)	375	432
Anxiety	1.96	0.05	38.1%	B. Park *et al.*, (2013)	362	417
Anxiety	1.96	0.05	45.0%	Katende and Nakimera, (2017)	380	**437**
Stress	1.96	0.05	25.0%	Mahadevan *et al.*, (2013)	288	332

Objective 2: To determine the factors associated with the prevalence of depression, anxiety and stress among caregivers of cancer patients in IKN, Putrajaya, during the COVID-19 pandemic.

The PS Software Version 3.1.2 was used to estimate the sample size based on the comparison of two independent proportion formula.

Table 3.2: Value of proportion of depression in caregivers of cancer patients according to factors

Variable / Factors	**P_0**	**P_1**	**m**	**n**	***n* x 2 + 15%**	**Literature Review**
Sex of caregiver (Female)	0.79	0.3	1	15	33	Katende and Nakimera, (2017)
ECOG PS (Group 4)	0.20	0.1	1	199	428	Y. Park *et al.*, (2018)

α = 0.05 Power = 0.8

P_0 = the proportion exposed to the risk factor among those without depression

P_1 = the proportion exposed to the risk factor among those with develop depression

Note: the proportions were obtained from reviewed literature

Table 3.3: Value of proportion of anxiety in caregivers of cancer patients according to factors

Variable / Factors	**P_0**	**P_1**	**m**	**n**	***n* x 2 + 15%**	**Literature Review**
Shared caregiving (No)	0.24	0.1	1	112	241	Din *et al.*, (2017)
Duration of caregiving (> 20 hours per week)	0.33	0.1	1	49	106	Din *et al.*, (2017)
ECOG PS (Group 4)	0.20	0.1	1	199	428	Y. Park *et al.*, (2018)

α = 0.05 Power = 0.8

P_0 = the proportion exposed to the risk factor among those without anxiety

P_1 = the proportion exposed to the risk factor among those with develop anxiety

Note: the proportions were obtained from reviewed literature

Table 3.4: Value of proportion of stress in caregivers of cancer patients according to factors

Variable / Factors	**P_0**	**P_1**	**m**	**n**	**n x 2 + 15%**	**Literature Review**
Employement status (Unemployed)	0.32	0.1	1	53	114	Mahadevan *et al.*, (2013)
Shared caregiving (No)	0.56	0.3	1	56	121	Mahadevan *et al.*, (2013)

$\alpha = 0.05$ Power = 0.8
P_0 = the proportion exposed to the risk factor among those without stress
P_1 = the proportion exposed to the risk factor among those with develop stress
Note: the proportions were obtained from reviewed literature

Therefore, the biggest sample size required for the study was 437.

3.11 Research tool

The proforma checklist, which includes ECOG PS, both English and Malay versions of Depression Anxiety Stress Scales, were the major instruments employed in this study.

3.11.1 Proforma checklist

The checklist comprises caregivers' sociodemographic factors, patient characteristics, and attributes of caregiving. The specific variables in each category are mentioned below:

- Caregivers' sociodemographic factors: sex, age, employment status, ethnicity, and income status. The income status is categorised into less than RM 3000, more than RM 3000 and no income (Shin *et al.*, 2020).

- Patient characteristics: sex, age, time since diagnosis and ECOG PS.

- Caregiving attributes: the presence of comorbidity (medical illness), relationship to the patient, shared caregiving, duration of caregiving, and cohabitation. The duration of caregiving is categorised into more than 20 hours per week or less (Din *et al.*, 2017; Mahadevan *et al.*, 2013).

3.11.2 Depression Anxiety Stress Scales in English and Malay version

This aspect comprises Depression Anxiety Stress Scales and 21 specific items (DASS-21). This instrument was developed by Lovibond and Lovibond (1995) and consisted of a self-administered questionnaire written in English. The questions in the instrument focus on the thoughts and feelings experienced in the past week. DASS-21 contains three subscales: depression, anxiety and stress. There are seven items in each scale, and they are presented using a four-point Likert scale ranging from 0 to 3, where 0 = not applicable to me at all, and 3 = applied to me at all times. The relevant items are added together to calculate the scores for each subscale. Thereafter, the sum of DASS-21 is multiplied by two, and the obtained value is used to classify the severity as presented in Table 3.6. Nevertheless, the instrument is not applicable for the clinical diagnosis of any of the subscales (i.e. depression, anxiety or stress). The instrument, DASS-21, was selected based on certain important features, including its wide usage for screening for the symptoms of depression, anxiety, and stress, as well as simplicity in terms of application in research and community health settings (Musa *et al*., 2007). In addition, the DASS-21 was also readily available and widely accessible to be used.

3.12 Validity and reliability

Validation of the Malay version of DASS-21 was extensively carried out among the local population. Reliability analysis showed that Cronbach's alpha values for the items under depression, anxiety and stress were 0.84, 0.74 and 0.79, respectively (Musa *et al.*, 2007). Also, the loading values for the majority of items ranged from 0.39 to 0.73, while the correlations among scales ranged from 0.54 to 0.68. Therefore, the authors described the Malay Version as a reliable and valid instrument for evaluating psychological symptoms.

3.13 Operational definition

3.13.1 Caregiver

In this study, the caregiver is the primary caregiver who mainly provides and assists with patients' daily living activities (Saria *et al.*, 2017). The caregiver being studied in this research is a family member who has a blood relationship with the patient. Hence, the following members are within the category: immediate parents (mother or father), siblings (brother or sister), couple (wife or husband), immediate children (son or daughter), grandparents (grandmother or grandfather), in-laws (mother or father), aunt, uncle, and other blood relatives.

3.13.2 Depression in caregiver

Described as the level of depression in caregiver measured by using the DASS-21 assessment tool and who scored ten and more were considered to have depression.

3.13.3 Anxiety in caregiver

Described as the level of anxiety in caregiver measured by using the DASS-21 assessment tool and who scored eight and more were considered to have anxiety.

3.13.4 Stress in caregiver

This was described as the caregiver's stress level as computed using the DASS-21 assessment tool. Those with a total score of 15 and above were classified to experience stress.

3.13.5 Cohabitation

Described the condition where the caregiver and the cancer patient are living together.

3.13.6 Shared caregiving

Described as when having someone to help in the caregiver role.

3.13.7 Physical functional status

Assesses how cancer affects the patients' daily living abilities. This is measured based on the following ECOG PS grade shown in Table 3.5 (Oken *et al.*, 1982).

Table 3.5: ECOG performance status

Grade	ECOG performance status scale
0	Completely active, unrestricted execution of all pre-disease performance
1	Limitation in performing physically strenuous activity but ambulatory and could perform sedentary or less strenuous activity including office jobs, house chores, etc.
2	Ambulatory and could take of him or herself but lacks the capacity to perform any work activities. Up and about more than 50% of waking hours
3	Self-care is limited and spends more than 50% of waking hours on the bed or chair.
4	Total disability. Self-care cannot be performed and completely confined to chair or bed.