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Caregiver Burden of Children with Chronic Disease at One of Teaching Hospitals in Kuala Lumpur

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Abstract

Handling children with chronic diseases may negatively impact caregivers' quality of life. This research objective is to identify the caregiver burden in children with chronic disease care. A cross-sectional study used the PedsQI Family Impact Module questionnaire to identify the caregiver burden among 230 caregivers of children with chronic diseases at UMCC. The participant perceived burden (n=154, 67%) with mean M=1.67 (SD 0.47). However, age and gender are not significantly associated with caregiver burden. In conclusion, caregivers perceive the burden of caring for children with chronic diseases. Therefore, continuous support from healthcare providers may help reduce the caregiver burden.

Keywords: Caregiver, burden, children, chronic disease

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1.0 Introduction

Taking care of children is not an easy job. However, if a child diagnoses with a chronic disease, the challenge is more significant. Chronic disease is a long-duration medical illness that is severe enough to affect daily activities (Consolini, 2020). Pediatric chronic diseases include the problem with respiratory, congenital heart disease, metabolic disorder, systemic inflammatory/autoimmune, and cancer (West et al., 2019). Children with chronic diseases require long-term support, protection, monitoring, and ongoing treatment by their caregivers (Consolini, 2020). Therefore, caring for chronic diseases children requires commitment from the caregiver.

Children's caregivers are usually a parent who ensures children is healthy and safe to be successful adult. A caregiver could be an unpaid family member or paid assistant. Caring for children with chronic diseases requires more attention from the caregiver (Consolini, 2020). Imagine shuffling between careers, personal life, family, and more attention needed for a chronic disease child; it is difficult for a person to manage everything without getting burnt out and affecting their family function. Caregivers who have frequent hospital visits will affect their emotional and physical disturbances, including mental stress and exhaustion (Ahmad Zubaidi., 2020). The caregiver burden can negatively impact the health of both children and caregivers (Farmer et al., 2018). In Malaysia, limited studies have assessed the effect of chronic childhood illness on the family (Isa et al., 2021; Rahman et al., 2011). Therefore, the study aims to explore caregiver burdens while caring for their child with chronic disease at one of the teaching hospitals in Kuala Lumpur. The study objective is to determine the relationships between age, education level, and occupation with caregiver burden.

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2.0 Literature Review

A caregiver, by definition, is a person who provides care to those who require assistance, such as children, the elderly, or patients with chronic illnesses or disabilities (National Cancer Institute, 2021). Caring for children is a parent's routine; however, the role is more challenging for children who experience chronic diseases. Ekim & Ocakçi, (2016) said that the caregivers need to adapt to new routine changes in their daily lives after the diagnosis has been established, such as extra expenditure on medication and medical equipment at home. Therefore caregivers play an important role in reducing healthcare costs and resources by caring for patients at home. A study in Malaysia indicates caregivers show the highest symptom of anxiety and depression, which negatively impact their quality of life (Isa et al., 2021).

Caregivers' burden has a complex response associated with physical, emotional, financial, social, and other adverse outcomes (Liu et al., 2020; Kunkle et al., 2021). Kunkle et al. (2021) also added that external support such as adequate financial aid helps carers adjust to facilitate duties, thus reducing the burden. Adib et al. (2019) found factors influencing caregiver burdens were education level, occupation status, family size, and the number of children with chronic diseases. The burden of care was related to a low-level education among caregivers and impacted the family functioning (Sabo et al., 2020). Therefore, it is important to assess factors influencing the caregiver burden.

Vaz et al. (2018) found that parents of children with chronic illness face many difficulties, such as less interaction with friends and relatives. Parents perceive they are tired more mentally and physically (Liu et al., 2020). Families with children who have chronic disorders have their routines disrupted, and they frequently lose control of managing their lives in the face of chronic illness. Depression and exhaustion show lower caregiver self-efficacy Hamovitch et al., (2019). Mothers with chronic diseases children also face a higher risk of mortality and cardiovascular disease than caregivers with healthy children (Cohn et al., 2020). Thus, healthcare providers must recognize the caregiver burden and provide the necessary support to reduce the burden.

3.0 Methodology

3.1 Study design, location, and population

The cross-sectional study was conducted in Paediatric outpatient services in one teaching hospital located in Kuala Lumpur. The study population was the caregivers of children with chronic diseases who bring the chronic illness children to the outpatient clinic for continuous follow-up and care. Raosoft software was used to calculate the sample size assuming the total sample is 500 population size, 95% confidence level, 5% margin error, and the recommended sample of 218. In addition, convenience sampling was used and selected a sample based on inclusion criteria. Inclusion criteria: (1) A caregiver can communicate and understand the English or Malay language, (2) Having children with chronic illness such as cardiology children, oncology children, diabetic children, children with a stoma, asthma patient, (3) A caregiver in this study must a Malaysian or Malaysian permanent resident, and (4) A caregiver in this study age must be 18 years old above. A total of 230 participants volunteered to participate in the study.

3.2 Instrument

This study questionnaire used an English version adopted from Varni et al. (2004) "PedsQL ™ Family impact Module". The PedsQL™ Family Impact Module aim is to measure the effect of pediatric chronic health conditions on parents and the family. Whereas, the Malay version was adopted from Rahman et al. (2011) "PedsQL™ Family impact Module". The questionnaire is a widely used instrument to measure parents' self-reports related to family functioning and quality of life in caring for children with chronic diseases (Rahman et al., 2011; Ekim & Ocakçi., 2016; Isa et al., 2021). The first part included the caregiver's demographic data who takes care of children with chronic disease such as gender, age, education level, occupation, relationship with the patient, and period of disease been diagnosed. Second part is The "PedsQL™ Family impact Module" is composed of 36 items including 8 dimensions: Physical Functioning, Emotional Functioning, Social Functioning, Cognitive Functioning, Communication, Worry, Daily Activities, and Family Relationships. A 5-point Likert scale is utilized (0 = never a problem; 4 = always a problem). The higher scores indicate better functioning (less negative impact). Reliability for English and Malay version of PedsQL ™ Family impact Module, the Cronbach alpha ranges from 0.70 to 0.90 (Varni et al.,2004; Rahman et al., 2011)

3.3 Data collection

Data collection began after approval from UiTM Research Ethics Committee REC/03/2021 (UG/MR/166) and Medical Research Ethics Committee UMMC 2021223-9868. All eligible participants were identified at the clinic and explained the study objectives. If they agreed to participate, the questionnaire were handed to them according to their preference in English or Malay version. The participant was given an ample time to answer the questionnaire, and all completed questionnaires were returned to the box located in front of the nurses' counter. The confidentiality of the data was maintained strictly, as only researchers could access the data.

4.0 Findings

4.1 Demographic Characteristics

More than half of the participants were 31-40 years old (n=123, 53.5%). Almost one-third of the caregiver who participated in this study hold a degree level of education (n=79, 34.3%). More than half of them are working (n=153, 66.5%). The most prolonged period of disease

was more than 24 months (n=105, 45.7%), as shown in Table 1.

Table 1. Demographic characteristics of the participant (n=230)			
Variables	Categories	Frequency (n)	%
Age	21-30	29	12.6
	31-40	123	53.5
	21-40	62	27.0
	51-60	16	7.0
Gender	Female	187	81.3
	Male	43	18.7
Education Level	SPM	73	31.7
	Diploma	58	25.2
	Degree	79	34.3
	Masters	20	8.7
Occupation	Working	153	66.5
	Not working	77	33.5
Relationship	Mother	185	80.4
	Father	39	17.0
	Others	6	2.6
Period of Disease (months)	0-6	51	22.2
	7-12	46	20.0
	13-18	9	3.9
	19-24	19	8
	>24	105	45.7

4.2 Caregiver Burden of Children with Chronic Disease

In Table 2, almost half of the participants perceived the burden is 'sometime' (41.7%,n=96). 2.6% (6) participants never felt a burden in the care of their children with chronic diseases. The mean of the caregiver burden while taking care of children with chronic disease was 1.38 (SD = 0.05).

Table 2. The scale of caregiver burden (n=230)			
Frequency (n)	Percentage (%)	Mean (SD)	
6	2.6		
70	30.4		
104	45.2	1 38 (0 05)	
44	19.1	1.00 (0.00)	
6	2.6		
	Table 2. The scale of caregive Frequency (n) 6 70 104 44 6	Table 2. The scale of caregiver burden (n=230) Frequency (n) Percentage (%) 6 2.6 70 30.4 104 45.2 44 19.1 6 2.6	

4.3 Eight Dimensions Family Impact of Caregiver Burden on Children with Chronic Disease

As shown in Table 3, under the physical functioning dimension, means were obtained for 'tired during the day' M=1.73 (SD 1.12). While under emotional functioning, the highest mean score was obtained for 'sad' M=1.73 (SD 1.21). The highest mean under social functioning was for 'difficult to find time for social activities' M=1.44 (SD 1.25). While under cognitive functioning, the highest mean 'difficulty paying attention is M=1.48 (SD 1.03). For the communication dimension, 'difficult to talk about the child's health' M=1.42 (SD 1.18). In addition, the highest mean under the worry dimension was 'the child's future' M=2.48 (SD 1.24). In the family relationship dimension, two same means are found for 'lack of communication among family members' M=1.10 (SD 1.02) and 'stress or tension among family members' M=1.10 (SD 1.12). The same means were found for daily activities take more time and effort' M=1.66 (SD 1.14) and 'feeling too tired to finish household tasks' M=1.66 (SD 1.09). Among these eight dimensions, the mean for worry was the highest noted M=1.89 (SD 0.99) in this study. Refer Table 3.

Dimensions	Mean	Standard Deviation (SD)
Physical functioning	1.37	0.89
Tired during the day	1.73	1.12
Tired when waking up in the morning	1.68	1.127
Too tired to do favorite things	1.47	1.093
Headaches	1.27	1.038
Physically weak	1.32	1.077
Sick to the stomach	0.76	0.909
Emotional functioning	1.40	0.91
Anxious	1.60	1.106
Sad	1.73	1.121
Angry	1.32	1.053
Frustrated	1.30	1.131
Helpless or hopeless	1.06	1.056
Social functioning	1.20	0.99
Isolated from others	1.04	1.038
Trouble getting support from others	0.97	1.109
Difficult to find time for social activities	1.44	1.252

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Inadequate energy for social activities	1.36	1.137
Cognitive functioning	1.28	0.913
Difficulty paying attention	1.48	1.033
Difficulty remembering things people say	1.30	1.019
Difficulty remembering things just heard	1.29	1.030
Difficulty thinking quickly	1.19	1.043
Difficulty remembering what I was just thinking	1.16	1.047
Communication	1.28	1.025
Others do not understand my family's situation	1.31	1.169
Difficult to talk about the child's health	1.42	1.156
Difficult to tell doctors and nurses their feeling	1.09	1.147
Worry	1.89	0.99
The child's medical treatment is working or not	1.89	1.114
Side effects of the medications/medical treatment	2.07	1.154
The reaction of others to the child's condition	1.58	1.229
The child's illness is affecting other family members	1.45	1.216
The child's future	2.48	1.242
Family relationships	1.038	0.95
Lack of communication among family members	1.10	1.019
Conflicts among family members	0.97	1.040
Difficulty making decisions together as a family	1.01	1.047
Difficulty solving family problems together	1.01	1.084
Stress or tension among family members	1.10	1.124
Daily activities	1.643	1.039
Family activities take more time and effort	1.66	1.144
Difficulty finding time to finish household tasks	1.62	1.122
Feeling too tired to finish household tasks	1.66	1.087

4.4. Relationship between Demographics Characteristic and Caregiver Burden of Children with Chronic Disease

When the difference was compared between occupation and caregiver burden, a working participant had more burden (n=103, 44.8%) compared to not working participant (n=51, 22.2%). However, there is no significant relationship between occupation and caregiver burden p=0.88. Furthermore, there is no statistically significant association between age $x^2(3) = 1.67$, p = 0.64, gender level $x^2(1) = 0.18$, p = 0.66, education level $x^2(3) = 6.90$, p = 0.08., and period of the disease $x^2(4) = 3.49$, p = 0.48 with caregiver burden in taking care of children with chronic disease as shown in Table 4.

Table 4. Relationship demographic characteristic and caregiver burden (n=230)

Variables	В	Burden,n(%)		p value
	No	Yes		
Age			1.67 (3)	0.64ª
21-30	9 (4)	20 (8.7)		
31-40	45 (19.6)	78 (33.9)		
41-50	18 (7.8)	44 (19.1)		
51-60	4 (1.7)	12 (5.2)		
Gender	. ,		0.18 (1)	0.66ª
Female	63 (61.8)	124 (125.2)		
Male	13 (14.2)	30 (28.8)		
Education Level	()	· · · ·	6.90 (3)	0.08ª
SPM	25 (10.9)	48 (20.9)		
Diploma	25 (10.9)	33 (14.3)		
Degree	18 (7.8)	61 (26.5)		
Masters	8 (3.5)	12 (5.2)		
Occupation				0.88 ^b
Working	50 (21.7)	103 (44.8)		
Not working	26 (11.3)	51 (22.2)		
Period of Disease (months)		· · · ·	3.49 (4)	0.48ª
0-6	14 (6.1)	37 (16.1)		
7-12	17 (7.4)	29 (12.6)		
13-18	5 (2.2)	4 (1.7)		
19-24	5 (2.2)	14 (6.1)		
>24	35 (15.2)	70 (30.4)		

Pearson Chi-Square

^bFisher Exact Test

5.0 Discussion

This study found a moderate burden experienced by the caregiver in caring for children with chronic diseases. However, this is slightly lower than the finding of Kong et al. (2019) in Sarawak, in which caregiver burden is common among cancer patients. The change in rates of caregiver burden may be clarified by the different caregiver demographics and types of caregiver burden assessment tools in the studies. The family's socioeconomic plays an essential role in determining the caregiver burden (Ismail et al., 2022). In this study, most of the

caregivers were in their middle age, held a degree level of education, and expressed good family relationships. Thus it could be a factor lower the degree of burden

This study showed the caregiver found it 'difficult to find time for social activities in terms of social functioning. Liu et al. (2020) agree that causes of caregiver burden are multiple obligations and reduction of social activities. In this study majority of the primary caregiver is women who have numerous role as a wife, mother, and employee. Care of their chronic diseases, children added more responsibility, required more time, and indirectly reduced their social activities. Meanwhile, the mean for the worry dimension was the highest noted in this study. Gugala (2021) supported the finding that emotions contributed to the highest level of burden. In addition, negative coping is associated with anxiety among caregivers (Toledano-toledano et al., 2019). The caregivers who receive social support and availability of supportive resources have less burden (Adib & Ahmadi, 2019). This study also indicates the caregivers feel 'tired during the day'. It may be because the caregivers did not have enough resting time and received quality sleep at night. Dale et al. (2020) found caregiver sleep disturbance in the care of children with nocturnal seizures. Sleep impairment affects caregivers' mental health and physical health (Riffin et al., (2018). Therefore in the future, identification of caregiver burden is essential in the healthcare setting to prevent the consequences of the burden.

There is no association between gender and caregiver burden in this study. Toledano-Toledano et al. (2019), justified the gender of the caregiver was not a significant level of caregiver burden in a multivariate study of the sociodemographic and psychological elements of caregiver burden. Most women look after a sick child, but both parents are presented with similar experiences and challenges. Whereas, studies by Javalkar et al. (2017), showed that the high education level of the mothers had less burden in managing their chronic diseases chidren. The educated mother was more knowledgeable and had a higher ability to manage and control her emotion better. Yet, in other studies, caregivers' age, economic status, and quality of life are associated with a caregiver burden (Toledano-toledano et al., 2019). Although the participant perceived burden, the independent variables were not significantly associated with caregiver burden in this study. Thus, there can be other reasons such as the family's income, types of job, and the total number of children that may influence the caregiver burden.

There are several limitations present in this study. Firstly, 230 participants were only from one state in Malaysia; as a result, the findings do not represent the whole group of caregivers in Malaysia. Secondly, this study employed a cross-sectional design, which does not allow for the cause of interpretations. Thus, the associations between caregiver burden outcome and other independent variables should be read cautiously. Thirdly, convenience sampling approaches used in this study might result in sample bias. The sample chosen may not be representative of the entire population of caregivers of chronic children, which includes both community and private medical center caregivers. Lastly, the data collection time is longer than expected but still within the ethics approval period which is from March 2021 until December 2021. Due to COVID-19, the number of outpatients who come to the clinic has been reduced to prevent the spreading of COVID-19. Although this study had a good sample size, however probably assumed the caregivers were rushing, time limitation, and probably the burden was not the same when the children were hospitalized.

On the other hand, this study discovered a few noticeable strengths. Despite being held in a single central location, it was carried out in a tertiary referral hospital facility with various sub-specialty of pediatric services. The caregivers were from different regions of Malaysia's state, with the multicultural background of participants making up for the range of the samples. This study examines the caregiver burden among the local family caregivers of various cultures and ethnicities. Therefore, it is not limited to caregivers of a single race. In general, this study has successfully achieved the objectives, and the scope of this study was focused only on the caregiver who takes a child with chronic disease.

6.0 Conclusion & Recommendations

In conclusion, caregivers perceived the burden of caring for children with chronic diseases. Caregivers feel worried about their children's chronic diseases, and caring for them impacts their routine daily activities. On the other hand, the caregiver burden has no relationship to demographic data (caregiver age, gender, educational level). That shows it could be other reasons that may affect the caregiver's burden. Thus, interviewing caregivers to ascertain their burden in the future is essential. Future studies should include additional variables that rule out caregiver functioning and coping mechanisms more closely related to their well-being. Furthermore, in future studies, exploration of family income, caregiver health status, number of children, and age of children with chronic illness can be factors that may affect caregiver burden. Therefore, continuous support and development of coping strategies in the future by healthcare providers could help minimise the caregiver burden.

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Paper Contribution to Related Field of Study

This study raises awareness of the caregiver burden while caring for children with chronic diseases. In addition, perhaps the outcome of this study could support developing strategies to minimise the burden of the caregivers and indirectly will improve their quality of life.

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