

QUALITY OF LIFE AMONG CAREGIVERS OF
PATIENTS WITH END-STAGE RENAL DISEASE IN
HOSPITAL UNIVERSITI SAINS MALAYSIA

NURUL FATIHAH BINTI ZUL

SCHOOL OF HEALTH SCIENCES
UNIVERSITI SAINS MALAYSIA

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PATIENTS WITH END-STAGE RENAL DISEASE IN
HOSPITAL UNIVERSITI SAINS MALAYSIA

by

NURUL FATIHAH BINTI ZUL

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Requirement for the Degree
of Bachelor of Nursing (Honours)

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CERTIFICATE

This is to certify that the dissertation entitled “Quality of life among caregivers of patients with end-stage renal disease in Hospital Universiti Sains Malaysia” is the bona-fide record of research work done by Ms Nurul Fatihah Binti Zul during the period from September 2019 to June 2020 under my supervision. I have read this dissertation and that in my opinion it conforms to acceptable standards of scholarly presentation and is fully adequate, in scope and quality, as a dissertation to be submitted in partial fulfilment for the degree of Bachelor of Nursing (Honours).

Main supervisor,

Co-Supervisor,

.....

.....

Mr. Ali Aminuddin Mohd Rasani
Lecturer,
School of Health Sciences,
Universiti Sains Malaysia,
Health Campus,
16150 Kubang Kerian,
Kelantan, Malaysia.

Dr. Norhasmah Mohd Zain
Lecturer,
School of Health Sciences,
Universiti Sains Malaysia,
Health Campus,
16150 Kubang Kerian,
Kelantan, Malaysia.

Date:

Date:

DECLARATION

I hereby declare that this dissertation is the result of my own investigations, except where otherwise stated and duly acknowledged. I also declare that it has not been previously or concurrently submitted as a whole for any other degrees at Universiti Sains Malaysia or other institutions. I grant Universiti Sains Malaysia the right to use the dissertation for teaching, research, and promotional purposes.

Signature

.....

Nurul Fatihah Binti Zul (Matric No: 134148)
Student of Bachelor of Nursing (Honours)
School of Health Sciences,
Universiti Sains Malaysia,
Health Campus,
16150 Kubang Kerian,
Kelantan, Malaysia.

Date:

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LIST OF ABBREVIATIONS

QOL	Quality of Life
CKD	Chronic Kidney Disease
ESRD	End-Stage Renal Disease
GRF	Glomerular Filtration Rate
HD	Hemodialysis
KT	Kidney Transplant
RRT	Renal Replacement Therapy
NPCR	Normalises Protein Catabolic Rate
HPT	Hypertension
DM	Diabetes Mellitus
HUSM	Hospital Universiti Sains Malaysia
USM	Universiti Sains Malaysia
WHO	World Health Organization
WHOQOL-100	World Health Organization Quality of Life - 100
WHOQOL-BREF	World Health Organization Quality of Life - BREF
RAM	Roy Adaption Model
HREC	Ethical Research Ethical Committee

**KUALITI HIDUP DALAM KALANGAN PENJAGA KEPADA PESAKIT YANG
MENGHIDAP PENYAKIT BUAH PINGGANG TAHAP AKHIR DI HOSPITAL
UNIVERSITI SAINS MALAYSIA**

ABSTRAK

Kualiti hidup didefinisikan sebagai anggapan individu mengenai posisi kehidupan mereka dalam konteks budaya dan sistem di mana ia berhubung rapat dengan matlamat, jangkaan, tahap dan beban. Penjaga memainkan peranan penting dalam memberikan penjagaan kesihatan kepada pesakit yang menghidap penyakit buah pinggang tahap akhir dan membantu mereka untuk menyesuaikan diri dan menguruskan penyakit kronik yang dihidapi. Kajian ini bertujuan untuk mengetahui tahap kualiti hidup dalam kalangan penjaga dan hubungan antara data sosiodemografi terpilih dan tahap kualiti hidup dalam kalangan penjaga di HUSM. Satu kajian '*cross-sectional study*' dilakukan dalam kalangan penjaga kepada pesakit yang menghidap penyakit buah pinggang tahap akhir menggunakan borang soal selidik. '*One-way ANOVA*' digunakan untuk mencari kaitan antara data sosiodemografi terpilih dan tahap kualiti hidup dalam kalangan penjaga di HUSM dengan signifikasi $p < 0.05$. Terdapat 40 responden telah mengambil bahagian. Hasil kajian menunjukkan 23 (57.5%) penjaga mempunyai tahap kualiti hidup yang baik dan 27 (67.5%) berpuas hati terhadap kesihatan mereka. Skor min yang tertinggi dalam kualiti hidup penjaga berada di domain sosial ($M = 3.93$, $SD = 0.50$). Terdapat perbezaan min yang signifikan antara tahap pendidikan dan tahap kualiti hidup dalam domain fizikal ($p = 0.019$) dan persekitaran ($p = 0.006$). Seterusnya, terdapat perbezaan min yang signifikan antara umur pesakit dan tahap kualiti hidup dalam domain fizikal ($p = 0.024$). Terakhir, terdapat perbezaan min yang signifikan antara tempoh masa pesakit yang menerima rawatan hemodialisis dan tahap kualiti hidup dalam domain persekitaran ($p = 0.043$). Kesimpulannya, domain fisiologi adalah domain yang paling banyak

mempengaruhi tahap kualiti hidup di kalangan penjaga. Domain fizikal dan persekitaran adalah domain yang paling terjejas kerana berkaitan dengan pemboleh ubah sosiodemografi. Para jururawat memainkan peranan yang besar dalam meningkatkan kualiti hidup dalam kalangan penjaga untuk mereka mendapat kualiti hidup yang baik.

QUALITY OF LIFE AMONG CAREGIVERS OF PATIENTS WITH END-STAGE RENAL DISEASE IN HUSM

ABSTRACT

QOL is defined as an individual's perception of their position in life in the context of culture and value system where they live, and in relation to their goals, expectations, standards, and concerns. Caregivers play an important role in providing care to patients with ESRD and help them to adapt and manage their chronic illnesses. This study aimed to determine the level of QOL among caregivers and the association between selected sociodemographic data and the level of QOL among caregivers in HUSM. A cross-sectional study was conducted among caregivers of patients with ESRD using self-administered questionnaire. One-way ANOVA was used to find the association between selected demographic data and the level of QOL among caregivers in HUSM with significance at $p < 0.05$. There were 40 respondents who was involved. The finding shows 23 (57.5%) of caregivers has rate their level QOL as good and 27 (67.5%) were satisfied in their health. The highest mean score of QOL were in the domain social (mean 3.93, SD = 0.50). There was a significant mean difference between education level and the level of QOL in domains physical ($p = 0.019$) and environment ($p = 0.006$). Next, there was a significant mean difference between the age of the patient and the level of QOL in physical domain ($p = 0.024$). Lastly, there was a significant mean difference between the length of the patient with ESRD receiving HD and the level of QOL in environment domain ($p = 0.043$). In conclusion, physiological domain was significantly the most affected domain in the level of QOL among caregivers. The physical and environment domain were most affected domains as associated with sociodemographic variable. Nurses have a big responsibility to improve the life of caregivers to have a better QOL.

CHAPTER 1

INTRODUCTION

1.1 Background of the Study

Quality of life (QOL) is defined as an individual's perception of their position in life in the context of culture and value system where they live, and in relation to their goals, expectations, standards and concerns (Anees et al., 2014). QOL is influenced by many various factors and conditions, such as accommodation, employment, income, material welfare, moral attitudes, personal and family life, social support, stress and crises, health-related quality of life, health care service, working conditions, nourishment, education opportunities, relationships with the environment, eco-factors, and others (Ruzevicius, 2014) .

Caregivers play the most significant role in providing suitable support, care and they have the most central role in patient's adapting and managing their disease (Ghane, Mansoreh Ashghali Farahani, & Haghani, 2019). Patients who are having chronic kidney disease (CKD) especially in the last stage of CKD really need family caregivers to assist them in managing their daily living and needs. CKD is one of renal disease and the main health problem around the world such as Japan, Thailand, and China (Jafari, Ebrahimi, Aghaei, & Khatony, 2018). The rising number of patients with CKD has become a global challenge due to its progressiveness to ESRD (Dariah, Junaiti, & Kueh, 2016). There are many risk factors that cause of CKD. In Sa'adeh, Darwazeh, Khalil, & Zyoud, (2018) have been write on their study that hypertension and diabetes mellitus are the main factors of CKD, with smoking, obesity, and leading a sedentary lifestyle worsening the degree of CKD.

End-stage renal disease (ESRD) is stage 5 of CKD with the glomerular filtration rate (GFR) is less than 15 ml/min (Oyegbile & Brysiewicz, 2017). Patients with ESRD needs to undergo treatment either hemodialysis (HD) or a kidney transplant (KT). The most preferred treatment modality for ESRD in Malaysia is HD. HD is a complex treatment procedure leads to fundamental changes in the patients' normal life and their increased dependence upon the caregiver (Azam, Ebadi, & Tayeb, 2017). HD will impact the QOL of the patient. Patient on HD has to deal every day with an incurable illness that forces them to follow a painful and long treatment that cause greater limitations and alterations that reflect on their QOL (Prithpal et al., 2011). Therefore, they need additional support from caregivers.

In giving care of patients with ESRD, the QOL among caregivers will be affected. Results of previous studies indicate that caregivers of patients with ESRD that receiving HD is under pressure in many aspects such as physically, emotionally, financially, and are therefore exposed to a variety of physical and psychological risks (Jafari et al., 2018). Caregivers will face emotional distress and psychological symptoms, including depression, anxiety, anger, despair, and feelings of guilt and shame (Ghane et al., 2019). Therefore, this study is to determine the level of QOL among caregivers of patients with ESRD receiving HD and the association between selected sociodemographic data and the level of QOL among caregivers in HUSM.

1.2 Problem Statement

In Malaysia, the prevalence of CKD has increased from 9.1% in 2011 to 15.5% in 2018. The incidence and prevalence of treated ESRD have risen markedly over the last 25 years. The Malaysian Dialysis and Transplant Registry reported that 7,967 new patients received dialysis in 2015 and by the end of 2016 there were 39,711 patients on

dialysis. If the present trend continues unchecked, the number of patients with ESRD is estimated to reach 51,000 in 2020 and 106,000 in 2040 (Malaysia, 2018). Patients with ESRD receiving HD have reduced in QOL. There are severe restrictions on activity daily living and movement due to the need for dialysis that can lead to feelings of anger, anxiety, hopelessness, or depression (Jafari et al., 2018).

The caregiver is the most important person who cares for their family member that having a chronic illness. Patients with ESRD often relies on an unpaid caregiver to assist them. Duties taken on by unpaid caregivers may include administration of medications, driving to dialysis and medical appointment, maintenance of personal hygiene, and provision of meals (Suri et al., 2011). This all responsibility of the caregiver makes the QOL impacted. They do not have time for themselves, cannot tolerate with other responsibilities like role at the workplace and have a financial problem. A caregiver who providing care for a long time, may experience burden and reduce QOL. This in turn may result in a more negative impact on the emotional and social aspects of caregiver's life (Bayoumi, 2014).

In time the patient has low QOL, the caregiver also gets the effect. Nobody knows and ignored it. The needs of the caregivers are often neglected and they more in experience stress and depression (Prithpal et al., 2011). So, this study is to know which level of QOL among caregivers of patients with ESRD receiving HD in HUSM and the factor that related to reducing of QOL.

1.3 Significance of Study

The finding of this study can be used as a reference to determine the level of QOL among the caregivers in caring patients with ESRD that receiving HD treatment in HUSM. It can contribute towards the improvement and help the caregivers to have better

QOL in future. Moreover, the finding also can provide some useful information and give benefit to community nurses and health management. It can guide health professionals to plan for better services in advance to help family caregivers increase the level of QOL in caring patients with ESRD. Finally, these study findings can be used as baseline data for future research related to this issue.

1.4 Research Questions

1. What is the level of QOL among caregivers of patients with ESRD in HUSM.
2. Is there any association between selected sociodemographic data (level of education, financial income, age of patients with ESRD and length of patients with ESRD receiving HD) and the level of QOL among caregivers.

1.5 Research Objectives

1.5.1 General Objective

The general objective of this study is to determine the level of QOL among caregivers of patients with ESRD in HUSM.

1.5.2 Specific Objective

The specific objectives of this study are:

1. To determine the level of QOL among caregivers of patients with ESRD in HUSM.
2. To determine the association between selected sociodemographic data (level of education, financial income, age of patients with ESRD and length of patients with ESRD receiving HD) and the level of QOL among caregivers.

1.6 Research Hypothesis

1.6.1 Hypothesis

H_O: There is no significant mean difference between selected sociodemographic data (level of education, financial income, age of patients with ESRD and length of patients with ESRD receiving HD) and the level of QOL among caregivers.

H_A: There is significant mean difference between selected sociodemographic data (level of education, financial income, age of patients with ESRD and length of patients with ESRD receiving HD) and the level of QOL among caregivers.

1.7 Conceptual and Operational Definitions

Below is the list of terms for defined the purposed of this research study.

Table 1.1: Conceptual and operation definitions

Term	Conceptual definitions	Operational definitions
QOL	According to WHO, QOL is an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns (Anees et al., 2014). It is a broad-ranging concept that affected in person's physical health psychological state, personal beliefs, social relationships, and their relationship to their environment (Hasanah et al., 2003).	QOL is so important to everyone. This study was to determine the level of QOL among caregivers who are taking care patients with ESRD. This study was also to determine either the QOL can be associated with selected sociodemographic data such as level of education, financial income, age of patient and length of patient receiving HD treatment (Azam Sajadi et al., 2017).

Table 1.1, continued

Term	Conceptual definitions	Operational definitions
Caregiver	A caregiver is a person who gives care to people who need help taking care of them. People who need help include children, the elderly, or patients who have chronic illnesses or are disabled. The caregiver can be nurse, maid, helper, friend, and family caregivers who are directly taking care of their family members with love and full of honesty (Rongzhi Zhang, 2016).	In this study, caregiver refers to family members such as parents (father or mother), partner (husband or wife), sibling (brother or sister), children (son or daughter), grandparent and grandson or granddaughter. This caregiver must take care of the patient with ESRD at minimum of 10 hours per week in at least within 2 months (Azam Sajadi et al., 2017). The researcher will determine the QOL of caregivers within last 2 week to know which level of their QOL (Hasanah et al., 2003).
ESRD	ESRD is the last stage (stage five) of CKD. This means kidneys are only functioning at 10 to 15 percent of their normal capacity. Kidneys are important organs that contribute to your overall well-being. When the kidney function too low, they cannot effectively remove waste or excess fluid from our blood. Many complications if it not treated. Because of this, patient need to undergo treatment either hemodialysis or a kidney transplant is necessary to stay alive (Prithpal et al., 2011).	In the article written by Oyegbile & Brysiewicz (2017), the study showed that patients with ESRD who are undergoing HD treatment are at risk of physical, cognitive, and emotional impairment. Therefore, it gives a negative effect to QOL among caregiver who is taking care of them in a long time and experience of burden because of it (Oyegbile & Brysiewicz, 2017). In this study want to know did the age of patients and the length of patients with ESRD receiving HD treatment can give an impact on QOL of caregivers.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

This literature review consists of QOL among caregivers of patients with ESRD, four domains in the level of QOL (physical, psychological, social relationship, environment health) that effects of caregiving, the relationship between selected sociodemographic data and the level of QOL among caregivers and caregiver assessment for measure the level of QOL. This chapter also discusses details about the theoretical and conceptual framework that was used to guide in this study.

2.2 QOL Among Caregivers of Patients with ESRD

From the literature review of patients with ESRD receiving HD treatment, previous literature shown that most of the caregivers get impacted and reduced QOL in a caring patient with ESRD. Family caregivers is a persons who are being responsible for the care of their patient, without receiving any money (Jafari et al., 2018). Caregivers is a most important person who help patients with their daily activities, household tasks, and personal care, such as bathing and dressing, while they undertake responsibility for technical health procedures in dialysis patient. They also manage their money or communicate with professional caregiver when appropriate. Additionally, their role involves management of medical treatment and symptoms caused by HD, transportation to HD unit and other appointment, management of diet, and helping in personal hygiene (Drahansky et al., 2016). Long-term HD cause the physiological, social and cultural problem to their family. Family caregiver play a vital role in caring patient with ESRD. In Jafari et al. (2018), caregiver of patient ESRD receiving HD are under high levels of

care burden. Most of studies shown the caregivers of patients with ESRD receiving HD treatment experience significant level of care burden affects their QOL.

Families of patients must accept many limitations derived from the disease, which have negative impact on their life. Difficulties with caregivers are mainly attributed to dietary and fluid restrictions, difficulty in going on holiday, financial problems, uncertainty about the future, reduced social life, changes in family roles, and limitation in physical activities (Drahansky et al., 2016).

2.2.1 Physical, Psychological, Social, and Environmental Factors Effects of Caregiving

To measure the QOL individually was based on four domains that is physical, psychological, social relationship, and environment. Article in the title of “ Caregivers of patients with HD” has said that taking care of patients for a long time is a stressful process for the caregiver and leads to low psychological status, decreased physical health, reduced social interaction, and physical and emotional burden (Gatua, 2017). More specifically, they feel physical and psychological distress, limitations to their personal and social activities, while caregivers are more feel anger, helplessness, guilt, isolation, and loss of freedom (Drahansky et al., 2016). The most common of physical signs in caregiver’s stress is disturbed in sleep, back and shoulder or neck pain, muscle tension, headaches, loss of hair, chest pain, skin disorder, and others.

Next, for psychological most effected emotional stress that leading to depression and anxiety-related signs and symptoms of caregiver stress. The example of emotional signs of caregiver stress such as moodiness, more to a negative feeling, feeling out of control, feeling of isolation and other emotional stress. Those who exhibit emotional stress report higher degrees of caregiver burden. Caregiver emotional disorders are driven

not only by the work of caregiving but from the daily contact with a suffering loved one. These disorders are more frequent in women than in men. Any emotional disorder results in reduced QOL among the caregivers as well as reduced quality of care to the care recipient (Jafari et al., 2018).

Moreover, psychological stress among caregivers can lead to social isolation as it leads to loss of personal time. Social relationship is very important and believed to be key to the health and well-being of family caregivers. Social support from others family members, friends, and neighbours provide is believed to be important because it serves either as a “buffer” that reduces the negative effects of caregiving or as a resource that caregivers use as part of their coping strategies like an emotional session for them to speak out the feel of burden inside (Phillips & Crist, 2012). Most caregivers socially isolated because of lack of time for social interaction with others (Gatua, 2017).

An environmental factor that included financial resources, freedom, physical safety, opportunities for acquiring new information and skills, physical environment, transport, and others can affect the QOL among caregivers. The caregiving environment in resource-limited countries presents with unique limitations and burdens. A study by Oyegbile & Brysiewicz (2017), in Nigeria, as in low-income countries, the unavailability of basic resources, and the limited healthcare infrastructure and personnel often delay treatment and increasing the burden for the caregivers. Family low financial income, make the caregivers and patient difficult to make access for private health care (Oyegbile & Brysiewicz, 2017).

2.3 The Association Between Selected Sociodemographic Data and the Level of QOL Among Caregivers

In Malaysia, limited studies have examined the association between selected sociodemographic data and the level of QOL among the caregivers. The previous study of sociodemographic and QOL shown the finding that the lower of caregiver's education level, low in financial income and the length disease duration more than 6 month were significant associated with the lower QOL among caregivers (Yusop, Mun, Shariff, & Huat, 2013). This result shown that the caregivers who have the high education level have the better QOL because of knowledge and concern about their health (Yusop et al., 2013). The result of the study also shown that low financial income gives an impact low QOL among caregivers. Caregivers feel stress and burden to pay every treatment that patient needed such as HD, medication, and others. The financial commitment that accompanies any RRT can be a source of burden to the caregiver (Gatua, 2017). Moreover, due to chronic of the disease, most patients cannot afford their dialysis beyond 3 months and need support from family caregivers (Gatua, 2017). In Azam Sajadi et al., (2017), it is reported that the factors associated with QOL among caregivers was significant with the age of patients, and prolonged HD treatment. The finding in this study shown that the caregivers who are taking care older patient undergoing HD who had lower QOL led to a decline in the quality in their life (Azam Sajadi et al., 2017). Furthermore, caregivers of patients with ESRD that prolonged HD treatment had lower QOL compared to the entire population (Azam Sajadi et al., 2017). The finding from previous study show that 53.9% patients with ESRD on prolonged HD and low care ability effect the caring pressure of caregivers (Jafari et al., 2018).

2.4 Caregiver Assessment

QOL conceptual models and instruments for research, evaluation and assessment have been developed since the middle of last century (McCall, 2005, Ruzevicius, 2014). Evaluation and assessment of QOL must encompass all element. The World Health Organization Quality of Life – 100 (WHOQOL-100) allows detailed assessment of each individual facet relating to QOL. But, WHOQOL-100 may be too lengthy for practical use. The common instrument to determine the level of QOL either patient or caregiver was World Health Organization Quality of Life – BREF (WHOQOL-BREF). Term of BREF, there was no article define the term. WHOQOL-BREF Field Trial Version has therefore been developed to provide a short form QOL assessment that looks at domain level profiles, using data from the pilot WHOQOL assessment and all available data from the Field Trial Version of the WHOQOL-100. The WHOQOL-BREF contains a total of 26 questions. The questionnaire contains of 4 domains. The domain was physical health domain, psychological domain, social relationship domain and environment domain (Hasanah et al., 2003).

2.4.1 Importance of QOL Assessment

It is anticipated that the WHOQOL assessments was used in broad-ranging ways. They were considerable use in clinical trials, in establishing baseline scores in a range of areas, and looking at changes in QOL over the course of interventions. Together with other measures, the WHOQOL-BREF was enable health professionals to assess changes in QOL over the course of treatment. It is anticipated that in the future the WHOQOL-BREF was prove useful in health policy research and was make up an important aspect of the routine auditing of health and social services (Orley, 1996).

2.5 Theoretical and Conceptual Framework

Theoretical framework in this study is take from the Theory of caregiver stress by Roy adaptation model. This theory is defined to predict caregiver stress and its outcomes from demographic characteristic, objective burden in caregiving, stressful life event, social support, and social roles. Roy adaptation model (RAM) was developed in 1970. The original RAM was developed by Sister Callista Roy in 1970, which incorporated with concept such as adaptation, stimuli, adaptation level and coping mechanism. In 1984, model incorporated in four adaptive modes of the theory of caregiver stress. In this theory, there are four assumptions, which are:

1. Caregiver can respond to environment change.
2. Caregiver' perception decides how caregiver respond to environmental stimuli.
Thus, the intactness of perception influences caregiver' adaptation.
3. Caregiver' adaptation is a function of environment stimuli and the adaptation level.
4. Caregiver' effectors, for example, physical function, self-esteem / mastery, role enjoyment, marital satisfaction – are result of chronic caregiving.

Assumption one and two are assertions made in the RAM. Assumptions three and four reflect the assumptions in the RAM (Tsai, 2003).

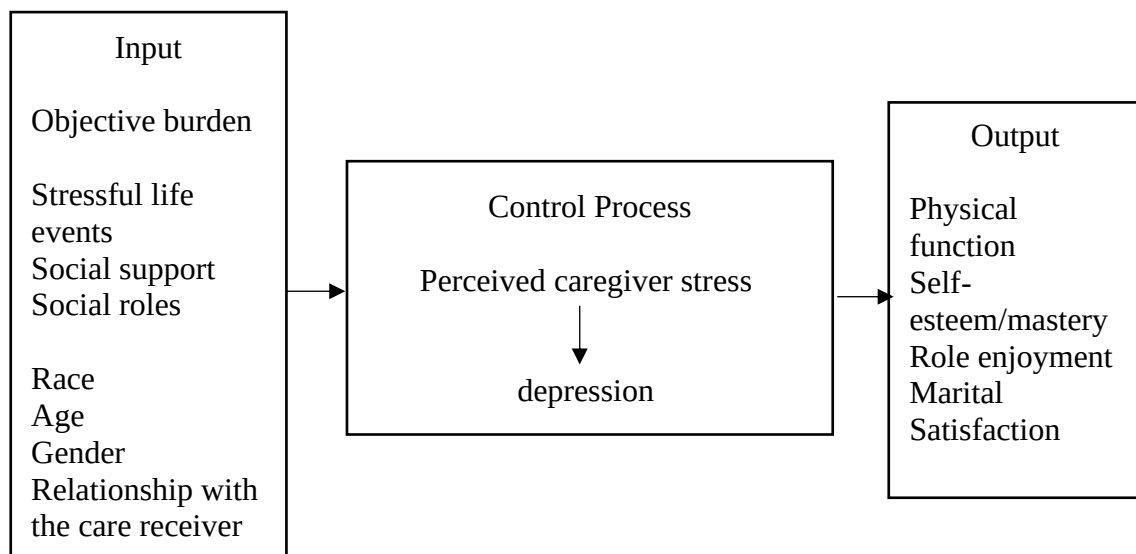


Figure 2.1 Theoretical framework: Theory of Caregiver Stress (Adopted from Tsai, 2003)

The concept of this theory can be related in this study. Theory of Caregiver Stress can be used to determine the association between the selected sociodemographic data and the level of QOL among caregivers. The box of input represented of sociodemographic data (level of education, financial income, age of patient with ESRD, and the length of patients with ESRD receiving haemodialysis treatment). Then, from the input, it will influence the box of output which was represented the level of QOL based on four domains (physical, psychological, social and environment domain) by going through control process. This shown in Figure 2.2.

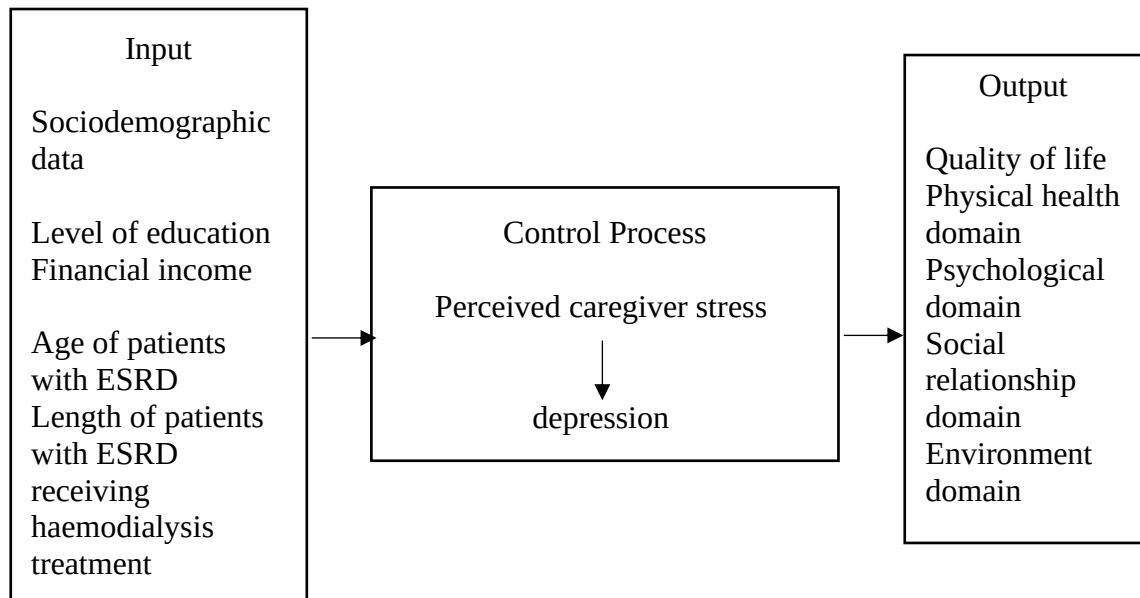


Figure 2.2 Conceptual framework: Theory of Caregiver Stress of the study

CHAPTER 3

RESEARCH METHODOLOGY

3.1 Introduction

This chapter describes the methodology of the research. It includes the research design, population setting, sampling plan, instrumentation, and variable. It also includes ethical consideration, data collection and flow chart, data analysis, and expected outcomes.

3.2 Research Design

This was a cross-sectional study design. In cross-sectional study, data are collected on the whole study population at a single point in time to examine variables of interest (Polit & Beck, 2013).

This study was conducted among caregivers of patients with ESRD that admitted to medical and surgical ward undergo routine HD in HUSM (7 Selatan, 7 Utara, 3 Utara, 2 Intan, and 1 Selatan).

3.3 Population and Setting

This study was conducted among caregivers of patients with ESRD that admitted to the medical and surgical ward in HUSM (7 Selatan, 7 Utara, 3 Utara, 2 Intan, and 1 Selatan). The rationale for selected medical and surgical wards was to expand the study area for data collection.

3.4 Sampling Plan

3.4.1 Inclusion and Exclusion Criteria

The sample of this study was among caregivers of patients with ESRD who fulfilled the inclusion criteria as follows:

Inclusion criteria:

1. Caregiver of patient with ESRD receiving HD treatment who are admitted to the medical and surgical ward in HUSM.
2. Caregiver of patient with ESRD undergoing HD treatment for more than 6 months.
3. Caregiver was the family member to patient with ESRD for at least 2 months of caregiving.
4. Age of caregiver more than 18 years old.
5. Contact/care hours of caregiver with patient more than 10 hours per week (Yakubu & Schutte, 2018).
6. Caregiver who understands Bahasa Malaysia.

Exclusion criteria:

1. Professional service as caregiver such as maid, helper, or home care nursing.
2. Caregiver who are refused to participate in this study.

3.4.2 Sample Size Estimation

Sample size for this study was determined firstly by calculating sample size based on each research objectives. Following that, the exact sample size was finalized by considering the one with the largest number.

Sample size for the first objective was estimated by using an online sample size calculation. Using the proportion sample size calculation, a web tool available at <http://www.sample-size.net/sample-size-proportions/> with $\alpha = 0.050$, $\beta = 0.2$, and key parameter shows in the table below:

Table 3.1: Sample size calculation for selected sociodemographic factors

Variable	Key parameter (%)		n	n + 10% dropout
	Q_1 = Proportion of subjects that are in Group 1 (exposed)	P_0 = Risk in Group 0 (baseline risk)		
Level of QOL	76	24	77	85

Total sample size is 77. Concerning 10% dropout, the total sample size is 85. The key parameter for level of quality of life is taken from previous study (Jafari et al., 2018).

α (two-tailed) =	0.050	Threshold probability for rejecting the null hypothesis. Type I error rate.
β =	0.200	Probability of failing to reject the null hypothesis under the alternative hypothesis. Type II error rate.
q_1 =	0.760	Proportion of subjects that are in Group 1 (exposed)
q_0 =	0.240	Proportion of subjects that are in Group 0 (unexposed); $1 - q_1$
P_0 =	0.2400	Risk in Group 0 (baseline risk)

The standard normal deviate for $\alpha = Z_\alpha = 1.960$

The standard normal deviate for $\beta = Z_\beta = 0.842$

Pooled proportion = $P = (q_1 * P_1) + (q_0 * P_0) = 0.514$

$A = Z_\alpha \sqrt{P(1-P)(1/q_1 + 1/q_0)} = 2.294$

$B = Z_\beta \sqrt{P_1(1-P_1)(1/q_1) + P_0(1-P_0)(1/q_0)} = 0.873$

$C = (P_1 - P_0)^2 = 0.130$

Total group size = $N = (A+B)^2/C = 77$

Figure 3.1 Proportion sample size calculation using online sample size calculation

For second objective, sample size was estimated by Raosoft sample size calculation software. According to the department of medical record in HUSM, in January until September 2019 there were 668 patients with ESRD admitted in the medical and surgical ward. This software used to ensure the accuracy by avoiding the sampling error. The parameter of the sample with the margin error can accept was 0.05 and confidence level 95%. The sample size recommended were 245. After adding 10% of dropout rate, the sample size was 270 in 9 months.

The totals of calculated sample size were:

$$= 245 + 10\%$$

$$= 245 + 24.7$$

$$= 269.5$$

$$\approx 270 \text{ caregivers per 9 months}$$

Caregiver for 3 months:

$$= 270 \div 9 \times 3$$

$$= 90$$

$$= 90 \text{ Caregiver}$$

After calculated sample size for 3 months, therefore the total size for this study was 90 respondents.

Raosoft Sample size calculator

What margin of error can you accept? %
5% is a common choice

What confidence level do you need? %
Typical choices are 90%, 95%, or 99%

What is the population size?
If you don't know, use 20000

What is the response distribution? %
Leave this as 50%

Your recommended sample size is **245**

The margin of error is the amount of error that you can tolerate. If 90% of respondents answer yes, while 10% answer no, you may be able to tolerate a larger amount of error than if the respondents are split 50-50 or 45-55. Lower margin of error requires a larger sample size.

The confidence level is the amount of uncertainty you can tolerate. Suppose that you have 20 yes-no questions in your survey. With a confidence level of 95%, you would expect that for one of the questions (1 in 20), the percentage of people who answer yes would be more than the margin of error away from the true answer. The true answer is the percentage you would get if you exhaustively interviewed everyone. Higher confidence level requires a larger sample size.

How many people are there to choose your random sample from? The sample size doesn't change much for populations larger than 20,000.

For each question, what do you expect the results will be? If the sample is skewed highly one way or the other, the population probably is, too. If you don't know, use 50%, which gives the largest sample size. See below under **More information** if this is confusing.

This is the minimum recommended size of your survey. If you create a sample of this many people and get responses from everyone, you're more likely to get a correct answer than you would from a large sample where only a small percentage of the sample responds to your survey.

Online surveys with Vovici have completion rates of 66%!

Alternate scenarios

With a sample size of	100	200	300	With a confidence level of	90	95	99
Your margin of error would be	9.04%	5.80%	4.20%	Your sample size would need to be	193	245	334

Figure 3.2 Raosoft calculation

From the two objectives, the largest sample size was found in the second objective.

Therefore, the total sample size for this study was 90 respondents among caregivers.

3.4.3 Sampling Method

Respondents of this study were selected through purposive sampling. The procedures for this sampling method, the respondent who was fulfilled the inclusion criteria will be invited to be a participant. Then, informed consent was given to the respondents.

3.5 Instrumentation

The instrument in this study was used a set of self-administered questionnaires. Only Malay Version of the questionnaire will be given to respondents.

3.5.1 Instrument

The instrument in this study was used a set of self-administered questionnaires by WHOQOL-BREF Malay Version in 2003 to determine the level of QOL among caregivers of patients with ESRD in HUSM. The WHOQOL-BREF has 26 items based on four domains: physical health (7 question), psychological domain (6 questions), social relationship health domain (3 question) and environment health (8 questions) and the first two questions was general question for QOL and not specific to any area. The questionnaire consists of 3 main sessions: Part A, Part B, and Part C.

Part A: Demographic data of caregivers

This section contains 12 questions: age, gender, marital status, level of education, employment status, financial income, relationship status, care hours per week, duration of caregiving and have health problem.

Part B: Demographic data of patients with ESRD

This section contains 8 question: age, gender, length of patient with ESRD receiving HD and other chronic disease (Yes/No) and care ability (patient's overall ability to perform daily tasks such as bathing and doing homework, the caregiver will ask a question, and they need to choose one of the option of low, medium or high.

Part C: QOL Assessment

In this section, respondent needed to answer 26 questions to determine the level of QOL. This section originally from WHOQOL-BREF question that have been translated in Malay Version that make easy to respondent answer the question. Consist of 26 items with included 4 domains of physical health domain, psychological domain, social relationship domain and environment domain.

Table 3.2: WHOQOL-BREF Domains

Domain	Question	Facets incorporated within domain
Overall question	Q1 Q2	General question of QOL
Physical health	Q3 Q4 Q10 Q15 Q16 Q17 Q18	Activities of daily living Dependence on medical substance and medical aids Energy and fatigue Mobility Pain and discomfort Sleep and rest Work capacity
Psychological	Q5 Q6 Q7 Q11 Q19 Q26	Bodily image and appearance Negative feelings Positive feelings Self-esteem Spirituality/ religion/ personal beliefs Thinking, learning, memory, and concentration
Social relationships	Q20 Q21 Q22	Personal relationships Social support Sexual activity
Environment	Q8 Q9 Q12 Q13 Q14 Q23 Q24 Q25	Financial resources Freedom, physical safety, and security Health and social care: accessibility and quality Home environment Opportunities for acquiring new information and skills Participation in and opportunities for recreation/ leisure activities Physical environment (pollution/ noise/ traffic/ climate) Transport

[Source: World Health Organization Quality of Life-BREF (WHOQOL-BREF) (1996)]

3.5.2 Translation of Instrument

The questionnaire WHOQOL-BREF was been translated to Malay language by the author, Professor Dr Hasanah Che Ismail (Hasanah et al., 2003).

3.5.3 Validity and Reliability

Hasanah, Naing, & Rahman, (2003) had been validated and tested as reliable to produce a stable and consistent result. The Cronbach alpha values which reflect the internal consistency of the 4 domains in the WHQOL-BREF (Malay), ranged from 0.64 in the domain 2 (psychological domain) to 0.80 in domain 1 (physical domain). Cronbach alpha values for domain three should be read with caution as they were based on three scores rather than the minimum of four as recommended for assessing internal reliability in general Cronbach alpha for question 3 to 26 (24 items) is 0.89.

3.6 Variable

Table 3.3: Study variable

Independent Variable	Sociodemographic data (level of education, financial income, age of patients with ESRD and length of patients with ESRD receiving HD)
Dependent variable	Level of QOL among caregivers

3.6.1 Variable Measuring

The measurement of data collection was on selected demographic data. The QOL among caregiver was assessed by using WHOQOL-BREF mean scores.

3.6.2 Variable Scoring

This questionnaire was based on the 5-point Likert scale, including very bad (1) to very good (5), very dissatisfied (1) to very satisfied (5), not at all (1) to very possible (5), and never (1) to always (5). All item in questionnaire was RECODE in (1=1), (2=2), (3=3), (4=4), and (5=5) except 3 question (Q3, Q4, Q26) was RECODE in reverse range such as (1=5), (2=4), (3=3), (4=2), (5=1). These items were transforms negatively framed to positively framed question. The range of score is between 26 and 130. A higher mean score indicates a better QOL (Prithpal et al., 2011).

3.7 Ethical Consideration

Ethical approval to conduct this study was obtained from the Human Research Ethical Committee (HREC), Universiti Sains Malaysia, USM. Permission to conduct the study was obtained from the Director Hospital USM. Permission to use the original questionnaire was sought from the author (Hasanah et al., 2003).

3.7.1 Confidentiality

Upon the data collection, respondents were informed that consent forms as well as the data collected from the questionnaire administration will be kept in private and confidential manner, and only be used for academic and research purpose. The data will be access and analyzed only by the researcher. Only anonymous data will be presented. Possible individual identifier data will be removed.

3.7.2 Vulnerability of the Subject

The study has minimal risk towards participants and patient with ESRD. The participants may obtain low score indicate low QOL however, the result will not be disclosed as individual to patient or respondent. If respondents feel disturbed while

answering question, they can withdraw from this study without any penalty. If respondents look stress or depressed with caregiver burden, they will be advice to see and talk to counsellor in seeking help and support.

3.7.3 Community Sensitive and Benefit

This study was less sensitive issues as it is about QOL however it might generate uncomfortable situations during answering the questionnaire. Result of each respondents will not be shared with others or patient itself. Researcher was highlighted the important of the study as it is not to condemn respondents with low QOL but to help them improving the level of QOL by giving some education about the ESRD. It is to increase caregiver's knowledge and at the same time, caregiver can manage all their stress and burden in a good way.

3.7.4 Conflict of Interest

A conflict of interest is a situation in which an individual has competing interests or loyalties because of their duties to more than one person or organization. A person with a conflict of interest cannot do justice to the actual or potentially conflicting interests of both parties (Jean, 2019). In this study, there was no conflict of interest.

3.7.5 Honorarium

This is totally a voluntary study. Participants was not be given honorarium and incentive however, brief pamphlet regarding ESRD and important of caregivers for ESRD and method to prevent stress among caregivers was been provided.