Journal of Integrated Sciences
Volume 5, Issue 1, December 2024
ISSN: 2806-4801

PERCEIVED BURDEN AMONG MALE AND FEMALE MALAYSIAN FAMILY CAREGIVERS OF HEMODIALYSIS PATIENTS

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ABSTRACT

This study examines the quality of life among male and female caregivers of hemodialysis patients. Literature focusing on the quality of life of caregivers of hemodialysis patients in Malaysia is notably lacking. This study uses the SF36 health survey among caregivers of hemodialysis patients and the Zarit Burden Interview (ZBI) which is a 22-item instrument for measuring the caregiver's perceived burden of providing family care. The study highlights the impact of difficulties and challenges faced by close family members and caregivers who had a spousal relationship with the patient (60.02 ± 8.85) and reported a significantly greater sense of burden compared to the caregiver who had a parent-child relationship with the patient (56.08 ± 9.61). A negative relationship was discovered between caregiver burden and quality of life (r (196) = -.174, p =.015). =.015), when the percentage of burden among the caregivers is high, their quality of life perception could be low. Caregivers who are at the primary level of education (60.28 ± 7.90) have a significantly greater burden as compared to those at the secondary level of education (55.97 ± 10.04), (Mean Difference = 4.31, p =.012). The overall difference between male and female caregivers in terms of their bodily pain percentage (U = 4375.5, Z

= -2.135, p <.05), with female caregivers (Median = 63) have a significantly lower quality of bodily pain as compared to male caregivers (Median = 72). This leads to the conclusion that there is a significant burden and lower QOL for couples as compared to children as caregivers in various aspects of their lives and that females need social support to help them deal with the duties and responsibilities of caregivers.

Keywords: *Quality of Life, Caregiver, Hemodialysis Patient, Caregiver Burden.*

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1. INTRODUCTION

Patients with chronic end stage renal disease need dialysis to survive and the family is also expected to perform some supportive functions which includes support for dialysis patients. The burden and quality of life experienced by caregivers have been investigated but have been unevenly examined. For the last decade, as Malaysia has witnessed an escalation in the prevalence of chronic kidney disease (CKD), from 9.07% in 2011 to 15.48% in 2018 (Saminathan et al., 2020), it is critical that we consider the burden borne by the family caregivers of hemodialysis patients.

This study aims to determine the perceived burden of male and female caregivers and health-related quality of life and to determine factors influencing this perceived burden. The caregivers of hemodialysis patients are critical agents in managing the disease and promoting the patient's quality of life (Sajadi, Ebadi, & Moradian, 2017). Although health care professionals in hemodialysis centers are responsible for patient care, this responsibility must be borne by the patient's family members at home (Kilic, 2017).

According to the literature, caregivers of hemodialysis patients are at a high risk of physical and emotional disorders, including stress, depression, fatigue, loss of self-confidence, and numerous physical health issues (Robbins, 2018). This study aims to characterize male and female caregivers' perceived burden and health-related quality of life and investigate factors influencing this burden. This study was conducted to assess the health-related quality of life (HRQOL) of male and female caregivers of hemodialysis patients in order to explore factors affecting their QOL. Quality of life (QOL) is defined as an individual's perception of their position in life in the cultural context and in the value systems in which they live and in relation to their goals, expectations, concerns and desires.

The critical role of caregivers on the front lines of the health care team is that careful attention needs to be given to the caregivers' QOL and promoting it may improve the patients' QOL. The interest in investigating this issue is justified by the fact that dialysis patients perform life-long outpatient treatment, with the caregivers being the basis of this process. However, the care provided by the nursing team is almost always intended only for the patient, making the patients' family or caregivers assume a supporting role in this context. Therefore, an assessment of quality of life among hemodialysis caregivers is important, for interventions targeted at improving patient's QOL (Griva, Kang, & Chan, 2016). This study has specific objectives: (1) to identify perceived burden of male and female caregivers and health related quality of life and (2) to determine factors influencing this perceived burden.

2. REVIEW OF LITERATURE

Research to date has tended to focus on a cross-sectional survey of informal caregivers and data from previous studies cited by Bakar et al. (2014), have only focused on caregivers of chronic and degenerative diseases (i.e. diabetes, hypertension, cardiovascular illness, stroke),

Phua (2009) and Wan et al. (2003) studied social support and burden among caregivers of patients with dementia, while Fatimah et al. (2008) examined families care-giving to persons with schizophrenia in Malaysia. Based on the above local 2014 study on self–support survey results, literature focused on the caregivers of hemodialysis patients' quality of life in Malaysia is notably lacking. Due to an increase in incidence and prevalence rates in recent years, chronic kidney disease has been considered a public health problem (Saminathan et al., 2020), and has generated high treatment costs (Marinho et al., 2017). Hemodialysis is a necessary therapy for maintaining the life of the kidney disease patient and leads to a series of changes in the life of these individuals, such as the time spent on treatment, affecting their quality of life.

The caregiver is expected to aid in the patient's daily life and most medical activities in between the dialysis sessions. On the other hand, when the patient becomes more ill or has an acute event such as new disease(s) and complication(s), the caregiver's workload and responsibilities become overwhelming, resulting in increased physical, emotional and financial burden and stress (Sajadi et al., 2017). The caregivers' quality of life decreases as their care burden increases (Karakurt, 2018).

To date the survey on caregivers for hemodialysis patients from other ethnicities and countries has revealed significant physical and psychological stress and burden that affect the quality of life and mental and physical health of caregivers (Rodrigues de Lima et al., 2017). Health conditions related to stress such as anxiety, depression, and isolation from friends and family may be linked to heart disease. Stressful situations can cause blood pressure to spike temporarily. Research shows the stressful demands of caregiving to chronic disease patients can have negative effects on the physical health of caregivers. These negative effects could include the immune system functioning, heart rate reactivity, raising blood pressure levels, and increasing the risk of mortality among some older spousal caregivers (Amankwaa, 2017). The present study by Mubarak and Rajasekhar, (2017) suggested that there is an occurrence of altered cardiovascular autonomic functions which is one of the early features of autonomic neuropathy among the caregivers.

In a study by Cagan (2018), which examines the care burden of caregivers of hemodialysis patients, it is stated that those with low socioeconomic status have a higher burden of care and an increase in health problems due to excessive care burden. It was noted that caregivers' age, health problems, role load, financial vulnerability, educational status, economic status, degree of kinship, living with the patient at the same household affected their quality of life (Karakurt, 2018). Caregiving is hard work and stressful; however, caregivers found the experience meaningful. Caregivers identified they need a support system and the stress of caregiving interferes with their own health (Caviness, Tri-counties, & Camper, 2018).

2.1 Conceptual Framework

In this study, we used Wilson and Cleary (1995) model as a conceptual framework which highlights five health concepts. There are five different levels in this model, namely, biological and physiological factors, symptoms status, functional status, general health perceptions and overall quality of life. The evaluation of physiological variables centers on cells, organs, and organ systems, while the assessment of symptom status shifts to the organism as a whole. Functional health has been defined as the ability of an individual to perform and adapt to one's environment, measured both objectively and subjectively over a given period. General health perceptions integrate all the health concepts plus others such as mental health. Overall quality of life has been described as the discrepancy between a person's expectations or hopes and their present experiences.

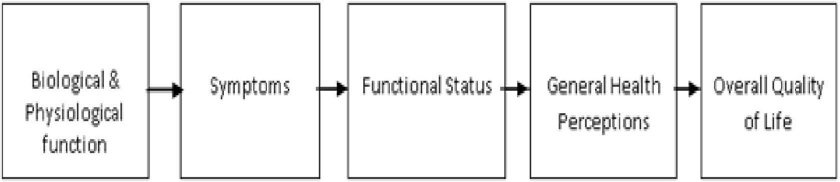

Figure 1. Wilson & Cleary (1995) Health Related Quality of Life (HRQOL) conceptual model

3. RESEARCH METHODOLOGY

3.1 Study Design

The research adopted a quantitative cross-sectional approach using a convenience sampling method. This descriptive cross-sectional study was conducted between 01 November 2019 and 30 January 2020, in two selected and well-established public hospitals in Kuala Lumpur and one from the state of Selangor. Inclusion criteria were applied as follows: spouses, children of patients, non-related to patients aged 18 years or over who are taking care of a patient receiving hemodialysis therapy minimum at three months period, and able to communicate in Malay and English language were directly approached and invited to respond to the study questionnaire. There was no restriction on gender, nationality or race to participate in the study. Exclusion criteria were applied as follows: caregivers who did not understand Malay or English. Out of 206 sets of the questionnaires distributed, only 196 sets of questionnaires were usable with the responsive rate of 95.15%.

3.2 Measurements

The MOS 36-item Short Form Health Survey to measure Quality of life indicates overall health status. Scoring for the SF-36 has eight scaled scores; the scores were weighted sums of the questions in each section. Scores range from 0 – 100, lower scores = more disability, higher scores = less disability.

The Zarit Burden Interview (ZBI) is a 22-item instrument for measuring the caregiver's perceived burden of providing family care. The 22 items were assessed on a 5-point Likert scale, ranging from 0 = ‘never’ to 4 = ‘nearly always’. Item scores were added up to give a total score ranging from 0 to 88, with higher scores indicating greater burden. The questions focus on major areas such as caregiver’s health, psychological well-being, finances, social life and the relationship between the caregiver and the patient.

3.3 Ethical Consideration

Ethics approval for this study was obtained from the National Medical Research Register (NMRR Ministry of Health; Malaysia) NMRR-18-2331-43442 (IIR) and OUM ethical committee. Permission obtained from all hospitals where the dialysis units existed, data were collected for each caregiver/participant using a sociodemographic characteristics data sheet. The sociodemographic information obtained included the caregiver’s gender, age, education, years of care giving, and relationship to the patient.

4. RESULTS

4.1 Reliability level Burden of Caregivers and Quality of Life

The reliability level for the Burden of Caregivers (' 'Cronbach's Alpha =

.938) and Quality of Life (' 'Cronbach's Alpha = .878) can be considered good as the variables were above 0.80.

Objective 1: Perceived burden of male and female caregivers and health related quality of life

Objective 2: Factors Influencing Perceived Burden

Based on the independent t-test reported at Table 1, it can be concluded that, the percentage level of caregiver's burden between males (57.92 ± 8.99) and females (58.56 ± 9.88) can be considered equal, since the independent t-test for this comparison analysis was not significant (t (194) = -0.475, p =.635). On the other hand, the analysis indicated that, a caregiver who has a spousal relation with the patient (60.02 ± 8.85) has a significantly greater sense of burden as compared to caregivers who have a child-parent relationship with the patient (56.08 ± 9.61), due to the significant result of independent t-test (t (194) = 2.980, p <.01).

The same scenario happened for those living with the patient as well as the main caregiver group variables, where the analysis also indicated that a caregiver who is living with the patient (59.05 ± 8.96) has a significantly greater feeling of being burdened as compared to a caregiver who is not living with the patient (53.73 ± 10.47), due to the significant result of independent t-test (t (194) = 2.956, p <.01). The analysis also indicated that there is a significant difference between the percentage level of caregiver's burden between caregivers defined as the main caregiver and those not in the main caregiver category (t (194) = 3.792, p <.01). Hence, it can be concluded that caregivers who are defined as the main caregiver category (59.30 ± 9.09) are significantly more having a burden feeling compared to a caregiver defined as not a main caregiver category (52.64 ± 9.06).

Table 1. Comparison analysis of ' 'Caregiver's Burden using independent t-test

Variable	Category	M ± SD	Levene's Test (p-value)	Degrees Freedom	oft-statistic (p-value)
Gender	Male	57.92 ± 8.99	3.073 (.081)	194	-0.475
	Female	58.56 ± 9.88			(.635)
Relation	Spouse	60.02 ± 8.85	2.489 (.116)	194	2.980
with patient	Children	56.08 ± 9.61			(.003)**
Living with	Yes	59.05 ± 8.96	2.120 (.147)	194	2.956
Patient	No	53.73 ± 10.47			(.004)**
Main	Yes	59.30 ± 9.09	0.020 (.887)	194	3.792 (<.01)**
Caregiver	No	52.64 ± 9.06			

Table 2 showed the independent t-test results based on caregiver's quality of life continuous variable. The analysis indicated that caregiver's quality of life showed the percentage level based on gender, relation with patient, living with patient, and main caregiver group variables can be considered equal, since the probability value of independent t-test for each group variable was not significant (i.e. p- value for t-statistic >.05).

Table 2. Comparison analysis of Caregiver's Quality of Life using independent t-test

Variable	Category	M ± SD	Levene's Test (p-value)	Degrees of Freedom	t-statistic (p-value)
Gender	Male	38.20 ± 8.78	0.033 (.856)	194	-1.519
	Female	40.14 ± 9.05			(.130)
Relation with patient	Spouse	39.07 ± 9.31	0.571 (.451)	194	-0.031
	Children	39.11 ± 8.53			(.975)
Living with Patient	Yes	39.41 ± 9.24	4.481 (.036)*	53	1.397 (.168)
	No	37.40 ± 6.94			
Main Caregiver	Yes	39.26 ± 9.16	2.956 (.087)	194	0.598 (.507)
	No	38.23 ± 7.75			

Note: M = Mean; SD = Standard Deviation; *p <.05.

There is a negative relationship between the burden of caregivers with quality of life (r (196) = -.174, p =.015). It is indicated that if the percentage of burden among the caregivers is high, then their percentage of quality of life is low. Besides that, the strength of this relationship can be categorized as a poor relationship since the Pearson's Coefficient was below 20.

Based on the ANOVA test reported at Table 3, it can be concluded that, at least one pair of the education level were different (F (2, 193) = 4.153, p <.05) based on the percentage level of caregiver's burden. It is because the probability value for the F-statistic was significant. The same conclusion can be made for the working status category, where the analysis also indicated that, at least one pair of the working status category were different (F (3, 192) = 3.182, p <.05) for the percentage level of the caregiver's burden.

Table 3. Comparison of Education Level and Working Status using ANOVA test

Variable	Category	M ± SD	Levene's Test (p-value)	F-statistic (p-value)	Comparison Analysis^b
Education Level	(1)	60.28 ± 7.90	2.521 (.083)	4.153 (.017)*	(1) vs (2)*
	(2)	55.97± 10.04			(1) vs (3)
	(3)	58.28 ± 10.08			(2) vs (3)
Working Status	(1^a)	58.83 ± 9.70	1.831 (.143)	3.182 (.025)*	(1^a) vs (2^a)*
	(2^a)	52.94 ± 8.26			(1^a) vs (3^a)
	(3^a)	57.47 ± 7.76			(1^a) vs (4^a)
					(2^a) vs (3^a)
	(4^a)	61.13 ± 10.64			(2^a) vs (4^a)*
					(3^a) vs (4^a)

Note: M = Mean; SD = Standard Deviation; (1) = Primary; (2) = Secondary; (3) = Tertiary; (1^a) = Working Full Time; (2^a) = Working Part Time; (3^a) = Housewife / Not Working; (4^a) = Retired; Comparison analysis was based on LSD comparison analysis; *p <.05.

Table 4 showed since the ANOVA test was significant, the analysis proceeded to multiple comparison analysis using Least Square Difference (i.e. LSD) multiple comparison analysis. The analysis indicated that caregivers who were at the primary level of education (60.28 ± 7.90) had a significantly greater burden as compared to caregivers who were at the secondary level of mean education (55.97 ± 10.04), (Mean Difference = 4.31, p =.012). However, the multiple comparison analysis also confirms that the percentage level of caregiver's burden for the other's pair of groups (i.e. (1) vs (3) and (2) vs (3)) were not significantly different.

As for the working status category, the LSD multiple comparison analysis indicated that caregivers who were working as full-time workers (58.83 ± 9.70) had a significantly greater sense of burden as compared to caregivers working as part time workers (52.94 ± 8.26), (Mean Difference = 5.89, p =.012). In addition, the LSD multiple comparison analysis also found that, caregivers working as mean part time workers (52.94 ± 8.26) had a significantly lesser feeling of burden as compared to caregivers who were retired persons (61.13 ± 10.64), (Mean Difference = -8.18, p =.004). However, the multiple comparison analysis also confirms that the percentage level of caregiver's burden for the other pair of groups (i.e. (1^{a}) vs (3^{a}), (1^{a}) vs (4^{a}), (2^{a}) vs (3^{a}) and (3^{a}) vs (4^{a})) were not significantly different.

The analysis of the results of ANOVA test based on the caregiver's quality of life continuous variable indicate that the percentage level of the caregiver's quality of life based on education level and working status group variables can be considered equal, since the probability value of ANOVA for each group variable was not significant (i.e. p-value for F-statistic >.05). Therefore, there is no need to further the analysis to the LSD multiple comparison analysis.

Table 4. Comparison analysis of Caregiver's Quality of Life using ANOVA test

Variable	Category	M ± SD	Levene's Test (p-value)	F-statistic (p-value)	Comparison Analysis
Education Level	(1)	39.02 ± 9.80			
	(2)	39.46 ± 8.18	2.807 (.063)	0.127 (.881)	N/A

	(3)	38.60 ± 8.69			
Working Status	(1^{a})	37.77 ± 8.21	2.369 (.072)	1.979 (.119)	N/A
	(2^{a})	40.41 ± 7.33			
	(3^{a})	39.64 ± 9.63			
	(4^{a})	42.15 ± 10.62			

Note: M = Mean; SD = Standard Deviation; (1) = Primary; (2) = Secondary; (3) = Tertiary; (1^{a}) = Working Full Time; (2^{a}) = Working Part Time; (3^{a}) = Housewife / Not Working; (4^{a}) = Retired; N/A = Not Applicable.

Correlation analysis concluded that there is a negative relationship between Burden of Caregivers with Physical Functioning (Rho (196) = -.345, p <.05). It is indicated that if the percentage of burden among the caregivers is high, then the percentage of physical functioning should be low. Besides that, the strength of this relationship can be categorized as a fair relationship since the coefficient is in the range of .21 and .40.

The same can be concluded for Physical Functioning, Bodily Pain, General Health, Role of Emotional and Mental Health. The analysis indicated that, there is a negative relationship between Burden of Caregivers with Role Physical (Rho (196) = -.276, p <.05), Bodily Pain (Rho (196) = -.559, p <.05), General Health (Rho (196) = -.587, p <.05), Role Emotional (Rho (196) = -.598, p <.05) and Mental Health (Rho (196) = -.308, p <.05). Therefore, it can be concluded that if the percentage of burden among the caregivers is high, then the percentage of role physical, bodily pain, general health, role emotional and mental health should be low. Besides that, the strength of this relationship can be categorized as a fair to good relationship since the coefficient is in the range of .21 and .60.

However, the analysis also indicated that, there is no significant relationship between Burden of Caregivers with Vitality (Rho (196) = -.054, p =.457) and Social Functioning (Rho (196) = -.080, p =.589). Therefore, if the percentages of burden among the caregivers are high, then the percentage of vitality and social functioning should be no effect.

5. DISCUSSION

Perceived burden of caregivers and HRQOL and factors influencing this perceived burden

The findings of this study highlight the impact of difficulties and challenges faced by close family members and caregivers who have a spousal relation with the patient (60.02 ± 8.85) and have a significantly greater feeling of burden as compared to the caregiver who has a child-parent relationship with the patient (56.08 ± 9.61). While this study has not fully clarified the degree of burden experienced by caregivers, one may logically conclude that there is some degree of impact to the caregivers. However, unmet needs have a detrimental effect on the caregivers' health and influences the extent to which they can effectively care for the hemodialysis patients (Matthews et al., 2022). Burden of Caregivers with Physical Functioning (Rho (196) = -.345, p <.05) presented associating perceived burden in caring for patients with chronic illness and according to Schneider (2003) physical fatigue is a prominent factor in the caregiver's Quality of life. This may suggest a direction in interventions that focuses more on rest and respite. A study using analysis of Structural Equation Modeling in Japan by Kukihara et al. (2020) revealed that resilience was fully mediated by the relationship between family functioning.

Kukihara and colleagues further elaborated that it was specifically the family adaptability, communication, and mental health well-being of the dialysis patients. However, Kukihara and colleagues revealed that family cohesion was not a factor associated with resilience.

More evidence suggests that caregivers of hemodialysis patients endure a high level of care burden. In fact, a study by Jafari et al. (2018) in Iran reported that the caregivers were experiencing high to very high levels (37.4%) of care burden and 42.7% of the caregivers were experiencing a moderate level of care burden. Another study in Iran revealed that family caregivers reported negative experiences like stress, depression, anxiety, and lack of self-confidence, fatigue, social isolation, financial and communicative constraints, and reduced quality of life (Ebadi et al., 2021) On the other hand, in case of reduced patient capability in self-care, the patient's incidence of other chronic diseases, and the increased age of the caregivers themselves, the level of care burden on the caregivers would be increased (Jafari et al., 2018). A qualitative study by DePasquale et al. (2019), the family members described a broad range of unexpected negative experiences with ESKD treatments. DePasquale and colleagues further suggested that the efforts to prepare family members for ESKD treatments through more holistic approach, such as interventions targeting care partner preparedness, health provider–family member communication, and relationship dynamics in family member–patient dyads are essential, too. Sajadi et al. (2022) in their psychometric study on the quality-of-life inventory for family caregivers of hemodialysis patients further confirmed that patient care burden, conflict, positive perception of situations, self-actualization, fear, and concern co-exist in the care of hemodialysis patients. Another similar study using ZBI questionnaire (Khatri & Baral, 2020) revealed that the median scores for burden among the caregivers was (39.30±11.68). Duggleby et al. (2016) revealed that the participants with significantly positive increases in their multi chronic conditions reported lower burden (ZBI, $p < 0.001$) based on baseline to six months. On the other hand, using ZBI questionnaire, a study by Perpiñá-Galvañ et al. (2019) in which, there was statistically significant correlations between the variables of burden, fatigue, post-traumatic growth, anxiety, and depression among caregivers of palliative care patients.

Between genders it is apparent the quality of general health of female caregivers (Median = 69) have significantly lower quality of general health as compared to male caregivers (Median = 85), $U = 4341.5$, $Z = -2.714$, $p <.05$. Overall, this seems to include, female caregivers (Median = 71) also have lower quality of role emotional as compared to male caregivers (Median = 82) with statistically significant difference ($U = 4179$, $Z = -2.207$, $p <.05$). The analysis also indicated that there is a significant difference between male and female caregivers in term of their mental health percentage ($U = 4675$, $Z = -2.347$, $p <.05$). It is indicated that female caregivers (Median = 61) have a significantly lower quality of mental health as compared to male caregivers (Median = 78). Only physical functioning analysis revealed that the quality of physical functioning between female caregivers (Median = 73) and male caregivers (Median = 75) are equal since the analysis of Mann-Whitney U comparison analysis did not significantly differ ($U = 4445.5$, $Z = -1.041$, $p =.298$).

In addition, the same scenario occurred for the quality of vitality, where the vitality quality for the female caregivers (Median = 66) was not statistically different with the vitality quality for the male caregivers (Median = 64), U = 4485, Z = -1.110, p =.267. General Health, Mental Health, Bodily Pain, and Role-emotional Functioning particularly in female caregivers were the most affected dimensions on the SF-36 has similarities study by Rivera-Navarro et al. (2009). Psychological and social support should be considered to reduce caregiver burden (Rivera- Navarro et al., 2009) This study concurs with Chan (2010) reviews on caregiver burden from an Asian cultural perspective, and found that middle-aged and older women who provided care for an ill or disabled spouse in Asia usually experienced more caregiver burden, which was consistent with the findings of Rinaldi et al. (2005) from an Italian point of view. Therefore, it is logical that caregiver burden could be influenced by cultural differences. More studies are needed to examine the trends over time in the HRQOL of Malaysian caregivers of persons with hemodialysis treatment. This is because most of the studies conducted with caregivers were limited to cross -sectional design.

6. CONCLUSION

With the increase in chronic kidney disease and chronic hemodialysis patients in Malaysia, a reduction in health care services, increased longevity, caregivers of all ages, races, and gender will only increase. Thus, the health care practitioners will be needed to attend frequently to assess and intervene with overburdened caregivers in addition to patients with chronic illness as there is the significant influence of caregiver's burden toward caregiver’s quality of life. A health-related policy should be formulated to help family caregivers receive more professional assistance. Training opportunities should be provided for family caregivers to reduce the impact of caregiving on the delivery of effective care. The development of supportive interventions is vital to ensure that caregivers have the requisite knowledge and skills. This, in turn, allows the caregivers of hemodialysis patients to continue their vital role.

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