

## ORIGINAL ARTICLE

## ASSESSING AND PREDICTING QUALITY OF LIFE AMONG CAREGIVERS OF PEOPLE SUFFERING FROM END STAGE RENAL DISEASE UNDERGOING HEMODIALYSIS: THE CASE OF YANGON, MYANMAR

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## ABSTRACT

*Diminishing quality of life of caregivers could increase their pressures, burdens and interfere with their quality services. The aim of this study is to determine the factors predicting the QoL of the caregivers who took care of end stage renal disease undergoing hemodialysis people. A cross-sectional study was conducted involving 210 caregivers providing services to patients suffering from end stage renal disease undergoing hemodialysis in Yangon, Myanmar. Purposive sampling was performed to selection the participants and the data were collected by using self-administered questionnaires. Hierarchical linear regression was performed with the QoL as dependent variable and three blocks of predictors (the first block; burden, the second block; caregiver's age and monthly family income, and the third block; marital status and relationships with patients). The study found that caregiver's burden and age negatively and significantly affected the QoL whereas monthly family income positively affected the QoL. The best model was [Quality of life =  $B_0 + B_1$  (level of burden) +  $B_2$  (caregiver's age) +  $B_3$  (caregiver's monthly family income)] where  $B_0$ ,  $B_1$ ,  $B_2$  and  $B_3$  were 98.135, (-0.395), (-0.149) and 0.010 respectively. The health professionals, related government agencies, communities, and health related officers should develop the proper strategies and programs for improving the QoL of caregivers.*

**Keywords:** Caregivers, end stage renal disease, hemodialysis, quality of life, Yangon, Myanmar.

## INTRODUCTION

Chronic kidney disease is a critical public health issue and may eventually lead to end stage renal disease (ESRD) called kidney failure that needs a regular dialysis treatment or kidney transplant to survive<sup>1</sup>. According to the study of global burden of disease in 2015, among the most common cause of death, kidney disease ranked 12<sup>th</sup> and has caused 1.1 million deaths globally. Over the past 10 years, the figure of death caused by CKD has risen by 31.7%, making it one of the surging main causes of death<sup>2</sup>. In 2010, 2.62 million people around the world received dialysis and by 2030, the demand for dialysis was forecasted to be double<sup>3</sup>.

Family caregiving service is the most suitable source for hemodialysis patients to fulfil their personal, domestic and medical needs, because the government or other care services cannot afford to deliver the equal care as provided by the family caregivers. These caregivers are important for several reasons as they offer huge amount of assistance; but the long-term task of caregiving has adverse effects on caregiver's quality of life both physically and mentally apart from social life to a greater extent that they may not be able to continue performing their caregiving services role. Supporting and encouraging the caregivers are, therefore, needed to qualify them so that

they can provide effective services over a long period of time, often many years and avert the significant stress that can be linked with caregiving<sup>4</sup>.

The quality of life (QoL) is the crucial element in people's life, especially in patients suffering from chronic diseases such as breast cancer, diabetes, hypertension, and renal disease<sup>5, 6, 7, 8</sup>. The definition of the QoL was defined as a personal well-being in the multi-dimensional, holistic, and perspectives including physical, psychological, social, and spiritual dimensions<sup>9</sup>. Moreover, the QoL is also a crucial issue among patients undergoing hemodialysis. In most cases, these patients have experienced some or all of the following emotional symptoms during or post hemodialysis: frustration, poor sleep, fear, sadness or even anger<sup>10, 11</sup>. The health problems and related health issues of renal disease patients also affect the QoL among caregivers and could result in the burden, anxiety, and depression of caregivers<sup>12</sup>. According to the path analysis result of burden, anxiety, and depression of caregivers looking after hemodialysis patients in Indonesia showed that, the burden had the positive correlation with anxiety/depression and negative correlation with QoL through the anxiety/depression. The QoL among caregivers of hemodialysis patients in Indonesia was found to be indirectly affected by the burden through anxiety

and depression<sup>12</sup>. This corresponds to the study of primary family caregivers of hemodialysis patients in Southern Ethiopia which revealed the family caregivers of hemodialysis patients experiencing the lifestyle changes, fatigue, emotional responses, and burden<sup>13</sup>.

In Myanmar, there is a disparity in the provision of hemodialysis treatment between Yangon and other districts. As of 2016, Yangon has 30 hemodialysis centers and 129 hemodialysis machines compared with all other districts which has 22 hemodialysis centers and 199 machines in total. Most of the patients across the country received treatment at Yangon which is more easily accessible at Yangon<sup>14</sup>. Therefore, this study aims to determine the factors predicting the QoL of the caregivers who took care of end stage renal disease patients undergoing hemodialysis that could influence the caregiver's quality of life.

## METHODS

The study design is a cross-sectional study and was conducted in May 2019 in 3 private hemodialysis centers in Yangon, Myanmar involving 210 caregivers of hemodialysis patients. For calculating sample size, the minimum ratio of observations to variables is 5:1<sup>15</sup>. This study used 10:1, and therefore, 180 samples are needed. Caregivers, over or equal 18 years old, daily and regularly taking care of patients were invited to participate in this study. Purposive sampling technique was used to organize caregivers who met the inclusion criteria. Ethical approval was obtained from the research ethics review committee for Research Involving human research Participants, Health sciences group, Chulalongkorn University and permission from authorities of 3 hemodialysis centers were also obtained (IRB Code: 055.1/62).

The dependent variable is the caregiver's QoL and the independent variables contain the caregivers' characteristics and burden. The measurement tool has 3 parts; Part 1. Caregivers' characteristics cover 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. Caregivers' burden, using Zarit Burden Interview questionnaire; Part 3. QoL of caregivers, using WHOQUALITY OF LIFE-BREF in Burmese version.

Zarit burden interview 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. Score between 0 to 20 indicates "little or no burden", 21-40 indicates "mild to moderate burden", 41-60 indicates "moderate to severe

burden" and 61-88 indicates "severe burden"<sup>16,17</sup>. In the present study, the internal consistency of the scale tested by Cronbach's alpha was 0.71. The authors obtained permission from Mapi Research Trust<sup>18</sup> which is the officially distributor of Zarit Burden Interview. This questionnaire was translated from English to Burmese by Myanmar experts who are well verse with English language and back translation was also done from Burmese language.

WHOQUALITY OF LIFE-BREF Burmese version covering 26 items and divided into 4 domains (1) Physical (2) Psychological (3) Social and (4) Environmental. 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<sup>19</sup>. Raw scores were used for data analysis. The mean score of items within each domain is used to calculate the domain score. Domain scores are scaled in a positive direction (i.e., higher scores denote higher Quality of life). The internal consistency of the scale tested by Cronbach's alpha was 0.86<sup>20</sup>. The authors were officially allowed to use the QoL (Burmese version)<sup>20</sup>.

## Statistical analysis

Statistical analysis was performed by using SPSS version 22.0. The variables were checked for normality. Characteristics of caregivers were presented in frequencies, percentages, mean and standard deviation. ANOVA test was used to analyze mean difference between groups. Simple linear regression analysis was used for each predictor to check for significance. Then, hierarchical linear regression was performed with QoL as dependent variable and three blocks of predictors. The first block included burden as a predictor. In the second block, caregiver's age and monthly family income, were added. The third block were marital status (married and others) and relationships with patients (daughter/son and others) were included. The regression coefficients, R square and R square change were reported. Statistical significance was set at a p-value of less than 0.05

## RESULTS

The mean age of caregivers is 44.2 (SD = 15.31). The majority of caregivers are female (64.3%), married (67.4%) and ≥ high school educational level (71.4%). For monthly family income, 23.1% of the caregivers has family income >300 kyats. Regarding their relationship with patients, most of them are spouses (47.2%) and have children (63.3%). About 86.9 % has taken care of the patients for more than 1 year and 76.0% has done other household works apart from taking care of patients.

The total scores of the QoL range from 38 to 119. The mean score for the total QoL is 84.2 (SD=11.93). The mean scores among the different

age groups are significantly different, [F (2,196) = 7.16, p value = 0.001]. The caregivers' age ≤ 30 has lower QoL than other age groups.

The mean score among Marital status also has significant effect on the total QoL [F (2,196) = 7.22, p value = 0.001]. The caregivers who are single have better QoL than the others. Educational level also significantly different among groups [F (2,196) = 4.05, p value = 0.019]. The total QoL was also

Monthly Family Income significantly differ income [F (2,196) = 4.60, p value = 0.011], 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]. The caregivers who got high family income, who are daughter/son, no children, and no extra household works has better QoL than others as shown in Table 1.

The caregiver's burden is showed in Figure 1. According to cut-offs from Zarit burden interview assessment tool, about one third of the caregivers felt little or no burden and approximately half of them (51.3%) experienced mild to moderate burden, and the rest of them suffered from moderate to severe and severe burden with 11.5% and 2% respectively.

**Table 1: The characteristics of caregivers and different mean scores of quality of life among the different groups of caregivers.**

Characteristics of caregivers	Caregivers (n = 199)		Quality of Life (Mean ±SD)				
	n	(%)	Physical	Psychological	Social	Environmental	Total
<b>Age</b>							
≤ 30	47	23.6	26.6±3.44	19.9±3.45	11.0±1.56	25.3±3.76	89.8 ± 10.64
31-50	76	38.2	23.7±4.03	18.1±3.81	10.5±1.61	23.6±4.06	82.7 ± 11.54
≥ 50	76	38.2	23.7±3.27	17.9±3.76	10.5±1.69	23.6±4.30	82.3 ± 12.15
p-value			<0.001**	0.009**	0.187	0.047**	0.001**
<b>Sex</b>							
Male	71	35.7	25.2±3.73	19.4±3.69	10.6±1.67	24.6±4.02	86.3 ± 12.04
Female	128	64.3	24.1±3.63	18.1±3.64	10.7±1.63	23.9±4.1	83.1 ± 11.76
p-value			0.046**	0.004**	0.097	<0.001**	0.066
<b>Marital Status</b>							
Single	53	26.6	26.3±4.03	19.7±4.13	10.9±1.88	25.6±4.53	89.3 ± 13.36
Married	134	67.4	23.8±3.40	18.3±3.30	10.5±1.54	23.5±3.62	82.5 ± 10.62
Widowed/Divorced	12	6.0	23.7±2.64	16.7±1.68	10.6±1.68	23.7±4.39	81.0 ± 13.39
p-value			<0.001**	0.015**	0.097	<0.001**	0.001**
<b>Education Level</b>							
≤ Middle School	57	28.6	23.7±3.69	17.3±3.82	10.3±1.65	23.2±3.94	80.7 ± 12.14
High School	63	31.7	24.6±3.66	18.7±3.68	10.7±1.76	24.1±4.04	84.5 ± 11.89
University	79	39.7	24.9±3.68	19.4±3.41	10.9±1.50	24.8±3.97	86.5 ± 11.34
p-value			0.152	0.004**	0.043**	0.080	0.019**
<b>Monthly Family Income (thousand kyats) *</b>							
≤ 200	82	41.2	23.7±3.36	17.8±3.92	10.4±1.75	23.2±3.91	81.6 ± 11.76
201-300	46	23.1	24.5±3.58	18.3±3.71	10.6±1.52	24.0±3.54	84.0 ± 10.88
>300	71	35.7	25.0±4.33	19.3±3.53	10.9±1.55	24.8±4.57	87.4 ± 12.18
p-value			0.103	0.038**	0.119	0.037**	0.011**
<b>Relationship with Patient</b>							
Parents	18	9.0	23.2±2.80	15.1±3.83	10.0±1.85	21.3±4.25	75.6 ± 11.51
Spouse	94	47.2	23.7±3.36	18.4±3.29	10.5±1.54	23.5±3.60	82.4 ± 10.59
Daughter/Son	47	23.6	26.0±3.71	19.8±3.51	11.0±1.52	25.5±3.95	89.2 ± 10.90
Other family members/ Friend/ Neighbors	40	20.0	25.0±4.16	19.0±3.85	11.0±1.82	25.1±4.09	86.7 ± 13.34
p-value			0.002**	<0.001**	0.020**	<0.001**	<0.001**
<b>Having Children</b>							
No children	73	36.7	25.8±3.95	19.5±3.75	10.9±1.77	24.9±4.39	87.8 ± 12.68
Have Children	126	63.3	23.7±3.30	18.0±3.58	10.5±1.56	23.6±3.72	82.2 ± 11.02
p-value			<0.001**	0.011**	0.039**	0.025**	0.001**
<b>Duration of caregiving (in years)</b>							
≤ 1 year	26	13.1	25.0±4.53	19.7±3.85	10.8±1.68	25.6±4.11	88.0 ± 13.54
>1-2 years	50	25.1	24.3±4.50	18.7±4.18	11.0±1.44	24.2±4.45	85.9 ± 12.24
>2 years	123	61.8	24.2±3.34	18.1±3.54	10.4±1.68	23.6±3.92	82.7 ± 11.26
p-value			0.624	0.126	0.073	0.073	0.059
<b>Do extra household works</b>							
No	48	24.0	25.4±4.06	19.3±4.89	10.9±1.96	25.5±4.49	87.9 ± 14.58
Yes	151	76.0	24.2±3.53	18.3±3.39	10.6±1.53	23.7±3.76	83.1 ± 10.76
p-value			0.036**	0.038**	0.155	0.014**	0.015**

\*1USD = 1535 kyats, \*\* p-value < 0.05, ANOVA test

The daily minimum wage in Myanmar was 4,800 kyats (US\$2.67) in 2018 and remained unchanged through 2021<sup>21</sup>.

### LEVEL OF BURDEN OF CAREGIVERS

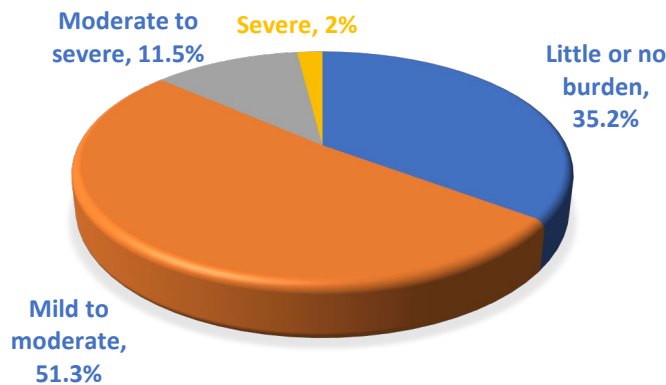


Figure 1: Level of burden of caregivers of end stage renal disease people

To find out the factors (independent variables) related to quality of life (dependent variable), hierarchical linear regression was conducted. 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, monthly family income in thousand kyats, marital status, and relationships with patients) and dependent variables (Quality of life).

From Model 1 (level of burden as the predictor variables) in table 2, level of burden explains a significant amount of the variance (22%) on quality of life [F (1,197) = 54.27, p <0.001, R<sup>2</sup>=0.22, adjusted R<sup>2</sup>=0.21]. From Model 2 with 3 predictor variables, there is an improvement over the earlier model with R<sup>2</sup>=0.31 and adjusted R<sup>2</sup>=0.30. The change in R<sup>2</sup> (0.094) is also significant [F (1,195) = 13.35, 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, it gave a higher value of R (0.57) and R<sup>2</sup> (0.32) than the previous models. The R<sup>2</sup> has also changed 0.011 is not significant [F (2,193) = 1.604, p value = 0.204].

So marital status and relationships with patients 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 3), 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 and caregiver’s age had a negative influence on the caregiver’s quality of life. Income is positively related with caregiver’s quality of life. 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.

$$\text{Model Quality of life} = B_0 + B_1 (\text{level of burden}) + B_2 (\text{caregiver's age}) + B_3 (\text{caregiver's monthly family income})$$

$$\text{Quality of life} = 95.638 - 0.395 \text{ burden} - 0.149 \text{ caregiver's age} + 0.010 \text{ caregiver's monthly family income}$$

Table 2: 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 <sup>a</sup>	.216	.212	.216	54.269	1	197	<0.001*
2	.557 <sup>b</sup>	.310	.300	.094	13.353	2	195	<0.001*
3	.567 <sup>c</sup>	.322	.304	.011	1.604	2	193	.204

\* p-value < 0.05

a. Predictors: (Constant), Level of Burden

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

c. Predictors: (Constant), Level of Burden, Caregiver Age, income in thousand kyats, marital status, relationships with parents.



**Table 3: 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	<0.001*	-0.395	-0.435	<0.001*	-0.370	-0.407	<0.001*
Caregiver's age				-0.149	-0.191	0.002	-0.107	-0.137	0.041
Monthly Family Income				0.010	0.232	<0.001*	0.009	0.222	<0.000*
Marital Status (married)							-1.769	-0.070	0.281
Relationships with Patients (daughter/son)							-4.360	-0.105	0.110

\* *p*-value < 0.05

**DISCUSSION**

The mean age of caregivers in this study is 44.2 ± 15.3. This is quite similar to the studies in two neighborhood countries, Thailand and India, in which the mean age of caregivers is 47.1 and 41.6 respectively<sup>22,23</sup>. So, the caregivers are still in the working age group. The majority of them are women (64%) which was also consistent with other studies in Thailand, India and Iran<sup>23, 24, 25</sup>. It can be compared with the developed countries such as US, UK and Australia where women are the predominant caregivers with 75%, 58% and 68% respectively<sup>26, 27</sup>. Generally speaking, women worldwide are culturally accepted by societies as those responsible for caregiving. In the context of Myanmar, it was expected that men should be leaders and women are socially expected to be in supportive roles. But the women are socially obligated and have to be in charge of the household, children, elderly relatives, and take on other caring responsibilities. It was found that 67.5% of the caregivers in this study are married and only 26.5% are single. This is also compatible with other studies<sup>23, 24, 28</sup>. The findings suggested that those performed caregiving services consist of the following: spouses of the patients (47.5%); daughter/sons (23.5%); other family members (20%); friends and parents (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 also 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.

The results of this study indicated that the caregiver's burden was the strongest predictor for quality of life which accounts for 21.6% after other variables were considered. Correspondingly, a study of caregivers in Iran also suggested that the caregiver's burden was the

most significant influencing factor which could explain about 44% of variance for poor quality of life<sup>29</sup>. Another study of caregivers in China using SF-36 tool for assessing quality of life reported that in their study, the caregiver's burden is the largest significant contributing factor to poor quality of life in mental aspects and the second most affecting factor to physical aspects<sup>30</sup>. A research evidence of caregiver's quality of life in Turkey also mentioned that the caregiver's burden could explain about 60% of the variance in total quality of life and burden significantly lower the quality of life of the caregivers<sup>31</sup>. 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. Patients need to receive treatment for their whole life and caregivers with lower family income experienced more burden which could further affect their quality of life. In western and developed Asian countries, the government would provide hemodialysis access to all their patients; whereas in South and Southeast Asian countries, the full access of hemodialysis to all patients is still not achievable yet; only a portion of patients can still receive it. Though the hemodialysis cost in Southeast Asian regions is much lower than in the western countries, the patients still find it hard to afford the expenses because of no health insurance from the governments<sup>32,33</sup>.

Since patients in many developing countries including Myanmar have not yet been provided the universal health coverage, the expenses for hemodialysis have to be born by the patients themselves and, would literally increase their financial burden. According to the 2018 health sustainable development goal profile of Myanmar published by WHO, out of pocket expenditure is about 74% of the total health care expenditure<sup>34</sup>. 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 insufficient hospitals

for dialysis and kidney transplantation in Myanmar, there are overcrowding issues 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 hospitals. A few hospitals are run by charitable organizations, whose charges are lower than those at private hospitals, and some provide free treatment<sup>35</sup>. Most of the patients have to receive hemodialysis 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.

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 quality of life decreased. This could arguably be attributed to their physical and mental strain resulting in poor performance.<sup>37,38</sup>. Besides, the older people are more vulnerable to illnesses as there is deterioration of the function of the body with the advanced age. Worth pointing out is that our findings correspond to the studies in Japan and Sudan<sup>39,40</sup>. However, the other studies in Hong Kong and Thailand reported that younger caregivers had lower quality of life<sup>41,42</sup>.

Regarding the research limitations, as this study was conducted only at the private and charity hemodialysis centers in Yangon, it could not represent all the caregivers in Yangon, Myanmar and also could not be generalized the conditions of the caregivers of end stage renal diseases in the whole country of Myanmar. That aside, the self-administered questionnaire could raise the response bias. The findings also provide baseline information for the future researcher to conduct further research and, more importantly, help the health professionals and governments in terms of considering and planning the programs so that the caregivers would achieve better quality of life.

## CONCLUSION

This study looked at the factors which could relate to quality of life among the caregivers of patients undergoing hemodialysis, including the characteristics of caregivers and the caregiver's burden. The most significant factors related with caregiver's quality of life were age and monthly family income of the caregivers and caregivers' burden. Promoting the public support measures such as social assistance is needed from government and non-governmental organizations and also the better payment system from government to relieve the financial issues of the caregivers and patients. Further studies (both quantitative and qualitative) are needed to explore more about the burden and quality of life of caregivers who take care of other chronic

diseases to find out the differences and compare their situations.

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## Conflict of interest

The authors have no competing interests to declare in this research.

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