

**FACTORS RELATED TO QUALITY OF LIFE AMONG THE
CAREGIVERS OF END STAGE RENAL DISEASE (ESRD)
PATIENTS UNDERGOING HEMODIALYSIS IN YANGON,
MYANMAR**



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ปัจจัยที่เกี่ยวข้องกับคุณภาพชีวิตในผู้บริบาลผู้ป่วยไตวายระยะท้ายที่รับ
การบำบัดรักษาโดยการฟอกเลือดด้วยเครื่องไตเทียม ณ เมืองย่างกุ้ง
ประเทศเมียนมา



วิทยานิพนธ์นี้เป็นส่วนหนึ่งของการศึกษาตามหลักสูตรปริญญาสาธาร
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ปัจจัยที่เกี่ยวข้องกับคุณภาพชีวิตในผู้บริบาลผู้ป่วยไตวายระยะท้ายที่รับการบำบัดรักษาโดยการฟอกเลือดด้วยเครื่องไตเทียม ณ เมืองย่างกุ้ง ประเทศเมียนมา. (FACTORS RELATED TO QUALITY OF LIFE AMONG THE CAREGIVERS OF END STAGE RENAL DISEASE (ESRD) PATIENTS UNDERGOING HEMODIALYSIS IN YANGON, MYANMAR) อ.ที่ปรึกษาหลัก : เนาวรัตน์ กาญจนาคาร, อ.ที่ปรึกษาร่วม : นุชนาฎ ทวนนาถกลาง

บทคัดย่อ

การดูแลผู้ป่วยโรคเรื้อรังเป็นงานที่ยากลำบาก โรคไตระยะท้ายเป็นหนึ่งในโรคเรื้อรังที่ทำให้ผู้ป่วยได้รับความทุกข์จากการฟอกเลือดด้วยเครื่องไตเทียมตลอดชีวิต ผู้บริบาลผู้ป่วยที่ฟอกเลือดด้วยเครื่องไตเทียมจะต้องเผชิญกับความกดดันอย่างมากในการดูแลผู้ป่วยซึ่งส่งผลกระทบต่อสุขภาพจิตที่ลดลงของผู้บริบาลผู้ป่วยอาจเป็นผลจากแรงกดดันและภาระในการดูแลผู้ป่วย งานวิจัยนี้มีวัตถุประสงค์เพื่อศึกษาคุณลักษณะของผู้ป่วยและผู้ดูแลผู้ป่วยไตวายระยะท้ายที่ฟอกเลือดด้วยเครื่องไตเทียม ภาระในการดูแลผู้ป่วยของผู้บริบาล และเพื่อศึกษาปัจจัยที่ทำนายคุณภาพชีวิตของผู้บริบาล

การวิจัยนี้เป็นการศึกษาแบบภาคตัดขวาง ซึ่งดำเนินการในศูนย์ฟอกเลือดด้วยเครื่องไตเทียม 3 ศูนย์ ใน เมือง ย่าง กุ้ง ประเทศ เมียนมา ใน ระหว่าง เดือน พฤษภาคม 2562 เก็บข้อมูลจากผู้บริบาลผู้ป่วยไตวายระยะท้าย จำนวน 199 คน โดยใช้เทคนิคการสุ่มตัวอย่างแบบเฉพาะเจาะจง ใช้แบบสอบถามในการวัดภาระและคุณภาพชีวิตฉบับย่อที่แปลเป็นภาษาพม่า เพื่อวิเคราะห์ข้อมูลทางด้านประชากร (อายุ เพศ การศึกษา อาชีพ รายได้ สถานภาพสมรส ความสัมพันธ์กับผู้ป่วย การทำงานบ้าน การมีบุตร) คุณลักษณะของผู้ป่วย (อายุ เพศ อาชีพ โรคที่ปรากฏร่วม) และโมเดลการทำนายคุณภาพชีวิตของผู้บริบาลผู้ป่วยไตวายระยะท้าย

การวิเคราะห์ข้อมูลใช้การวิเคราะห์การถดถอยเชิงชั้น โดยให้ภาระในการดูแลผู้ป่วยเป็นตัวแปรลำดับแรก และอายุและรายได้ต่อเดือนของผู้บริบาลเป็นตัวแปรลำดับที่สอง ผลการวิเคราะห์พบว่าภาระของผู้บริบาล อายุ และรายได้ต่อเดือนของผู้บริบาล มีผลต่อคุณภาพชีวิตอย่างมีนัยสำคัญ (p value < 0.001, 0.002 และ 0.001 ตามลำดับ) โดยภาระของผู้บริบาล และอายุมีผลต่อคุณภาพชีวิตทางลบ ในขณะที่รายได้ต่อเดือนมีผลต่อคุณภาพชีวิตทางบวก โมเดลของการทำนายคุณภาพชีวิตของผู้บริบาลเท่ากับ $คุณภาพชีวิต = \beta_0 + \beta_1 (ภาระ) + \beta_2 (อายุของผู้บริบาล) + \beta_3 (รายได้ต่อเดือนของผู้บริบาล)$ โดย β_0 β_1 β_2 และ β_3 มีค่าเท่ากับ 97.333 -0.395 -0.149 และ 0.010 ตามลำดับ

ในการบริบาลผู้ป่วยไตวายระยะท้ายเป็นการให้การดูแลผู้ป่วยที่เผชิญกับความทุกข์เนื่องจากภาวะของโรคและการรักษาด้วยการฟอกเลือดด้วยเครื่องไตเทียมที่ต้องดำเนินอย่างต่อเนื่องตลอดชีวิต ซึ่งมีผลกระทบต่อคุณภาพชีวิตของผู้บริบาล ดังนั้นบุคลากรทางด้านสาธารณสุขและภาครัฐควรให้ความสำคัญกับตัวที่ใช้ทำนายในผลการศึกษานี้ เพื่อใช้ในการพัฒนาคุณภาพชีวิตผู้บริบาลผู้ป่วย ศึกษาวิจัยทางเพื่อต่อยอดในจัดทำโครงการในการพัฒนาคุณภาพชีวิตผู้บริบาลในอนาคต

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Abstract

Background: Caring for the patients with chronic diseases are not an easy task. End stage renal disease is one of the chronic diseases and the patients suffering from these disease needs lifelong hemodialysis treatment. Caregivers of hemodialysis patients encounter lots of pressures in taking care of their loved ones with chronic conditions. It could negatively affect all aspects of their health including their quality of life. Diminish quality of life could increase their pressures or burdens and interfere with the proper patient care. Thus, the present study was designed to examine the characteristics of caregivers and patients undergoing hemodialysis, the caregivers' burden and determine the factors which predict the quality of life of these caregivers.

Method: A cross-sectional study conducted in three units of hemodialysis centers in Yangon, Myanmar during May 2019 involving 199 caregivers of End-stage Renal Disease Patients using the self-administered questionnaire for demographic assessment (age, gender, education, occupation, income, marital status, relationship with the patient, extra household works, having children or not), caregiving activities (duration of caregiving, incentive from the patient, caring hours per day) and patients' characters (age, sex, occupation, comorbid conditions). Purposive sampling was used for data collection and Zarit burden interview and WHO QoL BREF in Myanmar version were used to evaluate caregiver's burden and their QOL. Hierarchical linear regression was used to find out the predictors of caregiver's quality of life.

Results: The variables which are significant in hierarchical linear regression were caregiver's level of burden (p value < 0.001), caregiver's age (p value = 0.002) and caregiver's monthly family income (p value < 0.001). Caregiver's burden and caregiver's age were negatively affected the quality of life whereas monthly family income is positively affected quality of life. So, the best model to predict caregiver's quality of life was [Quality of life = β_0 + β_1 (level of burden) + β_2 (caregiver's age) + β_3 (caregiver's monthly family income)] where β_0 , β_1 , β_2 and β_3 were 97.333, (-0.395), (-0.149) and 0.010 respectively.

Conclusion: Health professionals and governments should consider the predictors revealed in the findings in dealing with the caregivers and do more research on other different types of caregivers to develop strategies and programs for improving the caregiver's quality of life.

Field of Study: Public Health
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Student's Signature
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List of Abbreviations

CKD	Chronic Kidney Disease
ESRD	End Stage Renal Disease
GFR	Glomerular Filtration Rate
HD	Hemodialysis
ICD	International Classification of Disease
MeSH	Medical Subject Headings
NCD	Non-Communicable Disease
QOL	Quality Of Life
RRT	Renal Replacement Therapy
WHO	World Health Organization
ZBI	Zarit Burden Interview

Chapter I

Introduction

1.1 Background and Rationale

Chronic diseases tend to be persistent over a long period and need prolonged treatment, regular checkup, aids and retention to maximize the activity of individual. They are results of combination of genetics, physiological, environmental and behaviors effects. They are progressively rising and stated to be the main cause of death around the world. 41 million people died each year because of chronic disease, equivalent to 71% of all deaths globally. People in low and middle-income countries have been disproportionately affected with chronic diseases accounting 32 million which is more than three quarters of global death from chronic diseases. (WHO, NCDs, 2018).

The growing of chronic disease cases has contributed to the rapid rise of informal caregivers. Because patients with chronic diseases have limitation in their functional abilities, they need informal caregivers to fulfill their personal, domestic and health needs. Informal caregiver may be a member of a family or a friend or a neighbor who do not get pay. These caregivers are important for numerous reasons. They offer huge amount of assistance, vital for the quality of life of dependent person. Government or other care services do not able or afford to provide the equal care provided by the caregivers. The task of caregiving has a great impact on the caregivers themselves. There can be adverse effects on their physical and mental health and also on their social life (1).

Caregivers play an important role in assisting patients with chronic diseases since most of them are not able to look after themselves and they have a weak physical performance and cognitive impairment. Caregivers are usually being ignored and often get little support or recognition of their work although they are essential to produce better outcomes in patients. Caregivers are not limited by culture or country, they are universal; sharing common traits and facing common challenges(2).

There are many factors that can adversely affect the quality of life of caregivers. Socio-demographic factors such as age and gender of caregivers also influence on the caregiver's quality of life. When the income level of caregiver is low, he or she may feel more distress and in addition, if those caregivers have other physical diseases, it can impact on them and have lower quality of life. Moreover, if they spend more hours (for more than 8 hours) in a day can worsen their quality of life as well. Social support also plays a big role in determining the quality of life of caregivers. Another factor that can contribute in predicting the quality of life of caregivers is the burden they experienced. If they suffer from higher burden, their quality of life can get lower as well (3) (4). Studies showed that high burden of caregivers also relates not only to lower quality of life but also to more depression (5, 6).

Caregiver's burden includes all the problems related with physical, mental, emotional, social and financial. These negative outcomes are associated with several key variables. These variables contain caregivers and care recipients' socioeconomic status, demographic factors, care recipients' type of illnesses, time duration spending in taking care of patients, caregivers' health condition and social support system (7). They face financial problems due to decrease of the working hours and they have to leave their job to provide care. These can give rise to negatives impacts on the health and occupation as well as financial security of the caregivers (8). It is found out that the caregiver burden is comparatively less in developed countries such as United states, United Kingdom and Australia because formal and paid caregivers are easily available in these countries (2). These burden are conventionally high in resource limited countries (9).

Caregiver burden contributes to changing the style of daily living, which can lead to depression, anxiety, diminishing physical health, social isolation and tension on economic. In caregivers with greater burden who had lower quality of life, mental health is more affected than other aspects. Compared with non-caregivers, caregivers have greater prone to experience psychological disorder than physical disorder and can be more associated with chronic diseases, particularly depression and reported to do more visits to doctors and more frequent use of medications (10, 11)

Caregivers face burden in many areas. They lose hope and they felt that they don't have freedom for their life, they mostly face difficulty in managing themselves and their time. Sometimes they could also feel embarrassment, anger and fear. They have a problem in their personal and social relationships. They felt that they have to depend on other family members and friends and they do not have ability or skills to do other job so that they lose their confidence as well. These all can affect their physical, social, psychological and environmental quality of life (12).

Due to a decline in caregiver's health related quality of life, they may not be able to continue in the caregiving role. Supporting and encouraging the caregivers are needed to qualify them so that they can provide the best care and to avert the significant stress that can be linked with caregiving, and to be able to persistently take a caregiving role over a long period of time, often many years (1). Therefore, it is essential to document their experiences, identify risks for negative outcomes and develop strategies to assist this hidden population of caregivers.

Chronic kidney disease is one of the chronic illnesses that contribute to the increasing need of informal caregivers. People worldwide regardless of their economic status or race can be affected by Chronic Kidney Disease (CKD). Hypertension and diabetes are the two common causes of CKD but it may also be caused by other disorders as well. Chronic kidney disease is a huge public health issue and may eventually lead to end stage renal disease (ESRD) which is called kidney failure which needed regular dialysis treatment or kidney transplant for survive (National Kidney Foundation)(13). According to the study of global burden of disease in 2015, among most common cause of death, kidney disease ranked 12th and causing 1.1 million death globally. Over the last 10 years, death due to CKD has risen by 31.7% , making it one of the surging main cause of death (14). Kidney disease is associated with incredible burden of economic. 2-3% of annual health care budget were spent by high income countries for treating end stage kidney disease. In 2010, 2.62 million people around the world received dialysis and by 2030, the demand for dialysis was forecasted to be double (15).

Hemodialysis extend the life span of individuals with ESRD. But because of the persistent nature of the disease and the need of lifelong hemodialysis, it causes physical,

financial, emotional and psychosocial problems in both patients and their caregivers. Patients undergoing hemodialysis rely on their unpaid family caregivers not only to assist in their daily activities but also to fulfil their medical needs (16).

Problems in diagnosis and management of Chronic Kidney Disease (CKD) in a developing country like Myanmar are numerous. It is difficult to assess the true magnitude of the problems, as there is no proper registration for CKD cases in Myanmar and health information system in Myanmar is also very weak. The estimated cases of End Stage Renal Disease (ESRD) in Myanmar is about 200/million population (17). It is 11th leading cause of death in Myanmar. According to the latest WHO data published in 2017, 2.77% of total deaths in Myanmar is due to kidney disease. The age adjusted Death Rate is 26.20 per 100,000 of population ranks Myanmar #37 in the world (Kidney disease in Myanmar) (18).

Researches about caregivers of chronic disease patients were done across the world including some countries in Asia, but there are only a few limited researches for Myanmar. There is only an article about a cross sectional descriptive study of the caregivers of stroke patients that can be assessed online. This study was done in 2011 and it studied about the level and nature of burden experienced by stroke patients and characteristics that influence the burden of caregivers. So, there is a notable gap in the study of caregivers of chronic disease patients including caregivers of end stage renal disease patients undergoing hemodialysis. Although, caregivers of patients with chronic illnesses share similar outcomes related with burden, the results cannot be applied in generally to caregivers of ESRD patients. There can be certain factors associated with specific illness that can rise burden differently among the caregivers. Moreover, as the economic and social status of each country is different, the burden experienced by the caregivers and their quality of life may also different. For this reason, this study is designed to determine the level of care burden and factors related to quality of life among caregivers of ESRD patients undergoing dialysis and will be carried out in Yangon as it is the place where most of the hemodialysis centers exist and where most people seeking health.

1.2 Research Questions

- (i) What are the characteristics of caregivers of patients with end stage renal disease (ESRD) undergoing hemodialysis?
- (ii) What are the characteristics of patients with end stage renal disease undergoing hemodialysis?
- (iii) What is the level of burden of caregivers of patients with end stage renal disease (ESRD) undergoing hemodialysis?
- (iv) What is the quality of life among caregivers of patients with end stage renal disease (ESRD) patients undergoing hemodialysis?
- (v) What are the factors related to quality of life among the caregivers of patients with end stage renal disease (ESRD) patients undergoing hemodialysis?

1.3 Research Hypothesis

- (1) Null Hypothesis – There is no relationship between characteristics of end stage renal disease (ESRD) patients undergoing hemodialysis and quality of life of caregivers
Alternative Hypothesis – There is a relationship between characteristics of end stage renal disease (ESRD) patients undergoing hemodialysis and quality of life of caregivers
- (2) Null Hypothesis - There is no relationship between characteristics of caregivers and their quality of life.
Alternative Hypothesis – There is a relationship between characteristics of caregivers and their quality of life.
- (3) Null Hypothesis - There is no relationship between caregiver’s burden and caregiver’s quality of life.
Alternative Hypothesis – There is a relationship between caregiver’s burden and caregiver’s quality of life.

1.4 Research Objectives

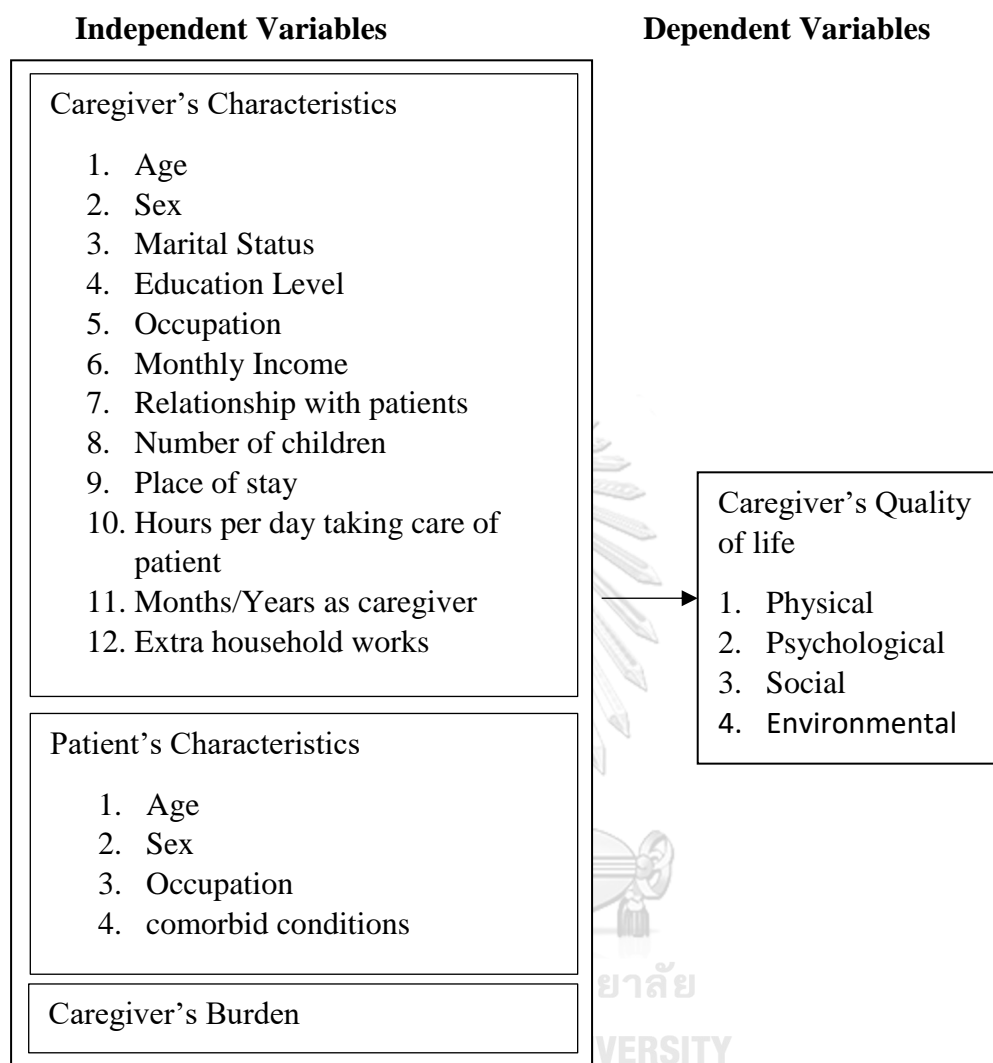
1.4.1 General Objectives

To determine factors related to quality of life among caregivers of end stage renal disease (ESRD) patients undergoing hemodialysis in Yangon.

1.4.2 Specific Objectives

- (i) To determine the characteristics of caregivers of end stage renal disease (ESRD) patients undergoing hemodialysis.
- (ii) To describe the characteristics of patients with end stage renal disease (ESRD) undergoing hemodialysis
- (iii) To describe the level of burden experienced by caregivers of end stage renal disease (ESRD) patients undergoing hemodialysis
- (iv) To identify the quality of life among caregivers of end stage renal disease (ESRD) patients undergoing hemodialysis
- (v) To discover the factors related to quality of life among caregivers of end stage renal disease (ESRD) patients undergoing hemodialysis

1.5 Conceptual Framework



1.6 Operational Definition

Education

Refers to the self-reported highest formal education attainment by respondents and classified into illiterate, primary school (Grade 1 to Grade 4), middle school (Grade 5 to Grade 8), high school (Grade9-10), higher education level (University and above).

Chronic Kidney Disease

Glomerular Filtration rate (GFR) <60 ml/min or presence of kidney damage that is present for more than 3 months. (WHO, ICD 11)

A disorder characterized by gradual and usually permanent loss of kidney function resulting in renal failure. (retrieved from ICD10data.com)

End Stage Renal Disease (ESRD)

Is a stage 5 of chronic kidney disease which is also called kidney failure, the condition when GFR is < 15 ml/min. (WHO, ICD 11).

Dialysis and kidney transplant is needed for a patient with kidney failure to survive because their kidney is not working well enough. (American Kidney fund)

Hemodialysis

Hemodialysis means the process of filtering blood. It is a treatment that eliminates the waste products and the excess fluid in the blood and body tissues as a result of kidney failure. The cleaning of the blood takes place outside the body in an artificial kidney termed a dialyzer. A patient usually require two to three treatment sessions of hemodialysis per week and each session usually lasts between 3 – 5 hours (19)

Comorbid condition

The presence of co-existing or additional diseases with reference to an initial diagnosis. Comorbidity may affect the ability of affected individuals to function and also their survival; it may be used as a prognostic indicator for length of hospital stay, cost factors, and outcome or survival. (MeSH)

In end stage renal disease patients (ESRD), hypertension, diabetes, various cardiovascular diseases and poor nutrition are the most common co-existing diseases that can lead to worsen outcomes in patients.

Caregiver

A person who provides support and assistance with various activities to person with disabilities or long-term conditions, or persons who are elderly. This person may provide emotional or financial support as well as hands on help with different tasks (WHO, 2004).

In this study, a caregiver is defined as a person (family member, friend or neighbor) who is responsible to take care and assist with the daily activities of a relative or loved ones who is diagnosed with ESRD and receiving only hemodialysis treatment. The person must be closely and consistently taking care of patient without being paid. Caregivers should involve everyday with taking care of patients.

Caregiver Burden

The extent to which caregivers perceive that care giving has had an adverse effect on their emotional, social, financial and physical functioning” (20), and will be measured by using Zarit Burden Interview questionnaires.

Quality of life

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 (WHO) and will be measured by using WHOQOL BREF questionnaires.



Chapter II

Literature Review

2.1 Chronic Kidney Disease

2.1.1 Definition and Causes

Chronic kidney disease (chronic kidney insufficiency) is a condition in which a kidney perform below the normal level for more than three months (21). According to ICD 10 (international classification of disease), it is defined when GFR <60 ml/min or presence of kidney damage that is present for more than 3 months (ICD 10: N 18) (22). Kidney diseases can be acute or chronic and therefore chronicity needs to be defined and duration of more than 3 months is used to represent the chronic conditions and to differentiate between acute and chronic (23).

Many communicable and non-communicable diseases can lead to damage of kidney resulted in chronic kidney disease and many other kidney related complications (15) . Although it is regarded to be caused mainly by diabetes and hypertension, there are also many other numerous causes of chronic kidney disease such as cardiovascular diseases, obesity , malnutrition, genetic factors, aging, glomerular related diseases, prolonged urinary tract infection, HIV infection and other environmental and occupational related conditions such as pollution of water, soil and food from heavy metals and chemical compounds including pesticides, fertilizers, dyes contain in food and processed and preserved food (24, 25). The increased population in urban areas also give rise to higher risk of non-communicable diseases including renal disease as this condition is related with high calorie and salty meal intake, decreased physical activity, crowded population with poor housing and pollution, poor sanitation and improper disposal of waste. Those imbalance and inappropriate diets commonly lead to hypertension and diabetes which are the major causes of chronic kidney disease (26).

2.1.2 Classification of chronic kidney disease (International Classification of Disease - 10)

Chronic kidney disease can be classified into 5 stages based on the glomerular filtration rate (GFR). GFR represents the rate of blood passing through the glomeruli (tiny filters in the kidney that filter the wastes from the blood) each minute. GFR is one of the measures used to determine the function of the kidney and it is widely accepted as the best index to measure the function of the kidney (13, 23)

Stage 1 (ICD 10: N18.1)

Damage of the kidney but the glomerular filtration rate is normal or more than 90 ml/min for over 3 months.

Stage 2 (ICD 10: N18.2)

Damage of the kidney with the glomerular filtration rate of 61-89ml/min for over 3 months.

Stage 3a (ICD 10: N18.3)

Glomerular filtration rate of kidney is 45-59 ml/min over 3 months.

Stage 3b (ICD 10: N18:3)

Glomerular filtration rate of kidney is 30-44 ml/min over 3 months.

Stage 4 (ICD 10: N18:4)

Glomerular filtration rate of kidney is 15-29 ml/min over 3 months.

Stage 5 (ICD 10: N18:5)

Glomerular filtration rate of kidney is 15 ml/min over 3 months.

2.1.3 Comorbidities of CKD

Most of the CKD patients have other diseases that can worsen their condition. Nearly 90% of the CKD patients have at least 1 comorbid disease. The common comorbid diseases in CKD patients are diabetes, hypertension, cardiovascular diseases, lung diseases, malnutrition and anemia. As the CKD stage progress, the prevalence of these diseases also increased. Early detection and treatment of these diseases are very important. It is very challenging for patients who have comorbid disease. Good patient's compliance and proper treatment for these diseases are needed as if they are not treated well, it can progress to kidney failure and dialysis and also associated with many other complications and high mortality rate. Caregivers may also take more responsibilities with these conditions as they need to make balanced diets and manage the intake of multiple drugs for the patients (27). A study in Taiwan also reported that hypertension is the most occurred comorbid disease with prevalence of 90% and it also revealed that patients with CKD stage 3-5 who have comorbid diseases more than 3 were associated with a rapid decline in renal function and decrease survival rate (28).

2.1.4 End Stage Renal Disease (ESRD) and treatment

According to ICD 10, Chronic kidney disease can be classified into 5 stages and the last stage is also known as end stage renal disease (ESRD) when patients need renal transplant or renal replacement therapy such as hemodialysis and peritoneal dialysis. The costs of treatments are relatively high and among 2.62 million people worldwide receiving renal replacement therapy, approximately 90% of them are from high income countries. The cost of renal transplant is much higher than hemodialysis, so patients in low and lower middle countries usually choose to do hemodialysis. Moreover, as there are social inequities in these countries, people from low socio-economic status demand more money and therefore the trafficking of kidney and other organs are a major concern in these countries. But overall, because there is limited health care access, poor awareness, late diagnosis of CKD, inequitable treatment access, no health insurance and need lifelong treatment, majority of CKD patients in low- and middle-income countries are not able to get treatment and lead to earlier death (25, 26).

2.1.5 Prevalence of CKD and ESRD

Chronic kidney disease is included in one of the neglected chronic diseases. The prevalence of CKD around the world is estimated to be 8-16% and it is about 500 million people worldwide and nearly 80% of them are from low- and middle-income countries. So, compared with the high income countries, low and middle income countries have much higher prevalence of CKD with (25). CKD prevalence by stage are Stage-1 - 3.5%, Stage-2 - 3.9%, Stage-3 - 7.6%, Stage-4 - 0.4% and Stage-5 - 0.1%. The low and lower middle-income countries in Asia, Africa, Latin America and Middle east have a higher prevalence of CKD than higher income countries. Among Asia countries, Thailand and China have 18-20% of prevalence rate and India, Pakistan, Nepal and Bangladesh have more than 20% of prevalence rates. The prevalence in Africa, Latin America countries is 15-20% and those middle east countries account for 20-25% (29). Incidence and prevalence of chronic kidney disease across the world vary according to various social determinants of health and different ethnicity. In high income countries, the Asian, Hispanic, Black and Indigenous people have higher risks than other ethnicities. Moreover, people in low socio-economic status have 60% increased risk of CKD than those in high socio-economic status (30). Due to behavioral and metabolic risk factors and also reduced access to health care, lower socio-economic people in high income countries have a higher risk of CKD. The burden of CKD caused by poverty in low- and middle-income countries much larger because of associated infections, dangerous work situation, low education level and poor socio-economic conditions (15).

The countries with highest occurrence of ESRD in the world are included in Asia continent. The number of ESRD patients in Asia requiring dialysis is growing at a rate higher than elsewhere in the world. In many Asian countries the growth of ESRD patients is in excess of 10% annually. This rate is likely to speed up further because the number of people with diabetes and hypertension are growing and aging population is expanding as well.

In Myanmar, there are many different problems to diagnose and manage the chronic kidney disease. It is difficult to assess the true magnitude of the problems, as

there is no proper registry for CKD cases in Myanmar. The estimated cases of End Stage Renal Disease (ESRD) in Myanmar is about 200/million population. Renal replacement therapy (RRT) is possible only for 10-15% of these cases. Health care system in Myanmar is an inclusive public and private system both in financing and provision. Hemodialysis (HD) in Myanmar's government hospital started in 1970 whereas private hospital provided hemodialysis treatment after 1986. There are more than 300 HD machines throughout the country, treating over 1800 patients. According to 2010 government hospital data, 20.1% of the CKD patients in Yangon received hemodialysis and it was recorded that among the patients receiving hemodialysis in Yangon, 80% took place in private hospitals and charity organization and 20% took place in public hospitals because of the limited HD machines in Public hospitals. The cost of HD per session is about 20-40 USD in charity and public hospitals whereas it is more than 50 USD in private hospitals depending on the other facilities and services they provide. Renal transplant therapy successfully began in 1995, and more than 400 cases had been performed up to now. Plans to expand the transplant program are reviewed. The problems of HD include funding (self-payment mostly), availability of resources and quality assurance of centers & staff. As in some of the other Asian countries, there is a shortage of nephrologists, insufficient health education for patients, and a lack of clinical engineers to conduct maintenance checks of equipment. There is currently no national association for kidney disease that could help foster advancements in HD. Other problem issues include lack of options & choices of RRT (HD predominant), and lack of public awareness. Management of these issues are also discussed. However, it is expected that the outlook for the future of CKD in Myanmar will be improved (17).

2.2 Caregiver

2.2.1 Definition

Caregiver is someone who care for their loved ones at care recipient's home or at health institutions. Caregiving include a broad range of tasks, such as supporting the physical and emotional wellbeing of patients. The caregiving time can be long term in the case of caring for patients with chronic diseases and physical disabilities and can be short or occasional time as in acute conditions (31). Caregivers can also be divided into

two types which are informal caregivers and formal caregivers. Informal caregivers are unpaid and assist with activities of daily living (ADLs) or instrumental activities of daily living (IADLs) for the patients whereas formal caregivers who are professionals and get paid for their services (32).

Moreover, caregivers are defined as family caregivers who offer the needs of patients in many aspects such as physical, mental, social and financial without receiving any benefits (9). Savage and Bailey defined caregiver as a relative, friend or neighbor who provides practical, day-to-day unpaid support for a person unable to complete all of the tasks of daily living. The person who receives care is the care recipient, defined as a person who lives with some form of chronic condition that causes difficulties in completing the tasks of daily living (33).

2.2.2 Physical Health of caregivers

Family caregivers faced with different kinds of physical problems. Sleep disturbance, fatigue, pain, deficient in physical strength, loss of appetite and weight are common physical problems (34). With regards to caregivers in US, when assess their lifestyles and behaviors, they tend to smoke and drink alcohol frequently than non-caregivers. Work and activity impairment were also occurred among them. Moreover, compared with non-caregivers, caregiver's utilization of health care resources and drugs prescription are greater and they had significant diagnosed of comorbid diseases. They have problem with insomnia as well because of the shift of work and sleep disorder (35).

The other physical health problem included tiredness, exhaustion, back, neck and should pain, blood pressure, heart and weight related problems, digestion and bowel related issues and also leg and foot illnesses (36). Most of the caregivers also suffered from fatigue and it leads to lack of concentration, reduced motivation, unable to perform usual activities and affected their mood and relationship. Caregivers also declared that they had sleep disturbance as they need to wake up frequently when patients need help at night. The sleep quality scores are higher in caregivers than in patients as well (36-38).

2.2.3 Psychological Health of caregivers

As they have to spend many hours in a day in taking care of patients, they cannot look after themselves and neglect their own health. It leads them to feel anger, abandoned, relationship problems and loss of freedom. They also feel stressful and emotional distress, fear and unsatisfied with their life, uselessness as they have to adjust their times in work or stop their job to take care of patients. Single caregivers also have difficulty in dating and getting married and feel that their physical and social activities are limited (39-41). A study in Australia remarked that caregiving noticeably affected the lives and choices of caregivers such that they could not be able to enjoy their holidays and travels, they do not have time to do their hobbies and socializing and resulted in social isolation and feeling of loneliness, grief and loss (36). An observational study of caregivers in India found out that almost all of them had some degree of anxiety and depression and 50% of participants in his study had severe level of anxiety and 63% had moderate to severe depression (42).

Another cross-sectional study in 2015, analyzed the psychological status of caregivers of hemodialysis group compared with those of renal transplant group and explained that the caregivers of HD group had considerable higher rates of anxiety and depression. Moreover, the insufficient sleep quality and greater care burden score were also occurred in caregivers of HD groups (43). The prolonged nature of disease and demanding care of hemodialysis contributes to worsen the mental health of the caregivers. Caregivers faced difficulties in nursing care especially if they do not get proper training. They mentioned that wound care is challenging for them and they also afraid that they would harm their patients by making mistakes with medication provision (44).

2.2.4 Caregivers of hemodialysis patients and their roles

Patients receiving hemodialysis need to receive regular checkup and appropriate proper and intensive care from health professionals as they can get dialysis related medical complications including cardiovascular, neurological, infections and electrolytes imbalance, etc. They also have a greater risk of getting physical, cognitive and emotional impairment because of their underlying diseases such as diabetes,

hypertension, cardiovascular diseases and other related metabolic diseases (45, 46). But they also have to rely on their family caregivers for their daily activities and medical care and nutrition because those family members are the most suitable source to take care of them (16). Patients with better family support are able to adjust themselves and resist to hemodialysis and follow the dietary plans which is very important especially in diabetes patients. But when patients perceive that they cause burdens to their caregivers, they might stop receiving hemodialysis. Therefore, caregivers are very important to well communicate and effectively support the patients (47).

Caregivers provide physical support of patients in daily activities, households chores such as cleaning home, washing, cooking and preparing appropriate meal for patients, personal care of patients in showering and dressing. They also have to give emotional support as the lifelong nature of illnesses and long-term treatment cause discomfort, impatient, negative thoughts, inability to cope with their sicknesses, loss of satisfaction in life, failure to concentrate, feeling isolated by other people, irritable, stress, anxiety and depression in patients (48, 49). Caregivers also have to do nursing care for the patients especially in diabetes patients, for example wound care and dressing, apply ointment and bandaging for skin care, monitor and check the blood glucose level and blood pressure daily and regularly. In patients with limitation of mobility, caregivers have to help them to get out of bed, help to move on wheel chairs, care for bedsores on bed (44). In addition, caregivers have to make decisions for the patients in appropriate treatment options, accompany and transport patients to hospitals. However, some caregivers have to take responsibility for financial expenses if there are no other family members are working and if they have younger children, it is also the task of that caregivers to take care of those children(45).

2.3 Caregiver's burden

2.3.1 Definition

Caregiver's burden is the negative outcomes suffered by the caregivers as the result of caregiving. These negative outcomes include physical, social, psychological and financial related problems (8). George and Gwyther (1986) defined 'caregiver burden' as strains of physical, psychological, emotional, social and financial experienced by an individual due to providing care (50).

Zarit et al., have defined caregiver burden as: "The extent to which caregivers perceive that care giving has had an adverse effect on their emotional, social, financial and physical functioning" (20). It is a multidimensional response to stressors (e.g., physical, psychological, emotional, social, and financial) resulting from caregiving. Caregivers usually face with physical and psychological troubles with limitation in social relations and activities while they are taking care of chronic and disabled patients. Moreover, they have stress over the financial issues. All of these burdens negatively affect not only on themselves but also on other family members and patients and their societies as well. Different kinds of health problems rises as the burden of care increase (51)

2.3.2 Financial/Economic Burden

Economy issues raise the concern in caregivers due to expenses in different areas in hemodialysis and other treatments and also family expenses. The economic burden is rarely evaluated in developing countries but it is estimated to be higher than in developed countries. Patients in developing countries are not affordable for treatment and so accessibility to treatment remain low compared to developed countries, and less than 7% in South East Asia and 7% in North Africa receive renal replacement therapy. Although the charges for dialysis is relatively low in many Asian countries, compared with the income, it is still unaffordable for them. One session in hemodialysis in developing countries cost 50-100 US \$ and as patients usually have to receive 2-3 times a week, it causes financial burden in patients and caregivers (25, 52).

Caregivers mentioned that they have to sacrifice their saving, investment and benefits as the medical cost and expenses are expensive for ESRD patients undergoing dialysis. The feeling of being exhausted seems to be generalized to relatives from different countries as well as cost associated with mental disorders, however, most diversities regarding QOL appear to be related to having a better access to and higher availability of health and economic resources for these caregivers. In developing countries, economic burden may be playing an important role in relative's QOL. Lack of psychiatrist, day hospitals, access to drug treatments, among others, could develop an ample concern in these relatives (53).

2.4 Quality of life

2.4.1 Definition

World Health Organization defined QOL as 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. It can also be explained as the satisfaction of an individual's values, goals and needs through the actualization of their abilities or lifestyle(54).

The quality of life is a broad scope of idea that contains the assessment of the positive and negative facets of one's life. It is the term also used to measure how much a person is healthy, comfortable, able to partake and satisfy or enjoy in their life events. So, it is generally referred to the wellbeing of an individual and societies. A person may state their quality of life according to their wealth and living standards whereas another one may define it as their level of performance and in relation to their physical and emotional health. When achieve his or her expectations and goals, a person may express he or she has a good quality of life. Hence, quality of life is multidimensional and related to many aspects of our life. A person quality of life is depended not only on their wealth or job or property but also associated with their physical, emotional health and social and environment factors such as education, recreation, neighborhood, supportive societies and freedom, culture, value and spirituality etc that can bring the positive or negative perceptions and consequences in life (55-57).

2.4.2 Components of quality of life

World Health Organization divided Quality of life into 6 domains

1. Physical Domain is the perceived physical condition of the person that affect daily life such as perception in strength of body condition, perception of pain and feeling of comfortable, manage the pain of the body, perception of power in daily life, perception of sleep and rest and perception of sex.
2. Psychological domain is the recognition of own mental state, positive feelings towards individual's image, recognition in the sense of pride, perception of self-confidence, decision making and ability to learn and dealing upon sadness and worry.
3. Level of personal independence perception of ability to move by themselves, ability to perform daily activities, ability to work and perception that individual do not have to rely on other people or any drugs.
4. Social relations include perception of relationship between self and others, awareness on how to get help from others in society, perception of being a help to others and sexual activity.
5. Environment domain contain perception of their freedom, safety and security in their life, their living environment and transportation, financial resources, whether having health services and social work to getting information or practice skill, and perception upon their recreation and leisure activities.
6. Spiritual and religion is about their religious beliefs and confidence against obstacles.

2.4.3 Quality of life among caregivers of patients with end stage renal disease

The quality of life of caregivers should be studied as it can impact on the patient suffering from chronic disease. The quality of life can be adversely affected in a complex way by the person's physical health, psychological state, personal beliefs, social and environmental relationships. Caregivers have to engage most of their time in taking care of the patients, so they have limited time to care for themselves, pay less attention to their needs and neglect their wellbeing which leads to arising of several

health problems. It can also impair their feelings regarding with body image and diminish their self-esteem. Because of the prolonged nature of the disease and demanding care, the caregivers can feel progressive exhaustion and their quality of life can reduce. It is noticed that there is a noticeable decline in general health including physical and mental health, and energy level and social performance of caregivers of ESRD patients undergoing hemodialysis (58). The long-term involvement in taking care of patients, regulating their physical, mental and emotional complications along with managing the family, occupational matters can emerge the problems in physical, mental and social areas of caregivers which can lower their quality of life. If the patients is their partners, these caregivers can have the sexual challenges and dysfunction as well (59).

A cross sectional, observational study (60) of caregivers was carried out, using WHO-QOL BREF and observed that the more morbidities present in caregivers, the lower quality of life he or she had especially in physical and psychological domains. A study done in India (61) comparing the caregivers of patients on dialysis and patients not on dialysis, found out that the quality of life among caregivers of patients who were not on dialysis, were better. By using WHO-QOL BREF scores (0-100), the raw score in all four domains (Physical, Psychological, Social and environment) were lower in caregivers of patients on hemodialysis. A study in US also using SF 36 scoring, also mentioned that caregivers have lower physical component summary and mental component summary compared to non-caregivers and there is a more enormous impact on mental health as caregivers appeared of having depression and anxiety (35). A descriptive study declared that half of the caregivers in the study had low to moderate quality of life and 85% complaint that they did not get enough social support and two third of them felt that there is no time for them to have fun and recreation in their life (62). Another study in Italy of caregivers also reported that caregivers encounter with decreased in the mental health and general health scores than the healthy population (63).

Study of burden and quality of life among 100 caregivers of hemodialysis patients in Brazil (11) pointed out that in health related QOL for caregivers, more disorder was seen in mental health, vitality and physical aspects. There was also a

significant relationship between lower scores of patients and perceived burden of care. Caregivers mental health and vitality had a huge impact on the emotional aspect of QOL. The same researcher did the research in 201 caregivers of elderly and non-elderly patients on hemodialysis and peritoneal dialysis therapy (64) and saw that the scores for caregivers of elderly and non-elderly patients on the dialysis were lower than the average score of QOL for the Brazilian general population. It is corresponded with the previous study in such a way that mental aspects (vitality, social aspects, emotional aspects and mental aspects) were the most affects subjects.

2.5 Related Literatures

2.5.1 Social-Demographic factors of caregivers related to their burden and quality of life

(1) Age

A study in Thailand about the caregivers reported that caregivers with advanced age tend to have lower burden and better quality of life (65). This is similar with the other studies that found out that older caregivers have higher quality of life than younger caregivers (66, 67). But there are some studies against with these findings and presented that younger caregivers have a higher quality of life (4, 63, 68, 69). Another study described that caregivers with more advanced age are more susceptible to negative impact of care and this may be due to less ability to defend illness because of the gradual deterioration of functional characteristics. In assessing the domain “functional capacity” of QOL, the score is higher among the advanced age caregivers (more than 60 years old). Functional capacity is the presence and extension of limitation due to physical capacity (70).

As the caregivers get older, they experience more burden. In a study of caregivers age above 18 years old and found out that the caregivers’ burden is higher in caregivers aged 60 and above followed by those of 39-59 years old (71). Another study also said that the caregivers older than 40 and 60 years old have larger burden compared with younger ones (72). Conversely, there are also other studies which said that younger caregivers suffered higher burden than older caregivers (10). A study said

that it may be due to younger people have less experience in caregiving and they also have committed to their jobs (73). But there are also other studies which showed no association between caregiver's age and their burden(16),(74),(75, 76).

(2) Sex

A study of quality of life of caregivers, conducted in United Kingdom in 2012 revealed that male caregivers had better quality of life than female caregivers (77). Another study also explained that the female caregivers have a reduced mental aspects of quality of life than male caregivers(78). These are similar with other studies which discovered the lower quality of life in female caregivers (63). The author in another study said that women are occurred to be more affected because they usually accumulate various roles throughout life both in society and in caring for the children, spouse and household chores (70).

In a study of 172 caregivers in Cyprus, the results came out that 68 % of caregivers were severely burdened and stated that women caregivers had higher burden than male caregivers and said that in a case of male caregivers, there is another family member and this could lead to less burden. But in the case of women caregivers, because they were traditionally assumed as the one who have to take responsibility in taking care of family members who got sick and they were also believed to fulfill these caregiving tasks without assistance. This study also mentioned that 65% had symptoms of depression and women showed more risk of depression because their career as caregivers was a long duration and they had tensions in this role as caregivers (79).

(3) Marital status

A study reported that single, young family caregivers have more burden with health problems (80). But another study found out that widower had increased burden and followed by single caregivers (81). It was discussed that may be because widower had no one to share their feeling with and feel more stress and burden than married whereas married people have their partners to share their stress and feeling. A study of caregivers in India found out that marital status is considerable associated with every aspects of quality of life. It discovered that married people had decreased QOL in physical and psychological aspects, widower also had more reduced scores in

psychological domain, single and separated had lower scores in social domain and any kind of marital status revealed strong positive association with environmental aspects of QOL (82). In addition the other two studies also proved that married caregivers have more risks to get depression (83, 84).

(4) Education Level

Caregivers with higher education level have higher quality of life than those with lower education level. A study concluded that caregivers with middle education level or above have a better quality of life (78).

A cross sectional survey of 50 caregivers done in Saudi Arabia (10), the care burden's total score ranged from 41-60, showed the burden as moderate to severe. This study also showed that care burden is higher caregivers with lower education level. This author mentioned that increased education level and awareness about a disease may make it more endurable for patients and their caregivers. Educated people can reach out to health resources, understand the disease process better and handle better with unpleasant situations and therefore it may be the reason of lesser burden in more educated population. Nevertheless, another study in Turkey (80) revealed that care burden is higher in people with higher education level and said that may be because educated caregivers are more knowledgeable of the complications of disease and make them more stressful and give them more burden.

(5) Occupation

Caregivers who employed in high skill job had better QOL and those who are homemakers or daily wage workers had lower QOL (82). There are also other studies that show the association between caregiver's quality of life and certain type of their occupation. A cross sectional study in China revealed that farmers have doubled burden than other occupation (85). Another study in Nigeria discovered that self-employed caregivers had a better quality of life than caregivers with other types of occupation (86).

(6) Monthly Income

A study stated that monthly income is also one of the factors that affect the quality of life of caregivers. Caregivers with low monthly income get more physical and mental distress (78). Caregivers with higher income have a more preferable quality of life in all aspects (4). Another study also declared that caregivers with less income got more burden and unemployed caregivers suffer huge burden (87). A study in Gaza also reported that few income caregivers had greater burden as they have to manage the expenses of the treatment and also try to meet the other needs of patients (88). Moreover, those who were being employed by an income generating job and who could not afford the health expenses reported that their role in the family and work is negatively affected and these people had a higher burden as well (76)

(7) Relationship with patients

A study of caregivers in China presented that spousal caregivers suffered burden and have worsen quality of life than those of other family members (78). There are also other studies that showed that the burden of spousal and parents of caregivers of patients is higher (75, 81). In one study of caregivers in Chile and France, it mentioned the caregivers who are mothers of the patients have inferior quality of life than other caregivers(89)

(8) Number of children

Caregivers with 3 or more children have greater burden than caregivers with fewer children (76). Caregivers who is the partner of the patients have larger burden as the responsibility of nurturing children and the expenses for these children falls on them (90).

(9) Duration (months/years) as caregivers

Caregivers devoted in caregiving for many years develop higher burden (91, 92). A study mentioned that caregivers who had taken care patients for more than 5 years have a significant huge burden (76). This study had similar results with another study that also revealed that duration of care more than 5 years has brought detrimental effect on the QOL of caregivers especially in physical and social areas (82). Another

study in Turkey described that caregivers taking care more than 14 months have higher burden (72).

2.5.2 Social-Demographic factors of patients related to burden and quality of life of caregivers

(1) Age

Even healthy adults, as they are getting older, they have limitation not only in the movement and functional capacity but also experience with poor cognition. So, it cannot be argued that older individuals who have chronic diseases will definitely lose their functional capacities and decreasing in their cognition level and they cannot do activities of daily living. For this reason, their dependency on their caregivers has increased and they usually need caregivers to assist them in most of the time. The increased demand of care by these older chronic disease patients can negatively influence on the caregiver's quality of life (93, 94). A study in Brazil found out that because of the more dependency of older patients and the increasing demand of care, caregivers have to change their routine plan to adapt and meet the needs of the patients. This leads to changes in the lifestyles of caregivers and significantly affected their mental health and social relationship. So, the caregivers of these older patients who have to change their routine plan have reduced quality of life (94).

A study in China mentioned that caregivers of older patients with greater reliance tend to have lower quality of life both in mental and physical components than caregivers of younger patients (78). A study in Nigeria also mentioned that individuals taking care of older patients experience greater burden as these patients are more dependent, lack of energy and have limitation in mobility (95)

(2) Sex

The gender of the patient significantly predicts the quality of life of their family caregivers. A study in Thailand concluded that caregivers of male patients have lower quality of life than those of female patients (96). It may be due to the changing of the roles in the family. Most of the men act as the breadwinner of the family and therefore if the male patients suffer from any diseases, their partners have to take the multiple

roles in the family and it can cause that caregivers to face with more burden and reduced quality of life (97). But another study in India explained the QOL scores among caregivers of male patients were better than those of female patients (98). This is corresponding with the other studies that showed that caregivers of female patients have worsen quality of life (99, 100). It was explained that the female are naturally more emotional and usually have more dysphoric mood (sadness, heaviness, irritability and mood swing) than male and therefore it can negatively impact on the quality of life of their caregivers (100).

(3) Occupation

The total cost for hemodialysis including direct medical cost, indirect medical cost and productivity loss are important matters with the increasing rate of ESRD patients who need hemodialysis. Both out of pocket money and productivity loss can lead to financial burden for both patients and caregivers. A study in Taiwan reported that the productivity loss of patients receiving hemodialysis is higher than those of patients receiving peritoneal dialysis and that out of pocket money and productivity loss can have impact on the quality of lives of patients and caregivers (101). There is no study that found out the association between occupation of ESRD patients undergoing hemodialysis and the quality of life of caregivers. But there are studies that showed that the quality of life of patients depends on whether they are working or not. A study about ESRD patients undergoing hemodialysis and their caregivers in Jordan found out that the quality of life of working patients are better than those of non-working patients (102). There are also other studies that revealed that unemployed patients has worsen quality of life compared to employed patients and explained that if the patient is working his/her dependence for financial on their family members is lower and possess better quality life (103, 104).

However, the quality of life of ESRD patients receiving hemodialysis treatment may also have impact on the quality of life of caregivers. And moreover, because of no health insurance system in Myanmar and the health expenditure of government is still low, patients' out of pocket cost are still very high according to world bank data in 2015. And as there are no studies about the quality of life of patients undergoing hemodialysis and their patients in Myanmar, I want to find out whether there is

association of employment and type of occupation of patients with the quality of life of their caregivers.

(4) Comorbid conditions

A study discovered that the diabetic patients receiving hemodialysis treatment have lower quality of life than non-diabetic patients because of complications of diabetes. Moreover, patients who have both diabetes and hypertension have poorer quality of life than patients having diabetes alone because of additional complications of hypertension (104). Not only the patients, but also the caregivers who have to take care of patients with more than one chronic disease received huge burden and have decreased quality of life (78, 105).

A study of caregiver's burden in 151 family caregivers in China discovered that caregiving related physical and emotional stress was present in 115 out of 151 caregivers. 77 (51%) experienced mild to moderate burden and 38 (25.2%) experienced moderate to severe burden. This study also stated that patients with multiple comorbidities have increased the burden of caregivers (75). Another study in Iran also found out that caregivers of hemodialysis patients with other chronic disease such as cardiovascular diseases and diabetes have a higher burden and lower quality of life compared to caregivers of patients with no other chronic disease (106).

2.5.3 Relation between caregiver's burden and their quality of life

There are many studies which reported the relation between caregiver's burden and their quality of life. A cross sectional descriptive study was conducted in Myanmar in 2009 to study the level of burden of caregivers of stroke patients, and patient's and caregiver's characteristics that influence on the care burden. In observing characteristics of caregivers, they also include quality of life of caregivers and assess it with SF 36. Caregivers' ages were ranged from 28 to 73 years old. It was discovered that the caregivers had moderate burden of care and advancing in age of both patients and caregivers (>40 years) were related to higher burden. Moreover, patient's higher dependency (disability and handicap) is a predictor of the level of burden. In addition, it is also found out that if the low level of health-related quality of life of caregivers (physical and mental health) was associated the greater burden of care. (107).

A cross sectional multicentric study of 221 hemodialysis patients/caregivers pairs in Spain (108) , using the tools SF 36 to assess quality of life and Zarit burden interview to assess the burden of caregivers. This study mentioned that the quality of life of caregivers is worse than those of general population and young family caregivers who were primary cares of older dialysis patients had lower health related quality of life and this was worsen when there is limited social support. In this study, 32.6% of participants had moderate burden and 7.3% had severe burden of care. Moreover, it also showed that the lower physical component summary (PCS) and the lower mental component summary (MCS) of quality of life are associated with higher burden of care. This is in line with another cross-sectional study done in Jordan in 2010 (102) which measured the quality of life of caregivers and patients undergoing hemodialysis patients by using SF- 36 form and discovered that the mental status was worse than physical status. It was also observed that both patients and caregivers had the poor quality of life than general population and caregiver's quality of life decrease as they get older.

A cross sectional descriptive study done in 2014 at Iran (6) analyzed the relations between depression, QOL and burden of caregivers of hemodialysis patients and reported there is a strong relation between these three variables, describing that the caregivers with higher care burden had more depression and low quality of life. In this study, 72.5 % of caregivers had moderate to severe burden, 66.7 % did not have pleasing quality of life and 74.4% of them also reported to have moderate to high depression. This is similar with other studies in Taiwan in which caregiver's burden negatively affect on their quality of life (109) and pointed out that caregiver burden was positively strongly associated with depression (81).

Another study in 2015 at Indonesia described that if caregivers suffered from greater burden, it can adversely affect their quality of life and it also mentioned that better social support is directly related with increased quality of life (110). A study in Nigeria also informed the strong relation between caregiver's burden and quality of life. Caregiver's burden can affect the general, physical and emotional wellbeing, level of energy and social activities (95). But another study said that caregiver's burden has no association with physical domain but only with mental component of quality of life (111).

Chapter III

Research Methodology

3.1 Research Design

This study is designed as a cross-sectional study.

3.2 Study Population

The population in the study are caregivers of end stage renal disease patients undergoing hemodialysis in Yangon, Myanmar.

3.3 Study Location

This study will be carried out at 3 hemodialysis centers in Yangon, Myanmar. (1) Muslim Free Hospital, (2) Iris Dialysis Center (3) Thuka Dialysis Center. There are many other public hospitals with dialysis centers but it will take a long process for permission if the research is conducted in those public hospitals. And among the private hospitals I have contacted, these 3 dialysis centers have given permission to conduct data collection at their dialysis centers.

3.4 Sample Size

The model for the factors related to quality of life among caregivers of ESRD patients is needed to develop by using multiple linear regression.

For calculating sample size, the minimum ratio of observations to variables is 5:1 but the preferred ratio is 15:1 or 20:1 (Joseph F. Hair. JR, 2010)

There are altogether 18 variables in this study, so $18 \times 10 = 180$ samples are needed.

Another 15% (27) of the samples will be added for missing and incomplete data. So, 200 samples are needed for this study.

3.5 Inclusion Criteria

- 1) Caregivers of end stage renal disease (ESRD) patients undergoing hemodialysis, who are willing to participate in the study.
- 2) Caregivers male and female with ≥ 18 years old
- 3) Caregivers who take care of end stage renal disease (ESRD) patients undergoing hemodialysis, for a minimum of 3 months (studies show that it takes more than 2-3 months for the caregivers to feel the burden) (2, 112, 113).
- 4) Caregiver's who take care patients every day and assist daily activities of patients.

3.6 Exclusion Criteria

- 1) A person who is not a regular persistent caregiver for the patient.

3.7 Sampling Technique

Purposive sampling will be done to organize caregivers who satisfied the inclusion criteria during the study period. First of all, the investigator will explain the objectives and process of the research to the responsible medical person at the hemodialysis centers and ask for permission to see the recorded lists of patients to identify patients attending hemodialysis on that particular day. Patients will be approached to assent to their caregivers being included in the study. Patients will also be explained that their few characteristics such as age, sex, occupation and comorbid conditions will be asked to their caregivers. After patients give permission, caregivers will be approached one by one and explained them about the research and caregivers that met the inclusion criteria will be provided with the study information and subsequently, those who consent to participate in this study will be administered for informed consent. Those caregivers who met the criteria will be enrolled until the desire sample size is obtained.

3.8 Research Instruments

3.8.1 Instruments Used

The questionnaire assessed the factors related to quality of life among caregivers of hemodialysis patients in Yangon. This questionnaire consists of 4 parts (see Appendix 1):

Part 1. Social Demographic factor of caregivers consist 12 items: (1) Age; (2) Sex; (3) Marital status; (4) Education; (5) Occupation; (6) Monthly Income; (7) Relationship with patients; (8); Number of Children (9) Place of Stay (10) Hours per day as caregivers (11) Months or Years as caregivers (12) Extra household works

Part 2. Social Demographic factor of patients has 4 items: (1) Age; (2) Sex; (3) Occupation; (4) Comorbid condition;

Part 3. Caregiver's burden using Zarit Burden Interview in Burmese version which contains 22 items.

Part 4. Quality of life of caregivers by using WHOQOL-BREF in Burmese version which has 26 items and divided into 4 domains (1) Physical domain (2) Psychological Domain (3) Social Domain and (4) Environmental Domain

3.8.2 Instruments Development

1) The socio-demographic characteristics of patients and caregivers in Questionnaire part 1 and part 2 are developed by the researcher according to the conceptual framework.

2) Zarit Burden Interview Questionnaire

The Zarit Burden Interview (ZBI) is used for measuring the caregiver's perceived burden. The questionnaire contains 22 items and score on a 5-points Likert scale varying from 0 = "never", 1 = "rarely", 2 = "sometimes", 3 = "quite frequently", 4 = "nearly always". Item scores are sum up and total score ranging from 0 to 88. The questions give attention to caregiver's health, psychological wellbeing, finances, social life and the relationship between the caregiver and the patient (114), (115).

The score values estimate the degree of burden (116).

0 – 20	Little or no burden
21 – 40	Mild to moderate burden
41 – 60	Moderate to severe burden
61 – 80	Severe burden

The English original version of Zarit Burden interview 22 items was already validated and it had good internal consistency reliability, with a Cronbach's alpha coefficient of 0.92, which was not significantly improved by the removal of any of the 22 items (117). Steven H. Zarit developed this tool, initially in 1980 to measure subjective burden among caregivers of adults with dementia. This instrument is the most widely referenced tool in the study of caregivers (115), (47), (118, 119).

Permission for using Zarit Burden Interview questionnaire was obtained from Mapi Research Trust which is the officially distributor of Zarit Burden Interview on behalf of Dr.Zarit. Translation was done from English version Zarit Burden Interview questionnaire to Burmese language questionnaire by Myanmar expert who are well verse with English language and back translate was also done from Burmese language of Zarit Burden Interview to English by English expert who are well verse with Burmese language.

3) WHOQOL-BREF

The WHOQOL-BREF (120), is an abbreviated 26 items version, derived from original instrument WHOQOL-100 and various studies used this tool to measure the quality of life . The questionnaire contains 24 items for assessing four domains: Physical Health, Psychological Health, Social relationships and Environment and another two items for assessing the Overall QOL and General Health. The four domain scores indicate an individual's perception of quality of life in each particular domain. For the 26 questions, the possible scores range between 26 and 130 points. Each item is rated on a 5-point Likert scale and scored from 1 to 5 on a response scale. Raw score will be used for data analysis. Raw domain scores are scaled in a positive direction (i.e.,

higher scores denote higher QOL). The mean score of items within each domain is used to calculate the domain score.

Domain	Facets incorporated within domains
1. Physical Health (score range; 7-35)	<ul style="list-style-type: none"> • Activities of daily living • Dependence no medicinal substances and medical aids • Energy and fatigue • Mobility • Pain and discomfort • Sleep and rest • Work capacity
2. Psychological Health (score range: 6-30)	<ul style="list-style-type: none"> • Bodily image and appearance • Negative feelings • Positive feelings • Self – esteem • Spirituality/ Religion/ Personal beliefs • Thinking, learning, memory and concentration
3. Social relationships (score range: 3-15)	<ul style="list-style-type: none"> • Personal relationships • Social support • Sexual activity
4. Environment (score range: 8-40)	<ul style="list-style-type: none"> • Financial resources • Freedom, physical safety, and security • Health and social care: accessibility and quality • Home environment • Opportunities for acquiring new information and skills

	<ul style="list-style-type: none"> • Participation in and opportunities for recreation/ leisure activities • Physical Environment (pollution/ noise/ traffic/ climate) • Transport
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The field trials of original WHOQOL-BREF was done in 23 countries and analyses of internal consistency, item–total correlations, discriminant validity and construct validity through confirmatory factor analysis, indicate that the WHOQOL-BREF has good to excellent properties of reliability and performs well in preliminary tests of validity. These results indicate that overall, the WHOQOL-BREF is a sound, cross-culturally valid assessment of QOL, as reflected by its four domains: physical, psychological, social and environment. It was found out that there is a strong correlation between items in different domains and stronger correlation among the items of each domain. Cronbach’s α were acceptable (>0.7) for Domains 1, 2 and 4 (i.e. physical health 0.82, psychological 0.81, environment 0.80) but marginal for social relationships 0.68 (121).

In this study, WHOQOL-BREF (English version) will be translated to Burmese language and use it for data collection. Permission for using WHOQOL-BREF Burmese version was obtained from previous researcher from Myanmar. Cronbach’s alpha coefficient of overall QOL for this Burmese language is 0.861 (with physical health 0.752, Psychological health 0.720, social relationship 0.744, environmental health 0.82)(122).

4) Pre testing of Burmese translated Zarit burden interview questionnaire was done with 30 caregivers from Myanmar and validity was obtained from the 3 Myanmar professionals. Reliability test of Zarit burden interview questionnaire was calculated and the Cronbach’s alpha coefficient is 0.71.

3.9 Data Collection

Before data collection started, permission was requested first from authorities of 3 dialysis centers of different hospitals. The authorities were explained about the purpose and process of research. After getting permission from authorities from hemodialysis centers and approval from Chulalongkorn Ethic Review Committee, data collection was conducted in May, 2019. The data collection process was started by approaching to the responsible medical persons in the dialysis centers and explained them a brief about the study and requested the recorded lists of patients receiving hemodialysis treatment. After that, patients were approached one by one, and explained them a brief about the study. The researcher also informed the patients that the patients' age, sex, occupation and comorbid conditions will be asked to their caregivers. After getting permission from the patients, the caregivers were recruited according to inclusion criteria. The caregivers were delivered the participant information sheet and informed consent form.

After getting consent from caregivers, data collection was started and those caregivers were explained them about the self-administered questionnaire they have to fill. For the caregivers, who could not read or write, the researcher read all the information in this document and in consent form in front of the literate witness who can read and write well and get the signature from witness. Questionnaire was read by the investigator to the caregivers who are illiterate and investigator filled the response of caregivers. All of them were told that it would take about 30-45 minutes to fill the questionnaire and after that the investigator would collect it once they finished filling it.

3.10 Data Analysis

Statistical Analysis was done by using SPSS version 22.0.

- Social-demographic characteristics were summarized into frequencies, percentage, mean and standard deviation.
- Burden was categorized according to the level resulted and showed in proportion.

- Quality of life was analyzed and presented with mean scores and standard deviation for each domain. ANOVA test was used to describe association between characteristics of caregivers, patients and each domain of QoL.
- To find out the factors related to quality of life among caregiver of ESRD patients, hierarchical linear regression was used.

3.11 Confidentiality and Rights of participants

Any information that is linked to participants will be kept confidentially. Even though the study will be published, names or other identifying information of the participants will not be mentioned in the report or summaries of the report. The data will be kept confidentially during the process of report and research and all data files together with the participants' answer on questionnaires will be destroyed after final report has been done.

No harms and/or risks of any kind can be inflicted upon participants. Participants may refuse to answer any question or not take part in a portion of the interview if they feel the question(s) are personal or if talking about them makes them uncomfortable.

3.12 Ethical consideration

Before conducting research, ethical approval was requested from the research ethics review committee for Research Involving human research Participants, Health sciences group, Chulalongkorn University.

Permission from authorities of 4 hemodialysis centers were also requested by written request letter with questionnaires attached and informed consent from caregivers.

Chapter IV

Results

4.1 Background Information

The study aimed to describe the independent variables namely caregiver's characteristics (age, sex, marital status, education level, occupation, monthly family income, relationship with patients, having children or not, stay together with patient or not, hours per day taking care of patients, duration taking care of patients, doing extra household works, receive incentives or not), characteristics of ESRD patients (age, sex, occupation, comorbid conditions) caregiver's burden and dependent variables which is the caregiver's quality of life and factors (independent variables) which are related to caregiver's quality of life (dependent variables). The study was done in 3 hemodialysis centers namely Muslim Free Hospital, Thuka dialysis center and Iris dialysis center in Yangon, Myanmar and consisted of 210 caregivers of ESRD patients and 210 ESRD patients.

The first part described about the descriptive results of these independent variables. The second part described about the descriptive and analytical statistical results of the dependent variables which is the quality of life and each domain by using ANOVA and Kruskal Wallis tests. To develop the model for factors related to caregiver's quality of life, hierarchical linear regression was used and results are reported.

Part 1 Descriptive findings of independent variables

4.2 Socio-Demographic characteristics of caregivers of ESRD patients

A total of 210 caregivers initially were included in the study but 10 were excluded from the sample because of missing data and one was removed as the outlier and thus reducing the sample size to 199.

The socio-demographic characteristics are showed in Table 1. The study population consisted of caregivers with mean age of 44.2 (SD = 15.31). The majority of caregivers are female (64.3%), married (67.4%) and (71.4%) of them had high school level and University level education. For monthly family income, 41.2% of the caregivers had low family income whereas 10.6% had the high family income. 64.8 % are employed with only 35.2 % of them had no job. With regards to their relationship with patients, most of them are spouses (47.2%) and parents, children and other relations (other family members, friends or neighbors) were accounted for 9.0%, 23.6% and 20.2% respectively. 63.3% of the participants have children and 88.4% were staying together with patients at the same house. Of the hours per day caring for patients, 58.8% of the participants spent about 12 or less than 12 hours and 41.2 % of them spent more than 12 hours. About 87 % had cared the patients for more than 1 year with 76.0% responded that they also need to do other household works in addition to taking care of patients. 92.0% of them did not receive any incentive from patients.

Table 1: Characteristics of caregivers of ESRD patients undergoing hemodialysis

Characteristics of caregivers	Caregivers (n = 199) n (%)
Age	
≤ 30	47 (23.6)
31-40	35 (17.6)
41-50	41 (20.6)
51-60	43 (21.6)
≥ 60	33 (16.6)
Mean ± SD	44.2 ± 15.31
Range	18-84
Sex	
Male	71 (35.7)
Female	128 (64.3)

Marital Status		
Single	53	(26.6)
Married	134	(67.4)
Widowed/Divorced	12	(6.0)
Education Level		
≤ Middle School	57	(28.6)
High School	63	(31.7)
University	79	(39.7)
Occupation		
Unemployed	70	(35.2)
Government sector	20	(10.1)
Private sector/NGO	22	(11.1)
Business or Entrepreneur	72	(36.2)
General worker	15	(7.5)
Monthly Family Income (thousand kyats) *		
≤ 200	82	(41.2)
201-300	46	(23.1)
301-400	15	(7.5)
401-500	35	(17.6)
> 500	21	(10.6)
Mean ± SD	342.9 ± 283.44	
Range	20-3000	
Relationship with Patient		
Parents	18	(9.0)
Spouse	94	(47.2)
Daughter/Son	47	(23.6)
Other family members/ Friend/ Neighbors	40	(20.2)
Having Children		
No children	73	(36.7)
Have Children	126	(63.3)

Staying status		
Not Together		23 (11.6)
Together		176 (88.4)
Caring hours per day		
≤12		117 (58.8)
>12		82 (41.2)
Mean ± SD		13.5 ± 8.18
Range		2 - 24
Duration of caregiving (in years)		
≤ 1 year		26 (13.1)
>1-2 years		50 (25.1)
>2-3 years		44 (22.1)
>3-4 years		30 (15.1)
>4-5 years		22 (11.1)
> 5 years		27 (13.5)
Mean ± SD		3.3 ± 2.23
Range		0.3 - 12
Do extra household works		
No		48 (24.0)
Yes		151 (76.0)
Receive something from patient		
No		183 (92.0)
Yes		16 (8.0)

* 1USD = 1535.5 Kyats

4.3 Characteristics of ESRD patients undergoing hemodialysis

Table 2 shows few characteristics of ESRD patients undergoing hemodialysis.

The mean age of patients is 49.8 (SD = 12.42). The proportion of gender of the patients is not much different with 45.7% were male and 53.3% were female. Most of the patients (59.8%) were unemployed with greater percentage (93%) also had one or more comorbid diseases such as diabetes, hypertension and cardiovascular diseases).

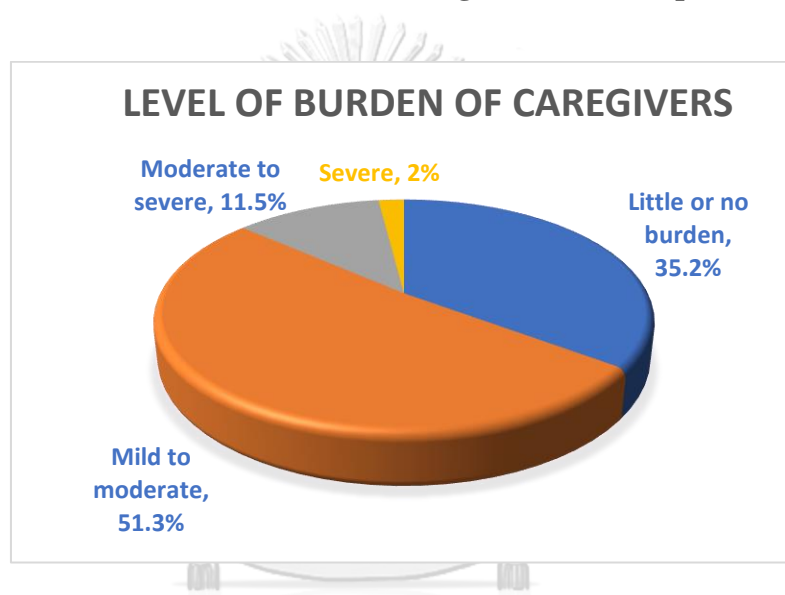
Table 2: Characteristics of ESRD patients undergoing hemodialysis

Characteristics of patients	Patients (n = 199)	
	n	(%)
Age		
≤ 30	15	(7.5)
31-40	28	(14.1)
41-50	55	(27.6)
51-60	60	(30.2)
> 60	41	(20.6)
Mean ± SD	49.8 ± 12.42	
Sex		
Male	93	(46.7)
Female	106	(53.3)
Occupation		
Unemployed	119	(59.8)
Government sector	29	(14.6)
Private sector/NGO	12	(6.0)
Business or Entrepreneur	32	(16.1)
General worker	7	(3.5)
Comorbid Diseases (e.g., Diabetes, Hypertension, Cardiovascular disease, Poor nutrition)		
Yes	185	(93.0)
No	14	(7.0)

4.4: Caregiver' burden

The caregiver's burden is showed in Figure 1. According to cutoffs from Zarit burden interview assessment tool, 70 of the participants (35.2%) felt little or no burden and 102 which is about half of them (51.3%) experienced mild to moderate burden, 23 (11.5%) had moderate to severe burden and only 4 (2%) had severe burden.

Figure 1: Level of burden of caregivers of ESRD patients



In assessing the burden of caregivers, among the 22 items, the items with higher mean scores included (1) Caregivers feel they should do more for patients (2.91 ± 1.23), (2) caregivers feel they should do better in caring patients (2.82 ± 1.16), (3) Financial burden (2.69 ± 1.16), (4) Afraid for the future of patients (2.61 ± 1.26) and (5) Patient is too dependent (2.48 ± 1.27).

Part 2 Descriptive and analytical findings of dependent variables (quality of life and each domain)

4.5 Descriptive findings of total QoL and 4 domains

Table 3 shows the mean scores of total QOL and each domain with different mean scores among the different groups of caregivers. The total scores of the WHOQOL-BREF range from 26 to 130 and in this study (Table 3), the participants got the scores range from 38 to 119. The mean scores for the total QOL is 84.2 with SD 11.93. The physical domain scores range from 7 to 35 in WHOQOL-BREF and in this study, the scores of participants range from 10 to 35. The mean score of physical domain in these caregivers is 24.8 with SD 3.69. The mean scores of psychological QoL of the caregivers is 18.6 with SD 3.69. This domain scores range from 6 to 30 in the questionnaire and the scores of participants in this study range from 7 to 18. The social domain scores range from 3 to 15 in the WHOQOL-BREF questionnaire and the scores of participants in this study ranged from 5 to 15. The mean score is 10.7 with SD 1.64. With regards to environmental QoL, the domain scores in the WHOQOL-BREF range from 8 to 40 and the scores in this study range from 10 to 38. The mean scores of environmental QoL in this study is 24.1 with SD 4.02.

4.6 Analytical Findings of total QoL and 4 domains

4.6.1 The total QOL

The mean scores among the different age groups are significantly different, [F (4,194) = 3.57, p value = 0.008]. Marital status also had significant effect on the total quality of life [F (2,196) = 7.22, p value = 0.001]. Education level also significantly affected the quality of life [F (2,196) = 4.05, p value = 0.019]. The total QoL was also significantly affected by income [F (4,194) = 4.14, p value = 0.003], relationship with patients [F (3,195) = 8.03, p value <0.001], having child or not [F (1,197) = 10.59, p value = 0.001] and doing extra household work or not [F (1,197) = 5.96, p value = 0.015].

Post hoc analysis was conducted using Bonferroni test. It was indicated that the mean score of the caregivers aged 30 and below was significantly higher than aged group 41-50, 51-60 and aged above 60. Married caregivers had a significant lower mean score than single caregivers. Caregivers with university level education had a significant better score than caregivers with below or at middle school level education. Moreover, caregivers who had monthly family income more than 500 thousand kyats scored significantly greater than those with monthly family income less than or equal 200 thousand kyats and 201-200 thousand kyats. Caregivers who are children of the patients had a significant high score than caregivers who are parents and spouses of the patients. Other relationship also scored significantly higher than parents. Caregivers who have children scored lower than those who do not have children. Caregivers who also need to do other extra household work such as cooking, washing and cleaning had lower QoL than who was responsible in only taking care of patients.

There is no significance difference among the other characteristics of caregivers such as sex, occupation, staying together or not together with patients, caring hours per day, duration of care giving in years, and receive incentives from patients or not.

4.6.2 Physical domain of QOL

The physical QoL is significantly affected by caregivers aged group [$F(4,194) = 6.27$, p value < 0.001], caregiver's sex [$F(1,197) = 4.05$, p value < 0.046], caregiver's marital status [$F(2,196) = 9.29$, p value < 0.001], caregiver's monthly family income [$F(4,194) = 3.23$, p value = 0.014], relationship with patients [$F(3,195) = 5.29$, p value = 0.002], having children or not [$F(1,197) = 16.8$, p value < 0.001], doing extra household work or not [$F(1,197) = 4.45$, p value = 0.036], receive incentives from patient or not [$F(1,197) = 8.07$, p value = 0.005].

Post hoc analysis using Bonferroni test showed that caregivers aged 30 and below had a significant higher mean score than the other groups who are more than 30 years old, male caregivers scored significantly greater than female caregivers, single caregivers had significant better QoL mean score than married caregivers. As in total QoL, the mean scores of the highest income group scored significantly more than the lowest income groups. Parents and spousal caregivers also had significance lower scores than

children caregiver and the score of caregivers who had no children was also significantly higher. Caregivers who also need to do other extra household work such as cooking, washing and cleaning had lower QoL than who was responsible in only taking care of patients. Caregivers who receive incentives such as tips or gifts also had significantly greater scores than those who receive nothing.

4.6.3 Psychological QOL

Unlike the physical domain scores, there is no significance difference among the caregivers of different income groups but there are still significance difference mean scores among the characteristics which are age groups [F (4,194) = 2.67, p value = 0.033], marital status [F (2,196) = 4.32, p value = 0.015], relationship with patients [F (3,195) = 8.24, p value < 0.001], having children or not (U = 3614.50, p value = 0.011) and doing extra household work or not [U = 2907.5, p value = 0.036]. There are additional two characteristics which showed significance differences, caregiver's sex (U = 3518.00, p value = 0.004) and educational level [F (2,196) = 5.57, p value = 0.004].

Bonferroni pairwise test is used for post hoc analysis and found out that age group less than or equal 30 has a significant better QoL than age group of 41-50. Female has a significant lower QoL than male. Single caregivers scored significantly higher than widowed, those with university level education had a significant better score than those with below or at middle school level education and those who have children scored less than those who do not have children. Caregivers who also need to do other extra household work such as cooking, washing and cleaning had lower QoL than who was responsible in only taking care of patients. The difference with total QoL is that in this psychological QoL, parents had significant lower QoL than all the other three groups.

4.6.4 Social domain of QOL

There are 4 characteristics of caregivers that shows significance difference in the mean scores among each group; Education level [chi-square = 6.29, p value = 0.043], caregiver's monthly family income [chi-square = 10.16, p value = 0.038], relationship

with patients [chi-square = 9.83, p value = 0.020], having children or not ($U = 3809.00$, p value = 0.039).

Dunn's pairwise test is used for post hoc analysis and presented that caregivers having university level education scored significantly higher than those with below and at middle school level education. Caregivers with highest income group scored significantly higher than all other groups except those with income 301-400 thousand kyats. Among the different relationship with patients, Children and other family members or friends/neighbors had significant better scores than parents and spouses. Caregivers who have children scored significantly lesser.

4.6.5 Environmental Domain of QoL

There are significance differences among the marital status [$F(2,196) = 5.49$, p value = 0.005], different income groups [$F(4,194) = 3.77$, p value = 0.006], relationship with patients [$F(3,195) = 6.94$, p value < 0.001] and do other household works [$U = 2773.5$, p value = 0.014].

Bonferroni pairwise test is used for post hoc analysis and presented that married caregivers significantly scored lower than single and the mean scores of the highest income group scored significantly more than the lowest income groups. Among the different relationship with patients, Children had significant better scores than parents and spouses. Other relations also scored better than parents. Caregivers who is responsible only for taking care of patients and do not need to do other extra household works has a higher score than those who also do other household works.

Table 3: Characteristics of caregivers and the mean scores of their total QoL and each domain QoL

Characteristics of caregivers	Caregivers (n = 199) n (%)	Total QoL (Mean ±SD)	Physical QoL (Mean ±SD)	Psychological QoL (Mean ±SD)	Social QoL (Mean ±SD)	Environmental QoL (Mean ±SD)
Total		84.2 ± 11.93 Range 38-119	24.8 ± 3.69 Range 10-35	18.6 ± 3.69 Range 8-28	10.7 ± 1.64 Range 5-15	24.1 ± 4.02 Range 10-38
Age						
≤ 30	47 (23.6)	89.8 ± 10.64	26.7 ± 3.45	19.9 ± 3.45	11.1 ± 1.57	25.3 ± 3.76
31-40	35 (17.6)	83.2 ± 10.26	23.6 ± 3.79	18.9 ± 2.99	10.4 ± 1.54	24.1 ± 3.20
41-50	41 (20.6)	82.3 ± 12.64	22.2 ± 3.73	17.8 ± 4.03	10.6 ± 1.70	23.7 ± 4.22
51-60	43 (21.6)	82.4 ± 12.30	23.9 ± 3.17	18.0 ± 3.85	10.5 ± 1.67	23.4 ± 4.37
≥ 60	33 (16.6)	82.2 ± 12.12	23.3 ± 3.44	17.9 ± 3.72	10.7 ± 1.74	23.8 ± 4.27
p value		0.008	<0.001	0.033	0.26	0.302
Sex						
Male	71 (35.7)	86.3 ± 12.04	25.2 ± 3.73	19.4 ± 3.69	10.6 ± 1.67	24.6 ± 4.02
Female	128 (64.3)	83.1 ± 11.76	24.1 ± 3.63	18.1 ± 3.64	10.7 ± 1.63	23.9 ± 4.01
p value		0.066	0.046	0.004	0.867	0.252
Marital Status						
Single	53 (26.6)	89.3 ± 13.36	26.3 ± 4.03	19.7 ± 4.13	10.9 ± 1.88	25.6 ± 4.53
Married	134 (67.4)	82.5 ± 10.62	23.8 ± 3.40	18.3 ± 3.30	10.5 ± 1.54	23.5 ± 3.62
Widowed/ Divorced	12 (6.0)	81.0 ± 13.39	23.7 ± 2.64	16.7 ± 4.85	10.6 ± 1.68	23.7 ± 4.39
p value		0.001	<0.001	0.015	0.097	0.00

Characteristics of caregivers	Caregivers (n = 199) n (%)	Total QOL (Mean ±SD)	Physical QOL (Mean ±SD)	Psychological QOL (Mean ±SD)	Social QOL (Mean ±SD)	Environmental QOL (Mean ±SD)
Education Level						
≤ Middle School	57 (28.6)	80.7 ± 12.14	23.7 ± 3.69	17.3 ± 3.82	10.3 ± 1.65	23.2 ± 3.94
High School	63 (31.7)	84.5 ± 11.89	24.6 ± 3.66	18.7 ± 3.68	10.7 ± 1.76	24.1 ± 4.04
University	79 (39.7)	86.5 ± 11.34	24.9 ± 3.68	19.4 ± 3.41	10.9 ± 1.50	24.8 ± 3.97
p value		0.019	0.152	0.004	0.043	0.08
Occupation						
Unemployed	70 (35.2)	82.1 ± 13.23	23.8 ± 3.67	17.9 ± 4.35	10.5 ± 1.83	23.4 ± 4.33
Government sector	20 (10.1)	83.8 ± 10.66	24.2 ± 3.44	18.1 ± 3.27	10.6 ± 1.70	24.4 ± 3.62
Private sector/NGO	22 (11.1)	87.4 ± 11.62	25.4 ± 3.98	19.9 ± 2.99	10.7 ± 1.86	25.0 ± 3.57
Business or Entrepreneur	72 (36.2)	86.5 ± 10.42	25.2 ± 3.42	19.2 ± 3.22	11.0 ± 1.21	24.7 ± 3.76
General worker	15 (7.5)	79.0 ± 12.16	23.1 ± 4.34	17.1 ± 3.24	9.9 ± 1.94	22.7 ± 4.37
p value		0.051	0.08	0.051	0.382	0.132
Monthly Family Income (thousand kyats) *						
≤ 200	82 (41.2)	81.6 ± 11.76	23.7 ± 3.37	17.8 ± 3.93	10.4 ± 1.76	23.3 ± 3.92
201-300	46 (23.1)	84.0 ± 10.88	24.5 ± 3.59	18.4 ± 3.72	10.6 ± 1.52	24.1 ± 3.55
301-400	15 (7.5)	86.7 ± 10.96	24.9 ± 3.68	19.3 ± 3.09	11.1 ± 1.13	24.7 ± 3.88
401-500	35 (17.6)	84.4 ± 12.22	24.5 ± 4.27	18.9 ± 3.04	10.4 ± 1.77	24.1 ± 4.23
> 500	21 (10.6)	92.9 ± 11.56	26.9 ± 3.32	20.5 ± 3.59	11.6 ± 1.21	26.9 ± 4.09
p value		0.003	0.014	0.111	0.038	0.006

Characteristics of caregivers	Caregivers (n = 199) n (%)	Total QOL (Mean ±SD)	Physical QOL (Mean ±SD)	Psychological QOL (Mean ±SD)	Social QOL (Mean ±SD)	Environmental QOL (Mean ±SD)
Relationship with Patient						
Parents	18 (9.0)	75.6 ± 11.51	23.2 ± 2.80	15.1 ± 3.83	10.0 ± 1.85	21.3 ± 4.25
Spouse	94 (47.2)	82.4 ± 10.59	23.7 ± 3.36	18.4 ± 3.29	10.5 ± 1.54	23.5 ± 3.60
Daughter/Son	47 (23.6)	89.2 ± 10.90	26.0 ± 3.71	19.8 ± 3.51	11.0 ± 1.52	25.5 ± 3.95
Other family members/Friend/neighbors	40 (20.0)	86.7 ± 13.34	25.0 ± 4.16	19.0 ± 3.85	11.0 ± 1.82	25.1 ± 4.09
p value		<0.001	0.002	<0.001	0.02	<0.001
Have Children						
No children	73 (36.7)	87.8 ± 12.68	25.8 ± 3.95	19.5 ± 3.75	10.9 ± 1.77	24.9 ± 4.39
Have Children	126 (63.3)	82.2 ± 11.02	23.7 ± 3.30	18.0 ± 3.58	10.5 ± 1.56	23.6 ± 3.72
p value		0.001	<0.001	0.011	0.039	0.025
Staying status						
Not Together	23 (11.6)	88.0 ± 13.85	25.7 ± 4.25	19.4 ± 4.37	10.9 ± 1.92	25.3 ± 3.62
Together	176 (88.4)	83.7 ± 11.61	24.3 ± 3.60	18.4 ± 3.60	10.6 ± 1.60	23.8 ± 4.05
p value		0.104	0.102	0.354	0.289	0.139
Caring hours per day						
≤12	117 (58.8)	83.6 ± 11.64	24.4 ± 3.65	18.3 ± 3.64	10.5 ± 1.63	23.8 ± 3.61
>12	82 (41.2)	85.2 ± 12.34	24.6 ± 3.77	18.9 ± 3.78	10.9 ± 1.64	24.5 ± 4.53
p value		0.332	0.595	0.105	0.05	0.154

Characteristics of caregivers	Caregivers (n = 199) n (%)	Total QOL (Mean ±SD)	Physical QOL (Mean ±SD)	Psychological QOL (Mean ±SD)	Social QOL (Mean ±SD)	Environmental QOL (Mean ±SD)
Duration of caregiving (in years)						
≤ 1 year	26 (13.1)	88.0 ± 13.54	25.0 ± 4.53	19.8 ± 3.85	10.9 ± 1.68	25.6 ± 4.12
>1-2 years	50 (25.1)	85.9 ± 12.24	24.7 ± 4.05	18.9 ± 3.87	11.0 ± 1.46	24.6 ± 3.99
>2-3 years	44 (22.1)	82.9 ± 8.96	24.3 ± 2.88	18.3 ± 2.66	10.5 ± 1.39	23.5 ± 3.46
>3-4 years	30 (15.1)	81.3 ± 13.52	23.6 ± 3.71	18.1 ± 4.07	10.3 ± 1.99	23.4 ± 4.42
>4-5 years	22 (11.1)	84.3 ± 11.07	25.1 ± 3.62	18.3 ± 3.81	10.5 ± 1.44	24.1 ± 3.88
> 5 years	27 (13.5)	82.6 ± 12.43	24.2 ± 3.45	17.8 ± 4.12	10.5 ± 2.01	23.6 ± 4.29
p value		0.264	0.697	0.383	0.312	0.234
Do extra household works						
No	48 (24.0)	87.9 ± 14.58	25.4 ± 4.06	19.3 ± 4.89	10.9 ± 1.96	25.5 ± 4.49
Yes	151 (76.0)	83.1 ± 10.76	24.2 ± 3.53	18.3 ± 3.39	10.6 ± 1.53	23.7 ± 3.76
p value		0.015	0.036	0.038	0.155	0.014
Receive something from patient						
No	183 (92.0)	83.8 ± 11.79	24.3 ± 3.64	18.5 ± 3.71	10.6 ± 1.61	24.0 ± 4.04
Yes	16 (8.0)	89.4 ± 12.68	26.9 ± 3.43	19.3 ± 3.67	10.9 ± 2.05	25.3 ± 3.61
p value		0.069	0.005	0.514	0.392	0.154

Characteristics of caregivers	Caregivers (n = 199) n (%)	Total QOL (Mean ±SD)	Physical QOL (Mean ±SD)	Psychological QOL (Mean ±SD)	Social QOL (Mean ±SD)	Environmental QOL (Mean ±SD)
Patient's age						
≤ 30	15 (7.5)	79.9 ± 11.95	24.0 ± 3.40	16.7 ± 4.22	10.2 ± 1.86	22.8 ± 4.21
31-40	28 (14.1)	80.3 ± 12.52	23.5 ± 3.85	17.6 ± 3.78	10.1 ± 1.69	22.9 ± 4.26
41-50	55 (27.6)	84.9 ± 12.02	24.9 ± 3.59	18.7 ± 3.97	10.6 ± 1.73	24.2 ± 4.21
51-60	60 (30.2)	85.4 ± 11.17	24.6 ± 3.53	18.9 ± 3.08	10.9 ± 1.43	24.2 ± 3.73
> 60	41 (20.6)	86.0 ± 12.08	24.4 ± 4.07	19.1 ± 3.77	10.8 ± 1.65	25.1 ± 3.79
p value		0.153	0.533	0.13	0.226	0.176
Patient's sex						
Male	93 (46.7)	83.7 ± 11.48	24.3 ± 3.74	18.4 ± 3.50	10.6 ± 1.69	24.1 ± 3.85
Female	106 (53.3)	84.7 ± 12.34	24.6 ± 3.65	18.6 ± 3.88	10.8 ± 1.59	24.1 ± 4.17
p value		0.561	0.528	0.586	0.473	0.98
Patient's Occupation						
Unemployed	119 (59.8)	83.3 ± 12.35	24.3 ± 3.71	18.2 ± 3.86	10.5 ± 1.75	23.8 ± 4.13
Government sector	29 (14.6)	86.9 ± 12.09	25.6 ± 3.69	19.3 ± 3.54	10.8 ± 1.71	24.5 ± 3.56
Private sector/NGO	12 (6.0)	83.8 ± 10.55	23.7 ± 3.47	18.8 ± 3.24	10.8 ± 1.55	24.1 ± 4.66
Business or Entrepreneur	32 (16.1)	85.6 ± 10.56	24.3 ± 3.64	19.3 ± 3.23	10.9 ± 1.29	24.9 ± 3.88
General worker	7 (3.5)	84.1 ± 13.07	25.0 ± 4.04	18.1 ± 4.30	10.8 ± 1.22	23.6 ± 3.69
p value		0.619	0.447	0.445	0.747	0.717
Patient's Comorbid Diseases						
Yes	185 (93.0)	84.1 ± 12.11	24.4 ± 3.73	18.5 ± 3.69	10.6 ± 1.68	24.1 ± 4.10
No	14 (7.0)	86.6 ± 9.26	26.0 ± 2.80	18.9 ± 3.99	11.1 ± 1.07	24.1 ± 2.71
p value		0.435	0.107	0.552	0.352	0.724

4.7 Factors related to quality of life

To find out the factors (independent variables) related to quality of life (dependent variable), hierarchical linear regression was conducted.

Prior to conduct hierarchical linear regression, the assumptions of analysis were assessed. Outliers, multicollinearity, independent errors, normality, homoscedasticity and linearity were tested. The assumption of collinearity was assessed by VIF or tolerance. If VIF is larger than 10 or tolerance is less than 0.1, the assumption is violated. The test of data showed that there is an absence of multicollinearity with the highest VIF value being 1.061 and the lowest tolerance value being 0.998. So, in this case, the assumption was met.

Homoscedasticity was interpreted through the standardized prediction versus standardized residual regression scatterplot. The data from the scatter plot revealed that the assumption of homoscedasticity and linearity was met. Because all the assumption was met, hierarchical linear regression was continued to carry out for data analysis.

Table 4: Model Summary of Hierarchical Linear Regression

Model	R	R Square	Adjusted R Square	R Square Change	F Change	df1	df2	Sig. F Change
1	.465 ^a	.216	.212	.216	54.269	1	197	.000
2	.557 ^b	.310	.300	.094	13.353	2	195	.000
3	.567 ^c	.322	.304	.011	1.604	2	193	.204

a. Predictors: (Constant), Level of Burden

b. Predictors: (Constant), Level of Burden, Caregiver Age, income in thousand

c. Predictors: (Constant), Level of Burden, Caregiver Age, income in thousand

Table 5: Summary of Hierarchical Regression Analysis for variables predicting Quality of Life

	Model 1			Model 2			Model 3		
	B	Beta	Sig	B	Beta	Sig	B	Beta	Sig
Constant	95.638			98.135			97.333		
Level of burden	-0.423	-0.465	0.000	-0.395	-0.435	0.000	-0.370	-0.407	0.000
Caregiver's age				-0.149	-0.191	0.002	-0.107	-0.137	0.041
Monthly Family Income				0.010	0.232	0.000	0.009	0.222	0.000
Marital Married							-1.769	-0.070	0.281
Relation Patients							-4.360	-0.105	0.110

A three steps hierarchical linear regression, enter method was conducted to find the relationship between the predicted independent variables (level of burden, caregiver's age, married caregivers, relation as parents, monthly family income in thousand kyats) and dependent variables (Quality of life).

From Model 1 (level of burden as the predictor variables) in table 4, level of burden explains a significant amount of the variance (22%) on quality of life [F (1,197) = 54.27, $p < 0.001$, $R^2=0.22$, adjusted $R^2=0.21$]. From Model 2 with 3 predictor variables (level of burden, caregiver's age and monthly family income), there is an improvement over the earlier model with $R^2=0.31$ and adjusted $R^2=0.30$. The change in R^2 (0.094) is also significant [F (1,195) = 12.35, $p < 0.001$]. So, 31% of variance in quality of life can be explained by these 3 variables in which additional 9.4% can be explained by including caregivers' age and monthly family income over the first model.

From Model 3 with 5 predictor variables (level of burden, caregiver's age, monthly family income of caregivers, married caregivers and relation as parents) in table 9, it gave a higher value of R (0.57) and R^2 (0.32) than the previous models. The R^2 has also changed 0.011 is not significant [F (2,193) = 1.604, p value = 0.204]. So married caregivers and parents are not included in the predictors of caregiver's quality of life.

Among the significant models, model 2 could explain the significant higher percentage (31%) than model 1. Thus, upon further exploration of model 2 (table 5), the results showed that level of burden, caregiver's age and monthly family income are significant predictors with p value <0.001, 0.002, <0.001 respectively. The level of burden had a negative influence on the caregiver's quality of life ($\beta = -0.435$). Caregiver's age also negatively related with caregiver's quality of life ($\beta = -0.191$). Income is positively related with caregiver's quality of life ($\beta = 0.232$).

So, the best model for predicting caregiver's quality of life from the above analysis would be linear combination of the constant, level of burden of caregiver's, caregiver's age and caregiver's monthly family income.

The Model

Model 1 Quality of life = $\beta_0 + \beta_1$ (level of burden)

$$\text{QoL} = 95.638 - 0.423 \text{ burden}$$

Model 2 Quality of life = $\beta_0 + \beta_1$ (level of burden) + β_2 (caregiver's age) + β_3 (caregiver's monthly family income)

$$\text{QoL} = 97.333 - 0.395 \text{ burden} - 0.149 \text{ caregiver's age} + 0.010 \text{ caregiver's monthly family income}$$

Chapter V

Discussion, Conclusion and Recommendation

5.1 Characteristics of caregivers

The mean age of caregivers in this study is 44.2 ± 15.3 . This is quite similar with the studies in two neighborhood countries Thailand and India in which the mean age of caregivers are 47.1 and 41.6 respectively (61, 123). So, the caregivers are still in the working age group. Majority of them are women (64%) which was also consistent with other studies in Thai, India and Iran (82, 106, 123). It can be comparable with the developed countries such as US, UK and Australia where women are the predominant caregivers with 75%, 58% and 68% respectively (124, 125). It could be understood that women worldwide are culturally accepted by societies as the one who is responsible for caregiving. In the context of Myanmar, it was expected that men should be leaders and women are socially expectable to be in supportive roles. But the women and girls are socially obligated and expected to be in charge of the household, children, elderly relatives, and take on other caring responsibilities.

67.5% of the caregivers in this study are married and only 26.5% are single. This is also compatible with other studies (11, 82, 123). It can be related to the relation with patients where nearly half (47.5%) of the participants are spouses of the patients. And the rest of the participants are related to as daughter/son, other family members or friends and parents with 23.5%, 20% and 9% respectively. We could see that married and spouses are the main caregivers in this study and not only they were taking care of the patients but they also could probably take extra roles for their families especially children as their spouses were not feeling well.

With regards to education level, there was only 28.5% of the caregivers who had less or equal to middle school level. Although it was not reported here in the results, among those 28.5%, only 12% are illiterate or in primary school education. Thus, about 71% of the participants in this study are at high school (32%) and above high school level (39.5%), so we can say that they are educated. The reason behind this could be because

the study was done in Yangon where we could see more educated people than suburban or rural areas.

Majority (65%) of the caregivers were employed with business or entrepreneur accounted for 36%. There were only 35% of caregivers who were unemployed. It could also be explained that because there are lots of job opportunities in the city like Yangon, it is logic that there were higher proportion who had jobs. Moreover, when compared with the relationship with patients, half of the caregivers are spouses and when their husbands or wives got sick, it is their responsibility to take the leading roles for families and work to cover the medical costs and other household expenditures.

Most of the caregivers (63.5%) had children and nearly 90% of the caregivers were staying together with their patients. Unlike the western cultures, families in Asia have more bonding and traditionally as mentioned in above, the caregivers are very committed, they usually stay close to the patients to assist with both physical and emotional support. About 60% of the caregivers spent less than or just 12 hours a day in taking care of patients and this can be related with employed rate in which most of the caregivers were employed and they took dual roles in both working outside and taking care of patients at home so that they could cover all the expenses for the patients and also for their households. 60% of the caregivers had taken care of patients approximately 3 years among which 13% was spent less than or for just 1 year. 40% had cared the patients for more than 3 years and among which 13.5% accounted for more than 5 years. Three quarter of the caregivers not only responsible to take care of patients but also had to do other household works such as cooking or washing or cleaning. That is why there is less proportion of caregivers who spent more than 12 hours a day taking care of patients. More than 90% of the caregivers received nothing from patients so they can be called unpaid caregivers and only 8% of them reported that sometime they received gifts or tips from their patients.

5.2 Characteristics of end stage renal disease patients

The mean age of the ESRD patients is 49.7 ± 12.3 . This is compatible with other studies in Brazil, Nepal and India which the average age of caregivers are just below and around

50 years old (11, 40, 81) but it was younger than the patients in other studies in Thailand, Brazil and Iran in which the patient's average age was about 60 years old (106, 123, 126). The proportion of male and female are approximately the same with 46.5% and 53.5% respectively. Unlike the caregivers, the unemployment percentage of patients is about 60%. It is understandable that because of their chronic conditions, they could not work. Among 40% who were still employed, 16.5% is doing the business or entrepreneur, so it means that with their self-managed jobs, they could take leaves and rest any time they wish and could ask the fellows manager to work for them. 93% of the patients have one or more than one comorbidity such as diabetes, hypertension, cardiovascular diseases.

5.3 Level of burden

The mean scores of caregiver's burdens in this study is 26.96 ± 13.09 , so it showed that caregivers had mild to moderate burden. On classification by the 4 groups of burden level, half of the caregivers (51.5%) in this study had mild to moderate burden. This is consistent with the results of other studies did in India, China and Japan which indicated that caregivers suffered from mild to moderate burden (2, 5, 12, 61, 75, 127). But this result contradicts with other studies where most of the caregivers felt moderate to severe and severe burden (9, 81, 106, 128).

In Myanmar culture, caregiving for a loved one is an integral part of the loved ones and they committed and take responsibility for their loved ones who suffer from terminal illnesses. They would never assume caring their patients as a burden. They accept this task and care for their loved ones out of love. Moreover, they could see it from religious view. For instance, in Christian, taking care of the sick and poor is showing Christ's love and to look after the family members is one of the biblical teaching. For the Buddhist and other religious, they regard it as the atonement or expiation of their sins or past deeds, and so they do it for love or to gain the merit. In addition, majority (59.5%) of the end stage renal disease who are treated with hemodialysis are unemployed and stay at home. Despite some patients totally depend on their caregivers for daily activities, some patients could still move around in the house to do their daily activities. For these reasons, caregivers probably did not express great burden in caring

of their patients. A study in Thai also stated that Thai caregivers have low burden because they bear in mind that taking care of the family members is their routine duty in their daily lives (123). A study in Japan also reported that caregivers in their study did not feel much burden and they would also not report that their social lives are affected because of caring patients and this may be due to different cultural norms with other countries (5).

In the burden assessment of this study, it was found out that caregivers score highest in questions related to their feeling that they should do more for patients and they should do better in caring patients. So, it is the cultures and perception of Myanmar, as similar as most of the Asia countries, that most of the people want to do as possible as they can in caring for their loved ones and always feel that they should do more to give the best care while their patients are still alive. The second highest score in burden assessment is related to financial issues. In Myanmar, there is still low financial protection in health care and lack of health insurance, out of pocket expenditure by households is the major source in health financing (129). According to 2018 health SDG profile Myanmar published by WHO, out of pocket expenditure is about 74% of the total health care expenditure. Because the health expenditure of Myanmar government is only about 5% of the GDP, most funding was spent to maintain the national programs, family planning and nutrition, staff salaries, and basic hospital infrastructure. Patients themselves have to pay for medications and disposables. Because of the inadequate number of major hospitals for dialysis and kidney transplantation, there are overcrowding and long waiting times for patients to receive these treatments. The inability of the states to provide adequate health care has led to the emergence of a large, but expensive, private sector. A few hospitals are run by charitable organizations, whose charges are lower than those at private hospitals, and some provide free treatment. The average payment for an HD session in Myanmar is about 20-40 USD in charity and public hospitals whereas it is above 50 USD in private hospitals and patients have to pay their medical cost by themselves. Most of the patients have to receive HD treatment 3 times a week and so they have lots of financial burden. Thus, there are still problems for patients and their caregivers. It could also lead to the withdrawal of treatment in patients who could not afford this lifelong treatment and therefore affect the survival rate of the patients.

The other burden items which caregivers scored high is about their feeling they afraid for the future of patients and patients' dependency upon them. The feeling of strain also increased their burden in caring patients. The caregivers in Asia countries are committed in taking care of patients and support the psychological of the patients as well. Moreover, unlike the western cultures, most of the patients in Asia are more dependent on their family members and so it could raise the burden and lower the QoL of the family caregivers as well (123).

5.4 Quality of life

5.4.1 Association of caregiver's and patient's characteristics with caregiver's quality of life

It was noticed that relationship with patients affected all four domains of QoL. This is similar with the study did in India (82, 89). It is significant that parents and spouses scored lower than daughter/son and other relationships. Because parents and spouses were more dedicated and had more concern to their loved ones, it could make their quality of life to be decreased. A study in Sudan and Chile also found out that parents significantly obtained the least scores in all 4 domains compared with other relationships (89, 130). Parents, naturally, in the case of taking care of their own children, they would be more emotional and could exacerbate if they are in older age. But another study in Turkey revealed that spouses had lower QoL than any other relationship (68).

The age of caregivers had significant impact on the physical and psychological domains. The more advanced age caregivers got worsen scores. This result was compatible with the other study that expressed that caregiver's age affected all domains and significantly on physical and psychological domains (68). The significant difference among sex was found only in Psychological domain and it is congruent with the another study done in Turkey (68) in which they found the difference in psychological and social domains and it was observed that male caregivers scored more than female caregivers. Another study in Bangalore, India also discovered that the score of male is significantly greater than that female in all 4 domains (131)

This study showed that education level significantly affected the psychological and social domains with higher level education got better scores than less educated ones. Other studies also described the similar result (68, 82, 130, 132). It can be rationalized that highly educated people have better jobs with higher income and more social resources which can raise their quality of life. They also have higher understanding of the diseases and consequences, and so they can also adapt easily to the difficult situation and provide better care and support to the patients.

The scores of married caregivers were also significantly lesser than other groups in all domains except in social domain. This result is also corresponded with the other study in which the scores of married caregivers were significantly reduced than others in above mentioned domains (68, 131). But this result is contrary to studies in China, India and Sudan in which married caregivers had scores more than divorced or widows (82, 130, 133). They argued that married caregivers could have more physical and emotional support and security from their partners. But this study would be different with them in such a way that the patients could be the spouse of these caregivers who were participated as married in this study. So, in this case as these married caregivers could not be supported by their partners, and they would have more emotional concern for their loved ones who were suffering the illnesses.

The significant scores difference in monthly family income was noticed in Physical and Environmental domains that caregivers with lower family income scores less than those with higher family income. This is consistent with the other study done in India (82) where family income is significant in Physical, Psychological and environmental domains.

There is no significant association of other variables with the 4 domains of WHOQOL-BREF. Patient's variables were not significantly associated with caregiver's quality of life (130).

5.4.2 Predictors of Quality of life

In this study, we could see that every unit increase by level of burden, quality of life will decrease by 0.395. Caregiver's burden was the strongest predictor for quality of life which accounts for 21.6% after other variables were considered. This is consistent with other studies which stated that caregiver's burden can explain more variance than other factors (4, 5, 108, 134-136). Other studies also described that caregiver's burden was negatively influenced on their quality of life (6, 102, 106).

A study of caregivers in Iran also discovered that the caregiver's burden was most significant influencing factor which could explain about 44% of variance for poor QoL(135). Another study of caregivers in China using SF-36 tool for assessing QoL reported that in their study, the caregiver's burden is the largest significant contributing factor to poor QoL in mental aspects and second most affected factor to physical aspects (4). The next study in Japan about the caregivers also stated that after controlling other characteristics and activities of caregivers, the burden is the greatest influencing factor which reduced the QoL of caregivers (5). A study in Spain about the caregivers of dialysis patients stated that Higher burden associated with lower quality of life in physical and mental component (108).

Another study of caregiver's QoL in Turkey also mentioned that caregiver's burden could explain about 60% of the variance in total QoL and burden significantly lower the QoL of the caregivers (136). We all aware that end stage renal disease is a chronic in nature that needs long term hemodialysis and also because of the limitation of diet, overtime, these burdens could affect both the quality of life of caregivers and patients. The other significant predictor of caregiver's quality of life is monthly family income of the caregivers. Every increase in one thousand kyat, will increase the quality life by 0.010. Most of the patients were unemployed and so they could not earn money for the expenses and so the financial burden only adds on the caregivers. As explained in the above in level of burden, because patients need to receive treatment for their whole lifetime and caregivers with lower family income experienced more burden which could further affect their quality of life. In western and developed Asian countries, they could provide hemodialysis access to all their patients, but in South and South East Asia countries, the full access of hemodialysis to all patients is still not achievable yet. Only

a portion of patients can still receive it. Although, the hemodialysis cost is much lower in South East Asia regions than in western countries, the patients cannot still afford for the expenses because of no health insurance from governments (52). Moreover, there are still many developing countries, including Myanmar, which still do not get the universal coverage, the expenses for hemodialysis will only be paid by out of pocket money, which eventually lead to more poverty and decline of quality of life.

In this study, the caregiver's age is also a significant factor that influenced their quality of life. The result showed that as the caregivers get older, their QoL decreased. With every year in age increase, the caregiver's quality of life by 0.149. It may be due to the performance of physical and mental of the older caregivers have declined. This result is the same as the other studies (5, 68, 130). However, in the study of caregivers in Japan (5), they used SF-36 to assess quality of life and they discovered that age was more affected to and could explain more variation to physical component of the QoL. But the other studies in Hong Kong and Thailand reported that younger caregivers had lower QoL (123, 132). In the study of caregivers in London and Nottingham, caregiver's age was not included in the significant predictors (137).

5.5 Limitation

- 1) As this study was conducted only at the private and charity dialysis centers in Yangon, it could not represent all the caregivers in Yangon and also could not be generalized the conditions of the caregivers of end stage renal diseases in the whole country of Myanmar.
- 2) This study used the purposive sampling, so it also limited the generalizability of the findings.
- 3) Because the study design is cross sectional, it is not possible to determine the relationship of the cause and effect.
- 4) The use of self-administered questionnaire can cause response bias as the participants could over or under rated their burden and quality of life and this might have affected the outcome of the study.

5.6 Conclusion

This study looked at the factors related to quality of life among the caregivers of end stage renal disease undergoing hemodialysis in Yangon, Myanmar. The factors which were studied, included the characteristics of caregivers and patients and also the caregiver's burden. The study found out that caregivers suffered from mild to moderate level of burden. Some of the characteristics of caregivers were related and affected the quality of life of caregivers but none of the patient's characteristics were associated with caregiver's quality of life. The most significant factors related with caregiver's quality of life were age and monthly family income of the caregivers and caregivers' burden. The monthly family income of the caregivers was positively associated with caregiver's quality of life whereas the caregivers' burden and caregiver's age were negatively associated with caregiver's quality of life.

It is hoped that this study shared new information about the factors which influenced the quality of life among the caregivers of end stage renal disease patients undergoing hemodialysis. The findings may also help the future researcher to conduct the research to improve the quality of life of caregivers. This can also help the health professionals and governments in considering and planning the programs so that the caregivers would achieve better quality of life.

5.7 Recommendation

1. To promote the public support measures such as social assistance from government and non-governmental organizations and also the better payment system from government to relieve the financial issues of the caregivers and patients (for example, government should create the system for registration of caregivers and provide allowance to caregivers, develop the health insurance programs and moreover government should cooperate together with the non-government organization who are interested and working for kidney disease and subsidize payment for patients)

2. To have a social worker in every dialysis unit who actively provide counselling and support to patients and caregivers on how handle and cope with difficult situations in caregiving.
3. Caregivers are needed to be supported by the government and Non-Governmental Organizations with web based educational information or published newsletters about the diseases so that they could learn the useful information and techniques for an effective management and care for patients. And the community could also learn how to prevent themselves from kidney disease and reduce the burden of disease.
4. Encourage the caregivers to take leisure time without feeling guilty
5. Further studies (both quantitative and qualitative) are needed to explore about the burden and quality of life of caregivers in Myanmar. The future studies should be done for caregivers of other chronic diseases as well to find out the differences among them and develop a better rehabilitation program.
6. Future studies need to consider the use of longitudinal design to address causal relationship among characters of caregivers, burden and QoL. And as the caregivers have to wait patients about 4 hours for an HD session, intervention program should be introduced to them to improve their quality of life.
7. As this study was done only at the private and charity dialysis units, further studies at government hospitals and dialysis units should also be done with the control group to know and compare the conditions of the caregivers.

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Annex 1: Self-Administered Questionnaire in English

Code Number

“Factors Related to Quality of life among caregivers of hemodialysis patients in Yangon”

Part 1: General Information about socio economic conditions of caregivers

- (1) Ageyears
- (2) Sex
(i) Male (ii) Female
- (3) Marital Status
(i) Single (ii) Married
(iii) Widowed (iv) Divorced/Separated
- (4) Education Level
(i) Illiterate (ii) Primary School (iii) Secondary School
(iv) High School (v) University (vi) other, please specify
.....
- (5) Occupation
(i) Unemployed (ii) Government sector (iii) Private sector
(iv) Business or Entrepreneur (v) General worker (vi) Non-Government sector
(vii) Others, please specify.....
- (6) Monthly Income Kyats
- (7) Relationship with patients
(i) Parents (ii) Spouse (iii) Daughter/Son
(iv) other, please specify
- (8) Number of Children
(i) None (ii) One (iii) Two
(iv) Three and above
- (9) Do you stay together with patients at the same house or different house from patient?
(i) Together with patient at the same house
(ii) Different house from patient

- (10) Hours per day taking care of patients hours
- (11) Months or Years as Caregivers
.....months or years
- (12) Extra Household works apart from taking care of patients
 (i) Nothing (only taking care of patient)
 (ii) Cooking
 (iii) Washing
 (iv) Cleaning
 (v) Others, please specify.....
- (13) Do you get any incentives or gifts from taking care of your patient?
 (i) Nothing
 (ii) Money
 (iii) Gift
 (iv) Others, please specify.....

Part 2: General Information about socio economic conditions of patients

- (1) Ageyears
- (2) Sex
 (i) Male (ii) Female
- (3) Occupation
 (i) Unemployed (ii) Government sector (iii) Private sector
 (iv) Business or Entrepreneur (v) General worker (vi) Non-Government sector
 (vi) Others, please specify.....
- (4) Comorbid conditions
 (i) Diabetes (ii) Hypertension (iii) Cardiovascular disease
 (iv) Poor nutrition (v) other, please specify

Part 3: Caregiver's burden

The following questions ask how you feel and your burden in taking care of patient. Please circle the response the best describes how you feel.

There are 5 options for answer and please choose only one answer that best describes your feeling.

0: Never

- 1: Rarely – in less than 10% of the chances
- 2: Sometimes – in about 50% of the chances
- 3: Quite Frequently – in about 70% of the chances
- 4: Nearly Always – More than 90% of the chances

Question		Score				
		Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1	Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4
2	Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
3	Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
4	Do you feel embarrassed over your relative's behavior?	0	1	2	3	4
5	Do you feel angry when you are around your relative?	0	1	2	3	4
6	Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0	1	2	3	4
7	Are you afraid what the future holds for your relative?	0	1	2	3	4
8	Do you feel your relative is dependent on you?	0	1	2	3	4

9	Do you feel strained when you are around your relative?	0	1	2	3	4
10	Do you feel your health has suffered because of your involvement with your relatives?	0	1	2	3	4
11	Do you feel that you don't have as much privacy as you would like because of your relatives?	0	1	2	3	4
12	Do you feel that your social life has suffered because you are caring for your relatives?	0	1	2	3	4
13	Do you feel uncomfortable about having friends over because of your relatives?	0	1	2	3	4
14	Do you feel that your relative seems to expect you to take care of him/her as if you were the only one, he/she could depend on?	0	1	2	3	4
15	Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4
16	Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
17	Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4

18	Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4
19	Do you feel uncertain about what to do about your relative?	0	1	2	3	4
20	Do you feel you should be doing more for your relative?	0	1	2	3	4
21	Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
22	Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4

Part 4: Quality of life

The following questions ask how you feel about your quality of life. Please circle the response the best describes how you feel.

There are 5 options for answer and please choose only one answer that best describes your feeling. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life in the last four weeks (The overall quality of life and general health facet).

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	Questions	Very poor	Poor	Neither poor nor good	Good	Very Good
1	How would you rate your quality of life?	1	2	3	4	5
2	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about how much you have experienced certain things in the last four weeks.

	Questions	Very poor	Poor	Neither poor nor good	Good	Very Good
3	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life?	1	2	3	4	5
6	To what extent do you feel your life to be meaningful?	1	2	3	4	5
7	How well are you able to concentrate?	1	2	3	4	5
8	How safe do you feel in your daily life?	1	2	3	4	5
9	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

	Questions	Very poor	Poor	Neither poor nor good	Good	Very Good
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	Have you enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5
15	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

	Questions	Very poor	Poor	Neither poor nor good	Good	Very Good
16	How satisfied are you with your sleep?	1	2	3	4	5
17	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity for work?	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21	How satisfied with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

	Questions	Very poor	Poor	Neither poor nor good	Good	Very Good
26	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Thank you so much for your help.

Annex 2: Self-Administered questionnaire in Burmese

ကျောက်ကပ်သန့်စင်ကုသမှုခံယူနေသောလူနာများကိုပြုစုစောင့်ရှောက်နေသူတို့၏ဘဝအရည်အသွေးနှင့်ဆက်စပ်နေသောအချက်များ

ကုဒ်နံပါတ် -

အပိုင်း (၁) လူနာပြုစုစောင့်ရှောက်သူ၏အထွေထွေအချက်အလက်များ

အောက်ပါမေးခွန်းများတွင်သင့်အဖြေကိုဝိုင်းပေးပါ။

၁. သင့်အသက်နှစ်

၂. (၁) ကျား (၂) မ

၃. အိမ်ထောင်ရေး

(၁) အိမ်ထောင်မရှိ (၂) အိမ်ထောင်ရှိ (၃) မုဆိုးဖို/မုဆိုးမ
(၄) ကွာရှင်းထား

၄. ပညာအရည်အချင်း

(၁) အတန်းပညာမရှိ (၂) မူလတန်း (၃) အလယ်တန်း (၄) အထက်တန်း
(၅) တက္ကသိုလ်ပညာ (၆) အခြားဖြစ်ပါကဖော်ပြရန်

၅. အလုပ်အကိုင်

(၁) အလုပ်မရှိ (၂) အစိုးရဝန်ထမ်း (၃) ပုဂ္ဂလိကဝန်ထမ်း
(၄) ကိုယ်ပိုင်စီးပွားရေး (၅) အစိုးရမဟုတ်သောအဖွဲ့အစည်း (၆) အထွေထွေ/နေ့စား
(၇) အခြားဖြစ်ပါကဖော်ပြရန်

၆. လစဉ်မိသားစုဝင်ငွေကျပ်

၇. လူနာနှင့်မည်သို့တော်စပ်သနည်း။

(၁) သူ့မိဘ (၂) အမျိုးသား/အမျိုးသမီး (၃) သား/သမီး
(၄) သူငယ်ချင်း/အိမ်နီးချင်း (၅) အခြား၊ ဖော်ပြပေးပါ

၈. ကလေးဘယ်နှယောက်ရှိသနည်း



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- (၁) မရှိ (၁) ၁ယောက် (၂) ၂ယောက်
- (၂) ၃ယောက်နှင့်အထက်

၉. လူနာနှင့်တအိမ်တည်းနေပါသလား(သို့မဟုတ်)အခြားအိမ်တွင်သီးခြားနေပါသလား။
 (က) လူနာနှင့်တအိမ်တည်း (ခ) အခြားအိမ်

၁၀. ၁ရက်အတွင်းလူနာကိုအချိန်မည်မျှပေး၍ကြည့်ရှုသနည်း။နာရီ

၁၁. လူနာကိုပြုစုလာသည်မှာဘယ်နှစ်လ/ဘယ်နှနှစ်ရှိပြီလဲ။လ နှစ်

၁၂. လူနာကိုပြုစုစောင့်ရှောက်သည့်အပြင်အခြားအိမ်မှုကိစ္စလုပ်ရပါသလား(တခုထက်ပိုပြီးရှိပါကဖြေဆိုနိုင်သည်)

- (၁) မလုပ်ရပါ (၂) ထမင်း/ဟင်းချက် (၃) အဝတ်လျှော် (၄) အိမ်သန့်ရှင်းရေး
- (၅) အခြားရှိပါကဖော်ပြပေးရန်

၁၃. လူနာကိုပြုစုစောင့်ရှောက်သောကြောင့်လူနာထံမှတစ်ခုခုရရှိပါသလား။

- (၁) မရရှိပါ (၂) မုန့်ဖိုး (၃) လက်ဆောင်ပစ္စည်း
- (၄) အခြားရှိပါကဖော်ပြပေးရန်

အပိုင်း(၂) လူနာ၏အထွေထွေအချက်အလက်

၁. လူနာအသက်နှစ်

၂. (၁) ကျား (၂) မ

၃. အလုပ်အကိုင်

- (၁) အလုပ်မရှိ (၂) အစိုးရဝန်ထမ်း (၃) ပုဂ္ဂလိကဝန်ထမ်း
- (၄) ကိုယ်ပိုင်စီးပွားရေး (၅) အစိုးရမဟုတ်သောအဖွဲ့အစည်း (၆) အထွေထွေ/နေ့စား
- (၇) အခြားဖြစ်ပါကဖော်ပြရန်

၄. လူနာထံတွင်ရှိသောရောဂါများ (တခုထက်ပိုရှိပါကဖြေဆိုနိုင်ပါသည်)

- (၁) ဆီးချို (၂) သွေးတိုး (၃) နှလုံးသွေးကြောဆိုင်ရာရောဂါ
- (၄) အာဟာရချို့တဲ့ခြင်း
- (၅) အခြားရှိပါကဖော်ပြရန်

အပိုင်း (၃) လူနာပြုစုစောင့်ရှောက်သူ၏ဝန်ဖိစီးမှု

အောက်ပါမေးခွန်းတို့သည်

သင်လူနာကိုပြုစုစောင့်ရှောက်ရာတွင်ခံစားရသောဝန်ဖိစီးမှုအတွက်မေးခွန်းများဖြစ်ပါသည်။ အဖြေ ၀ မှ ၄ အတွင်း သင်ခံစားရသည်နှင့်ကိုက်ညီသည့်အဖြေတစ်ခုကိုသာဝိုင်းပါ။

၀ = လုံးဝမဖြစ်

၁ = ဖြစ်ခဲ - ၁၀% လောက်သာခံစားရပါက

၂ = တခါတရံ - ၅၀% လောက်ခံစားရပါက

၃ = မကြာခဏ - ၇၀% လောက်ခံစားရပါက

၄ = အမြဲတမ်းလိုလို

စဉ်	မေးခွန်း	အမှတ်				
		လုံးဝ မဖြစ်	ဖြစ်ခဲ	တခါ တရံ	မကြာ ခဏ	အမြဲတမ်း လိုလို
၁	သင့်ဆွေမျိုး(လူနာ)သည်လိုအပ်သည်ထက်ပို၍ အကူအညီပိုတောင်းသည်ဟု သင်ခံစားရပါသလား	၀	၁	၂	၃	၄
၂	သင့်ဆွေမျိုး(လူနာ)ကို အချိန်ပေးရသောကြောင့် သင့်အတွက်ကိုယ်ပိုင်အချိန်မရှိဟု ခံစားရပါသလား	၀	၁	၂	၃	၄
၃	သင့်ဆွေမျိုး(လူနာ)ကို ပြုစုစောင့်ရှောက်ခြင်းနှင့် မိသားစု(သို့မဟုတ်) အလုပ်နှင့်ဆိုင်သော အခြားတာဝန်ဝတ္တရားများကို ဖြည့်စည်းနိုင်အောင် ကြိုးစားရာမှ အကြားတွင် စိတ်ဖိစီးမှုခံစားရပါသလား	၀	၁	၂	၃	၄
၄	သင့်ဆွေမျိုး(လူနာ)၏ အပြုအမူကြောင့် သင်အရှက်ရခြင်းကို ခံစားရပါသလား	၀	၁	၂	၃	၄
၅	သင့်ဆွေမျိုး(လူနာ)အနားတွင် ရှိနေစဉ် သင်ဒေါသထွက်ခြင်းကို ခံစားရပါသလား	၀	၁	၂	၃	၄
၆	သင့်ဆွေမျိုး(လူနာ)ကြောင့် သင်သည် အခြားမိသားစုဝင်များ(သို့မဟုတ်) သင့်သူငယ်ချင်းများနှင့် ပေါင်းသင်းဆက်ဆံရေးအဆင်မပြေခြင်း၊ အပျက်သဘောဆောင်ခြင်းများ(ပျက်ယွင်း) ရှိသည်ဟု သင်ခံစားရပါသလား	၀	၁	၂	၃	၄
၇	သင့်ဆွေမျိုး(လူနာ)၏ ရှေ့ရေးအတွက် ကြောက်ရွံ့စိုးရိမ်မှုများ ရှိပါသလား	၀	၁	၂	၃	၄

၈	သင့်ဆွေမျိုး(လူနာ)သည်သင့်အပေါ်တွင်အားထားမှီခိုသည်ဟုခံစားရပါသလား	၀	၁	၂	၃	၄
၉	သင့်ဆွေမျိုး(လူနာ)အနားတွင်ရှိနေစဉ်သင်သည်အားအင်ကုန်ခမ်းပြီး ပင်ပန်းသည်ဟုခံစားရပါသလား	၀	၁	၂	၃	၄
၁၀	သင့်ဆွေမျိုး(လူနာ)ကိုပြုစုစောင့်ရှောက်ခြင်း၊ အချိန်ပေးခြင်းတို့ကြောင့်သင့်ကျန်းမာရေးထိခိုက်သည်ဟုသင်ခံစားရပါသလား	၀	၁	၂	၃	၄
၁၁	သင့်ဆွေမျိုး(လူနာ)ကြောင့်သင်သီးသန့်တစ်ယောက်တည်းနေလိုသည့်အတိုင်းမနေရဟုသင်ခံစားရပါသလား	၀	၁	၂	၃	၄
၁၂	သင့်ဆွေမျိုး(လူနာ)ကိုပြုစုစောင့်ရှောက်ခြင်းကြောင့်သင်၏ လူမှုရေးဘဝထိခိုက်သည်ဟုသင်ခံစားရပါသလား	၀	၁	၂	၃	၄
၁၃	သင့်သူငယ်ချင်းများကိုအိမ်သို့ဖိတ်ကြားသောအခါတွင်သင့်ဆွေမျိုး (လူနာ)ကြောင့်သင်စိတ်ကသိကအောက်ခံစားရခြင်းများရှိပါသလား	၀	၁	၂	၃	၄
၁၄	သင့်ဆွေမျိုး(လူနာ)သည်သင်တစ်ဦးတည်းကိုသာမှီခိုအားထားပြီးသင်သာလျှင်သူ့ကိုပြုစုစောင့်ရှောက်ရန်သူ့မျှော်လင့်သည်ဟုသင်ခံစားရပါသလား	၀	၁	၂	၃	၄
၁၅	သင့်ဆွေမျိုး(လူနာ)ကိုပြုစုစောင့်ရှောက်ရန်လိုအပ်သောကုန်ကျစရိတ်အပြင်အခြားသောသင်၏ ကုန်ကျစရိတ်များအတွက်သင့်ထံ၌လုံလောက်သောငွေ ကြေးပမာဏမရှိဟုသင်ခံစားရပါသလား	၀	၁	၂	၃	၄
၁၆	သင့်ဆွေမျိုး(လူနာ)ကိုကြာရှည်ပြုစုစောင့်ရှောက်ပေးနိုင်မည်မဟုတ်ဟုသင်ခံစားရပါသလား	၀	၁	၂	၃	၄
၁၇	သင့်ဆွေမျိုး(လူနာ)စတင်နေမကောင်းသည့်အချိန်မှစ၍သင့်ဘဝသည်အထိန်းအကွပ်မဲ့(ကောင်းမွန်စွာမတွေးခေါ်နိုင်ခြင်း၊မပြုမှုနိုင်ခြင်းများ) ဖြစ်သွားသည်ဟုသင်ခံစားရပါသလား	၀	၁	၂	၃	၄
၁၈	သင့်ဆွေမျိုး(လူနာ)အားပြုစုစောင့်ရှောက်မှုကိုအခြားသူတစ်ဦးထံသို့ပေးအပ်လိုက်ချင်သည်ဟုသင်ခံစားရပါသလား	၀	၁	၂	၃	၄
၁၉	သင့်ဆွေမျိုး(လူနာ)အတွက်ဘာလုပ်ပေးရမည်ဆိုသည်ကိုသေသေချာချာမသိဟုသင်ခံစားရပါသလား	၀	၁	၂	၃	၄

၂၀	သင့်ဆွေမျိုး(လူနာ)အတွက်ဒီထက်ပို၍လုပ်ပေးသင့်သည်ဟုသင်ခံစားရပါသလား	၀	၁	၂	၃	၄
၂၁	သင့်ဆွေမျိုး(လူနာ)ကိုပြုစုစောင့်ရှောက်ရာတွင်ပိုပြီးကောင်းမွန်စွာလုပ်ပေးနိုင်သည်ဟုသင်ခံစားရပါသလား	၀	၁	၂	၃	၄
၂၂	ယေဘုယျခြံငုံကြည့်လျှင်သင့်ဆွေမျိုး(လူနာ)ကိုပြုစုစောင့်ရှောက်ရာ တွင် သင်ဝန်ထုပ်ဝန်ပိုး ခံစားရပါလား	၀	၁	၂	၃	၄

အပိုင်း (၄) ဘဝအရည်အသွေးဆိုင်ရာမေးခွန်းများ

အောက်ပါမေးခွန်းများသည် သင်၏ဘဝအရည်အသွေးနှင့် ပတ်သက်သော မေးခွန်းများဖြစ်ပါသည်။ သင့်အတွက် အသင့်လျော်ဆုံးသော အဖြေတစ်ခုကို ရွေးချယ်ပါ။ လွန်ခဲ့သော(၄)ပတ်အတွင်းခံစားရခြင်းနှင့်ပတ်သက်၍ဖြေကြားပေးပါ။

		အလွန်ဆိုးသည်	ဆိုးသည်	အသင့်အတင့်	ကောင်းသည်	အလွန်ကောင်း
၁	သင်၏ ဘဝအရည်အသွေးကို သင်မည်ကဲ့သို့အဆင့်သတ်မှတ်မည်နည်း။	၁	၂	၃	၄	၅
၂	သင်၏ကျန်းမာရေးအခြေအနေကို သင်မည်မျှကျေနပ်အားရမှု ရှိပါသလဲ။	၁	၂	၃	၄	၅

အောက်ပါမေးခွန်းများသည် จุฬาลงกรณ์มหาวิทยาลัย လွန်ခဲ့သော(၄)ပတ်အတွင်းသင်တွေ့ကြုံခံစားရသည်နှင့်ပတ်သက်၍မေးထားပါသည်။

		လုံးဝမရှိ	အနည်းငယ်ရှိ	အသင့်အတင့်	အလွန်ရှိ	အများအပြားရှိ
၃	ကိုယ်လက်ကိုက်ခဲမှုကြောင့်သင့်အလုပ်ကို မည်မျှအဟန့်အတား ဖြစ်စေသနည်း။	၁	၂	၃	၄	၅
၄	သင့်တန့်တောလုပ်ငန်းများကိုဆောင်ရွက်ရန် ဆေးဝါးသောက်သုံးမှုမည်မျှလိုအပ်ပါသနည်း။	၁	၂	၃	၄	၅
၅	ဘဝကို သင်မည်မျှပျော်ရွှင်ပါသနည်း။	၁	၂	၃	၄	၅
၆	သင့်ဘဝအဓိပ္ပာယ်ပြည့်စုံသည်ဟု မည်မျှထင်ပါသနည်း။	၁	၂	၃	၄	၅
၇	သင်မည်မျှကောင်းစွာအာရုံစူးစိုက်နိုင်သနည်း။	၁	၂	၃	၄	၅

၈	သင့်ဘဝလုံခြုံမှု မည်မျှရှိသနည်း။	၁	၂	၃	၄	၅
၉	သင်၏အိမ်နှင့်အလုပ်ပတ်ဝန်းကျင်သည် သင်၏ကျန်းမာရေးအတွက် မည်မျှကောင်းမွန် ပါသနည်း။	၁	၂	၃	၄	၅
၁၀	သင်၏တနေ့တာလုပ်ဆောင်ချက်များအတွက် အင်အားအလုံအလောက် ရှိပါသလား။	၁	၂	၃	၄	၅
၁၁	သင့်ရုပ်အဆင်းကိုသင်ကျေနပ်မှုရှိပါသလား။	၁	၂	၃	၄	၅
၁၂	သင်၏လိုအပ်ချက်များကိုဖြည့်ဆည်းရန် ငွေကြေးအလုံအလောက်ရှိပါသလား။	၁	၂	၃	၄	၅
၁၃	သင့်ဘဝအတွက် လိုအပ်သော သတင်းအချက်များကို သင်မည်မျှရရှိပါသလဲ။	၁	၂	၃	၄	၅
၁၄	အားလပ်ချိန်ကိုယ်လက်လှုပ်ရှားမှုအတွက် အခွင့်အရေးရှိပါသလား။	၁	၂	၃	၄	၅
၁၅	သင်၏ပတ်ဝန်းကျင်တွင် မည်မျှကောင်းစွာ သွားလာနိုင်သနည်း။	၁	၂	၃	၄	၅

အောက်ပါမေးခွန်းတို့သည်သင့်ဘဝတွင်လွန်ခဲ့သော(၄)ပတ်အတွင်းတွေ့ကြုံရသည်များနှင့်ပတ်သက်၍ မည်မျှကျေနပ်မှုရှိသည်ကိုမေးထားခြင်းဖြစ်ပါသည်။

		အလွန် မ ကျေနပ်	မကျေနပ်ပါ	အသင့် အတင့်	ကျေနပ် ပါသည်	အလွန် ကျေနပ် ပါသည်
၁၆	သင်၏အိပ်စက်ချိန်ကို သင် ကျေနပ်မှုရှိပါ သလား။	၁	၂	၃	၄	၅
၁၇	သင်၏တနေ့တာလုပ်ငန်းများ ဆောင်ရွက် နိုင်စွမ်းကို ကျေနပ်အားရပါသလား။	၁	၂	၃	၄	၅
၁၈	သင်၏လုပ်ငန်းခွင်တွင် အလုပ်လုပ်နိုင်စွမ်း ကို ကျေနပ်အားရပါသလား။	၁	၂	၃	၄	၅
၁၉	သင်ကိုယ်သင် ကျေနပ်အားရပါသလား။	၁	၂	၃	၄	၅
၂၀	သင်၏ကိုယ်ရေးကိုယ်တာ ဆက်ဆံမှုကို ကျေနပ်အားရပါသလား။	၁	၂	၃	၄	၅
၂၁	သင်၏လိင်မှုရေးရာ(သို့) အပျိုလူပျိုဘဝ ကိုကျေနပ်အားရပါသလား။	၁	၂	၃	၄	၅

၂၂	သင်၏မိတ်ဆွေသူငယ်ချင်းများထံမှ ရရှိသော အကူအညီများကို သင်ကျေနပ် အားရပါသလား။	၁	၂	၃	၄	၅
၂၃	သင်၏နေထိုင်မှုအခြေအနေကို သင်ကျေနပ် အားရပါသလား။	၁	၂	၃	၄	၅
၂၄	သင်၏ ကျန်းမာရေးစောင့်ရှောက်မှုခံယူနိုင် စွမ်းကို သင်ကျေနပ် အားရပါသလား။	၁	၂	၃	၄	၅
၂၅	သင့်အတွက် လမ်းပန်းဆက်သွယ်ရေး အခြေအနေကို သင်ကျေနပ်အားရပါသလား။	၁	၂	၃	၄	၅

		လုံးဝမရှိ	အချို့အချိန်	မကြာခဏ	ခဏခဏ	အမြဲတမ်း
၂၆	စိတ်မရွှင်လန်းမှု၊ ပူပန်သောကရောက်မှုတို့ကို မကြာခဏ ခံစားရပါသလား။	၁	၂	၃	၄	၅

ယခုကဲ့သို့ဖြေကြားပေးခြင်းအတွက်အထူးကျေးဇူးတင်ရှိပါသည်။

Annex 3: Participant Information Sheet

Title of Research: **Factors Related to Quality of life among caregivers of end stage renal disease (ESRD) patients undergoing hemodialysis in Yangon, Myanmar**

Name of Principal Researcher: **Ms. Naw Wah Ka Paw**

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1. You are being invited to take part in a research project. Before you decide to participate it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and do not hesitate to ask if anything is unclear or if you would like more information.
2. The purpose of this study is to determine the characteristics of caregivers of hemodialysis patients in Yangon, to discover their burden and quality of life and find out the factors related to the quality of life of caregivers.
3. In this research, the participants will be caregivers of hemodialysis patients in Yangon, Myanmar. This study will need at least 200 participants. Participants who meet inclusion criteria and who do not meet the exclusion criteria will be involved in this study.

Inclusion Criteria	Exclusion Criteria
<ol style="list-style-type: none"> 1. Caregivers of end stage renal disease patients undergoing hemodialysis, who are willing to participate in the study. 2. Caregivers both male and female ≥ 18 years' old 3. Caregivers who take care of end stage renal disease patients undergoing hemodialysis, for a minimum of 3 months 4. Caregivers who involve in caring and assisting with daily activities of patients 	<ol style="list-style-type: none"> 1. A person who is not a regular, persistent caregiver for the patient.

4. The list of samples of participants will be selected according to lists from hemodialysis centers. This maximum sample size to collect the data is 200 samples. Then, the principal researcher will explain about the information regarding the study and taking consent in both oral and written consent.
5. After the principal researcher explain you regarding the study using participant information sheets, they will ask your will to participate in this study and they will take oral consent and written consent using informed consent form. If the participant is illiterate, the researcher will read all the information in this document and in consent form in front of the literate witness who can read and write well and get the signature from witness. If participant willing to participate, they can give written consent and sign in the consent form. If you do not want to participate, you do not need to give consents and you do not need to give an explanation.
6. After getting consent from you, data collection will be started by letting the participants fill the self-administered questionnaire. Researcher will read the questionnaires and fill the response for those caregivers who cannot read or write. The questionnaire consists of 4 parts; Part 1 contains 12 items and it is

about the socio demographic factors of caregivers, Part 2 contains 4 items and is about the socio demographic factors of patients, Part 3 contains 22 items and it is about your burden in caregiving and Part 4 has 26 items related with your quality of life. It will take about 30-45 minutes to fill the questionnaires and the researcher will collect it once you finished it. You can fill the questionnaire form in the other room closed to hemodialysis room or you can fill it just besides your patients.

7. The study will not give benefit directly to you as it provides the baseline information for institute and country to develop a policy and intervention for wellbeing of caregivers and also for the researcher to develop the further study. However, your participation will be beneficial for your community and your country. Nevertheless, the researcher will give you *a towel and a pen* as appreciation for your participation.
8. No harms and/or risks of any kind can be inflicted upon participants. You may refuse to answer any question or not take part in a portion of the interview if you feel the question(s) are personal or if talking about them makes you uncomfortable.
9. Any information that is linked to you will be kept confidentially. Even though the study will be published, your names or other identifying information will not be mentioned in the report or summaries of the study. The final report can be available from principal researcher and the report will not be used with another intension. The data will be kept confidentially during the process of report and research and all data files together with the participants' answer on questionnaires will be destroyed after final report has been done.
10. You have the right to choose or refuse for giving consent and participating in this study. Even after giving consent, you can withdraw from the study at any time and no need to give any reason. There will not be any bad consequence to you for this reason. You can also ask anything you want to know before, during

and after the study conduct any time. You can contact the principal researcher with given address mentioned above or you can make report to the Research Ethics Review Committee, Chulalongkorn University (RECCU), Jamjuree 1 Bldg., 2nd floor., 254 Phayathai Road., Pathuwam District, Bangkok 10330, Thailand, Tel/Fax +662218-3202 E-mail: eccu@chula.ac.th at any time if you have any questions or complaints about this study or the researcher does not treat the participant according to the indications above.



Annex 4: Informed consent form

Address.....

Date.....

Code number of participants.....

I who have signed here below do agree to participate in this research project.

Title: “Factors related to Quality of life among caregivers of end stage renal disease (ESRD) patients undergoing hemodialysis in Yangon, Myanmar.

Name of Principal Researcher: Ms. Naw Wah Ka Paw

Contact Address: Karen Baptist Theological Seminary Hill, East Gyogone, Insein, Yangon.

Telephone: 09 540 5526

I have read or been informed in details about the rationale and objectives of this research study what I will be engaged with, risk and benefits of the study and the rights of the participants. I have already received the contact details of the principal researcher. I have been explained by the researcher in information sheet and I clearly understand with satisfaction.

I am willing to participate in this research and to response the questionnaires which are focusing on socio-demographic information about me and my patient, my burden of caregiving and quality of life. I have been informed that the interview will take about 30-45 minutes, and will be done only 1 time.

I have my right to withdraw from this study at any time if I wish and I would not need to give any reason for withdrawal. This withdrawal will not have any negative impact on me. The researcher has guaranteed that procedures acting upon me would be exactly the same as identified in participant information sheet. All personal information about me will be kept in confidential. Results of the study will be described by using the overall picture. Any of personal information which could be able to identify me will not be described in the report.

If I am not treated as mentioned in the participant information sheet, I have known that I can report to Ms. Naw Wah Ka Paw, principal researcher, Master Student at College of Public Health Sciences, Tel: 09 540 5536, email address: wkapaw@gmail.com, or to the Research Ethics Review Committee for Research Involving Human Research Participants, Health Sciences Group, Chulalongkorn University (CCU). Jamjuree 1 Bldg., 2nd floor, 254 Phayathai Road, Pathumwan district, Bangkok 10330, Thailand, Tel./ax, +66-2218-3202 email: eccu@chula.ac.th.

I have read the information in this consent form, or it has been read to me. Furthermore, I have received a copy of participant's information sheet and informed consent form.

Researcher's Name – Naw Wah Ka Paw	Participant's Name
Signature of researcher	Signature of participant
Date ___/___/___/	Date ___/___/___/
(Day /month /year)	(Day /month /year)

If illiterate

I have witnessed the accurate reading of the consent form to the potential participant, and the individual had the opportunity to ask questions. I confirm that the individual has given consent freely.

Witness's Name
Signature of witness
Date ___/___/___/
(Day /month /year)

Annex 5: Administration and Time Schedule

Research Activities	Time Frame 2018				Time Frame 2019						
	Sep	Oct	Nov	Dec	Jan	Feb	March	April	May	June	July
Literature Review	■	■	■								
Proposal Writing			■	■							
Tool Development for data collection				■	■						
Proposal Examination						■					
Ethical approval							■	■			
Pretesting and data collection									■		
Data Analysis									■	■	
Thesis Writing										■	
Thesis Examination											■
Submitting Final Thesis											■

Annex 6: Budget

No	Description	Estimated expenses (Baht)
1	Questionnaire for pretesting	50
2	Buying stationary	900
3	Questionnaire for data collection	600
4	Transportation	5,000
5	Gifts for participants	12,000
7	Miscellaneous	2,000
	Total	20,550



Annex 7: Certificate of Ethical Approval



AF 02-12

The Research Ethics Review Committee for Research Involving Human Research
Participants, Health Sciences Group, Chulalongkorn University
Jamjuree 1 Building, 2nd Floor, Phyathai Rd., Patumwan district, Bangkok 10330, Thailand,
Tel/Fax: 0-2218-3202, 0-2218-3409 E-mail: eccu@chula.ac.th

COA No. 129/2019

Certificate of Approval

Study Title No. 055.1/62 : FACTORS RELATED TO QUALITY OF LIFE AMONG CAREGIVERS
OF END STAGE RENAL DISEASE (ESRD) PATIENTS UNDERGOING
HEMODIALYSIS IN YANGON

Principal Investigator : MISS NAW WAH KA PAW

Place of Proposed Study/Institution : College of Public Health Sciences,
Chulalongkorn University

The Research Ethics Review Committee for Research Involving Human Research
Participants, Health Sciences Group, Chulalongkorn University, Thailand, has approved constituted
in accordance with Belmont Report 1979, Declaration of Helsinki 2013, Council for International
Organizations of Medical Sciences (CIOM) 2016, Standards of Research Ethics Committee (SREC)
2013, and National Policy and guidelines for Human Research 2015.

Signature: 
(Associate Prof. Prida Tasanapradit, M.D.)
Chairman

Signature: 
(Assistant Prof. Nuntaree Chaichanawongsaroj, Ph.D.)
Secretary

Date of Approval : 3 May 2019

Approval Expire date : 2 May 2020

The approval documents including;

- 1) Research proposal
 - 2) Participant Information Sheet and Consent Form
 - 3) Researcher
 - 4) Questionnaire
- 
- Protocol No. 055.1/62
Date of Approval - 3 MAY 2019
Approval Expire Date - 2 MAY 2020

The approved investigator must comply with the following conditions:

1. The research/project activities must end on the approval expired date of the Research Ethics Review Committee for Research Involving Human Research Participants, Health Sciences Group, Chulalongkorn University (RECCU). In case the research/project is unable to complete within that date, the project extension can be applied one month prior to the RECCU approval expired date.
2. Strictly conduct the research/project activities as written in the proposal.
3. Using only the documents that bearing the RECCU's seal of approval with the subjects/volunteers (including subject information sheet, consent form, invitation letter for project/research participation (if available)).
4. Report to the RECCU for any serious adverse events within 5 working days
5. Report to the RECCU for any change of the research/project activities prior to conduct the activities.
6. Final report (AF 03-12) and abstract is required for a one year (or less) research/project and report within 30 days after the completion of the research/project. For thesis, abstract is required and report within 30 days after the completion of the research/project.
7. Annual progress report is needed for a two- year (or more) research/project and submit the progress report before the expire date of certificate. After the completion of the research/project processes as No. 6.

VITA

NAME Naw Wah Ka Paw

DATE OF BIRTH 07 July 1989

PLACE OF BIRTH Yangon

**INSTITUTIONS
ATTENDED** College of Public Health and Science

HOME ADDRESS Soi Petchaburi 18, 488/18, Phayathai, Ratchathewi
District, Bangkok, Thailand



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CHULALONGKORN UNIVERSITY