

ORIGINAL ARTICLE

Burnout Among Caretakers of Paediatric Patient with Chronic Kidney Disease

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ABSTRACT

Introduction: Caring for children who have chronic kidney disease (CKD) is challenging. The goal of this study was to find out the prevalence of burnout and what factors contribute to it. We also want to know the correlation between caretaker's strain and burnout. **Methods:** This was a cross-sectional study that involved caretakers of children with CKD. They were recruited from a university hospital in Kelantan, Malaysia. Self-administered questionnaire in Malay language comprised of Demographic Information Form, Copenhagen Burnout Inventory (CBI-M) and Caregiver Strain Index (CSI-M) was used. **Results:** Eighty-eight caretakers were involved in this study. The mean age of caretakers was 42 years old, majority were female (72.4%), Malay (99.0%) and Muslim (99.0%). The mean age of children with CKD was 11 years old, most of them were on medication (69.3%) and mean duration of illness was 4.6 years. The prevalence of burnout in all domains (personal, work-related, client-related) among the caretakers was 5.7%. Eight caretakers had personal burnout (9.1%) while five (5.7%) had client-related and work-related burnout respectively. Multiple linear regression showed positive association of duration since the initial diagnosis and total ward admission within six months with total burnout score. Pearson correlation revealed a positive and fair correlation between strain and burnout. **Conclusion:** Prevalence of burnout among caretakers was generally low, but personal burnout outnumbered other domains. Children with CKD with longer duration of illness and more frequent ward admission are the important factors leading to burnout among caretakers. A high number of caretakers having significant strain indicated that there were possibilities of developing burnout later on.

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INTRODUCTION

Chronic Kidney Disease (CKD) is defined as kidney structural or function problems that have been present for more than 3 months and have health concerns (1). CKD can be divided into 5 stages according to latest Kidney Disease Improving Global Outcomes (KDIGO) guideline, based on Glomerular Filtration Rate (GFR). GFR is one of the greatest indicators of renal function since it declines in tandem with most other kidney functions following significant structural damage. GFR can be calculated using Schwartz equation. Patient with CKD stage 3 and above (GFR < 60ml/min/1.73m²) will show some health implication such as growth, nutrition,

endocrine and metabolic issues (1).

CKD in children differs from the adult population, especially in terms of causes, prevalence, and mortality (2). Children with CKD face lifelong morbidity and mortality that may affect their quality of life and the whole family dynamics. The causes for CKD in children are mostly due to congenital anomalies of the kidney and urinary tract (CAKUT), and subsequently were hereditary nephropathies and glomerulonephritis (2).

Multiple complications are seen in paediatric CKD patients. Due to numerous reasons, their growth and nutrition are affected, namely lack of appetite due to uremia, metabolic acidosis, and salt-losing nephropathies. These may cause stunted growth if not carefully managed and subsequently cause delayed puberty in later age. They may also develop renal osteodystrophy, which may cause bone deformities and

pathological fracture if not treated. Anaemia is also one of the complications that must be treated as it is linked to a low quality of life and neurocognitive deficit (2).

Patients with glomerular illness progress to CKD more quickly than patients with CAKUT anomalies, according to a retrospective cohort study (3). The factors that lead to a faster deterioration in renal function in non-glomerular disease patients, according to Wong et al. and Warady et al., were urinary protein-creatinine ratio >2 mg/mg, hypoalbuminemia, raised blood pressure (BP), dyslipidemia, male gender, and anaemia (4,5). Paediatric CKD differs from adult CKD in term of management for bladder dysfunction (4-5). Paediatric patient especially teenagers also have issues like compliance to medication and transition care to adult services (2).

All these issues related to CKD patient especially in paediatric patient which might cause significant impact to both patient and family. Frequent visit to hospitals as well as multiple medication and treatment for a long period of time could be a chronic stress that might lead to a toxic strain and give a negative impact not only to patient but also the caretakers.

Taking care of a chronically ill patient is a stressful ordeal, especially in a paediatric age patient. Many studies have identified factors that may affect high stressor, but little study describes the prevalence of burnout among caretakers in chronically ill patients. It is well established that caregivers of children on chronic peritoneal dialysis (PD) have a much inferior quality of life, as well as a higher rate of probable depression (6).

Caretaker is defined as one that give physical or emotional care and support, the primary guardian or parent. Here, the term "caretaker" refers to care provided by family members or friends rather than a professional who is paid for their services. A caretaker has all of the symptoms of chronic stress owing to a variety of factors that necessitate a high level of awareness and attention (7). This causes long-term physical and psychological stress, as well as a high level of unpredictability and uncontrollability (7). These can cause secondary stress in multiple aspects of life, including relationship within family and career (7).

Herbert Freudenberger, an American psychologist, coined the word "burnout" in the 1970s. There is a wide range of symptoms that is due to work-related or stress. Taking care for a family member is an example of a cause of stress outside of work. Burnout was classified as an occupational phenomenon rather than a medical disease in the 11th revision of the International Classification of Diseases (ICD-11). It is defined as "a syndrome resulting from chronic workplace stress that has not been managed successfully" (8). Burnout is defined by three key criteria: a sense of tiredness or

depletion of energy, a mental detachment from one's job or a sense of negativism or cynicism about one's employment, and a reduction in professional efficiency (8).

The goal of this study was to find out how often burnout is among caregivers of paediatric patients with CKD in Kelantan, as well as the factors that contribute to it. We also want to know the correlation between strain and burnout among caretakers of paediatric patients with CKD in Kelantan. Recognizing caretaker's burnout might help us with holistic approach in managing paediatric patient with CKD.

MATERIALS AND METHODS

We have carried out a cross-sectional study design using validated questionnaires – Copenhagen Burnout Inventory – Malay version (CBI-M) and Caregiver Strain Index (CSI). The recruitment period was from November 2019 to November 2020. This study involved caretakers of patients with CKD, that come to a local hospital. We enrolled 88 patients with CKD stage 3-5 according to inclusion and exclusion criteria. They were under our paediatrics clinic follow-up in our hospital or referred to our paediatric nephrology clinics. All patients' records were traced manually. All subjects were local ethnicity. The Human Research Ethics Committee (HREC) gave their approval to this investigation.

The sample size calculation was based on the single proportion formula with estimated prevalence based on research by Lindstrom et al.(9). The minimum required sample was 88, with considering 10% dropout and 10% precision, the total sample needed is 96. The convenience sampling was used in this study. We included patients aged three months to 18 years old with CKD stage 3 and above. The caretaker must be around age of 18 years and above, taking care of the patient most of the time (the one who will be with patient, give medications and other care) and not being paid for the care. Exclusion criteria applied if the caretaker did not understand Malay or English.

We defined paediatric patients with CKD as a patient from aged 3 months to 18 years old with abnormalities of structure or function of the kidney, with more than three months duration of calculated glomerular filtration rate (eGFR) < 60ml/min/1.73m², that is stage 3 and above (1). The caretaker was defined as one that gives physical or emotional care and support, primary guardian or parent (10).

This study used one form and two set of questionnaires that requires the caretakers to answer. First was the CBI-M questionnaire, consisting of 19 Likert-scale questions (score 0-4) with three domains. This questionnaire comprised of three main domains with 19 questions. The domains are personal burnout, work-related burnout,

and client-related burnout. Minimum expected score was 0, and maximum expected score was 76. Mean score was used for interpretation purposes whereby a mean score of 50 or more signified a significant burnout. The Malay version was validated by Andrew et al. in 2017 with satisfactory level of face validity index. The fact that factor loading was greater than 0.5 showed good convergent validity, while Cronbach's alpha values for the three factors varied from 0.83 to 0.87 (1).

The 3 domains were personal burnout, work-related burnout and client-related burnout. Personal-related burnout was defined as a person's level of physical and psychological fatigue and exhaustion (15). 'How often do you feel tired?' and 'how often do you feel weak and susceptible to illness?' were examples of question in the domain of personal-related. Work-related burnout referred to degree of physical and psychological fatigue and exhaustion that was perceived by the person as related to his or her work (15). Example of work-related burnout questions were 'do you feel burnout because of your work?' and 'do you have enough energy for family and friends during leisure time?'. Client-related burnout was defined as a person's level of physical and psychological stress and exhaustion as a result of his or her work with the youngster they are caring for (15). Example of client-related questions were 'do you find it hard to work with clients?' and 'does it drain your energy to work with clients?'. Stressor was defined as a stimulus that caused stress (10). Strain was defined as toxic stress. It resulted from a stressor that occurred for a long time and did not stop. Stress response built up to toxic levels and this is called strain. It had negative physical and psychosocial effect (16). Strain was assessed in this study using the Caregiver Strain Index (CSI).

The second form was the Caregiver Strain Index (CSI), which comprised of 13 questions that measure the level of strain on caregivers while taking care of patients at home. Some of the items given include emotional status, financial, time, physical, and family relationship. The question has a simple yes/no answer. Minimum expected score is 0, and maximum expected score is 13. Scores of more than 7 indicate a high level of stress (12). The questionnaire has been validated both in English and Malay versions (12). The Cronbach's alpha value was 0.79 (12).

The form used was the sociodemographic Pro-forma that comprised of a description of caretakers like gender, race, age, education level, relationship to the patient, job, and monthly income. It also included a duration of patient's diagnosis, treatment received, and the period of admission to ward within six months. Malaysians household income were classified into 4 categories, below poverty line (< RM2500), bottom 40% (B40 - RM2501 - RM5000), middle 40% (M40 RM 5001 -

RM10000) and top 20% (T20 - > RM10001) (13).

Data were entered and analysed using IBM SPSS Version 26 (IBM Corp. 2020). Descriptive analysis was used to summarise the sociodemographic characteristics of participants. Numerical data presented as mean (standard deviation (SD)). Categorical data will be presented as frequency (n) and percentage (%).

Simple and multiple linear regression is used to test and estimates relationships between factors and categorical outcomes. The correlation between strain and burnout was investigated using Spearman's correlation analysis.

RESULTS

Sociodemographic characteristics of 88 participants were summarised in Table I. Majority of respondents were female (72.4%), Muslim (99.0%) and Malay ethnicity (99.0%). Most of them were parents (94.3%), and another 5.7% were siblings. About 88.5% were married and another 5.7% were divorced.

The caretakers' mean age was 42 years old, with a standard deviation of 8.4 (age ranging from 20 to 60

Table I: Socio demographic data of caretakers of patient with CKD (n=88)

Variables	n (%)
Gender	
Female	64 (72.4)
Male	24 (27.6)
Race	
Malay	87 (99.0)
Chinese	1 (1.0)
Religion	
Muslim	87 (99.0)
Buddha	1 (1.0)
Age (in years)	42 (8.4) *
Academic qualification	
Primary school	2 (2.3)
Secondary school	41 (47.1)
Diploma	26 (29.9)
Degree or higher	18 (20.7)
Household income	
< RM2500	26 (30.3)
RM2500-5000	17 (20)
RM 5000- 10000	36 (41.4)
>RM 10000	7 (8.0)
Family dependent (number)	4.5 (2.2)*
Occupation	
Unemployed	29 (33.3)
Private sector	22 (25.3)
Government sector	19 (21.8)
Self-employed	17 (19.5)
Relationship	
Parents	82 (94.3)
Siblings	5 (5.7)
Marriage status	
Married	77 (88.5)
Divorced	5 (5.7)
Single	5 (5.7)

*Mean (Standard deviation)

years old). Regarding academic qualifications of caretakers, about 47.7% went until secondary school, and another 29.9% and 20.7% had a diploma and degree respectively. Thirty-four-point one percent of respondent were unemployed, while others worked in various sectors. Thirty-point three percent of caretakers had income less than RM2500, while another 41.4% were having income in between RM5000 to RM10000. Another 8.0 % had income more than RM10000.

Table II summarised sociodemographic characteristics of paediatric CKD patient involved. Mean age was 11 years old with 3.6 standard deviations (age ranging from 1 to 17 years old). Initial causes of CKD were unknown for 35.2%, followed by nephrotic syndrome 28.7%, structural anomalies 21.8% and others 14.7%. Mean years for the duration since initial diagnosis was 4.6 years with standard deviation 3.4 (duration 6 months to 13 years). Sixty-nine per cent were on medication, 18.4% on continuous ambulatory peritoneal dialysis (CAPD) and 12.6% on hemodialysis (HD).

Table II: Socio demographic data of CKD patients (n=88)

Variables	n (%)
Age (in years)	11 (3.6) *
Diagnosis	
Unknown	30 (34.5)
Nephrotic	25 (28.7)
Structural	19 (21.8)
Others	13 (14.7)
Duration from the initial diagnosis (in years)	4.6 (3.4)*
Type of treatment	
Medication	60 (69.0)
Continuous Ambulatory Peritoneal Dialysis (CAPD)	16 (18.4)
Haemodialysis	11 (12.6)
Ward admission in the last six months	
None	58 (66.7)
>1	29 (33.3)

*Mean (standard deviation)

From 88 caretakers included in the study, 5 had mean score of 50 or higher in all components in CBI, making the prevalence of burnout among the caretakers of 5.7%. The prevalence of burnout differed for each specific domain. A total of 8 caretakers had personal burnout (9.1%), 5 had client-related burnout (5.7%), and 5 had work-related burnout (5.7%) (Table III).

Thirteen participants (14.8%) from the total of 88 caretakers have reported significant score (>7) for caregiver strain index (CSI).

Simple and multiple linear regression analysis was used to analyse the relationship between various factors with total mean score CBI-M (Table IV). From the univariable analysis, there was a significant association between income <RM2500 (p-value = 0.003), unemployed (p-value = 0.040), CAPD as type of treatment (p-value= 0.027) and total ward admission within six months (p-value = 0.035). Multiple linear regression analysis

Table III: Prevalence of burnout among caretakers of CKD patient (n=88)

Burnout	n (%)
Overall burnout	
Yes	5 (5.7)
No	83 (94.3)
Personal burnout	
Yes	8 (9.1)
No	80 (90.9)
Work-related burnout	
Yes	5 (5.7)
No	83 (94.3)
Client- related burnout	
Yes	5 (5.7)
No	83 (94.3)

was done for both caretaker’s and patient’s age, income, family dependent, duration since the initial diagnosis, type of treatment and total ward admission within six months. From the analysis, there were a statistically significant relationship between time from initial diagnosis (p-value = 0.008) and total admission to ward within six months (p-value = 0.015) with burnout score. The duration of initial diagnosis and the total mean CBI-M score had a significant linear positive connection. Those with one year increase in the span of initial diagnosis had 1.5 higher total mean score of CBI-M when adjusted for total of ward admission within six months. There was a significant linear positive relationship between the sum of ward admission within six months and the total mean score of CBI-M. Those with 1 time increase in total ward admission within six months had 2.4 higher total mean score of CBI-M when adjusted for duration of initial diagnosis. Twenty percent of the variation in the total mean score of CBI-M was explained by duration of initial diagnosis and total of ward admission within six months according to multiple linear regression model (R² = 20%). There was a significant positive and fair correlation between burnout and strain (r = 0.383).

DISCUSSION

From the demographic data, we can conclude that most of our caretakers were parents, at middle age, but minority of them were siblings at young age group. Most of them were female, Malay ethnicity, Muslim, mothers and married. In this study, the average age of paediatric CKD patients was 11 years old, and the majority of them were only on medication, with a mean time from initial diagnosis of 4.6 years. This demographic data showed similar pattern with other study by Tsai et al., whereby the mean age of caretakers and gender were similar (6). Another research of parents of children with Type I diabetes and inflammatory bowel disease found that moms had a greater response rate than fathers, and that the children had a mean disease duration of 5 years (9). Parenting was often regarded as an essential domain in mothers than fathers. This can partly explain the higher participation of mothers in this study. Fathers as the breadwinner may also not be in the picture as they need to be working to ensure food on the table.

Table IV: Factors associated with total mean score CBI-M (n=88).

Variables	SLR *		MLR †	
	Crude b (95% CI)	p-value	Adjusted b § (95% CI)	p-value
Caretakers				
Age	0.4 (-0.60 – 0.87)	0.090		
Gender				
Male	0			
Female	4.14 (-4.87 – 13.16)	0.363		
Income				
>RM 10000	0			
< RM2500	26.70 (9.29-44.13)	0.003		
RM 2500 – 5000	10.07 (-4.02 – 24.15)	0.159		
RM 5001- 10000	6.46 (-7.54 – 20.48)	0.361		
Education level				
Degree or higher	0			
Primary school	- 1.24 (-29.10 – 26.64)	0.930		
Secondary school	9.64 (-0.94 – 20.21)	0.074		
Diploma	4.42 (-7.05 – 15.89)	0.445		
Occupation				
Government sector	0			
Private sector	-3.05 (-16.35 – 10.25)	0.649		
Self- employed	6.85 (-5.57 – 19.27)	0.270		
Unemployed	4.71 (-6.43 – 15.85)	0.040		
Marriage status				
Single	0			
Married	1.19 (-14.82 – 17.22)	0.883		
Divorced	-6.34 (-29.32 – 16.55)	0.583		
Family dependent	1.8 (-0.16 - 3.75)	0.072		
Patient				
Age	0.94 (-0.14 – 2.04)	0.090		
Duration initial diagnosis	1.52 (0.38- 2.65)	0.090	1.54 (0.41 – 2.67)	0.008
Type of treatment				
Medication only	0			
CAPD	11.64 (1.35 – 21.92)	0.027		
Hemodialysis (HD)	10.28 (-1.71 – 22.27)	0.092		
Total ward admission within 6 months	2.1 (0.15-0.41)	0.035	2.42 (0.48 – 4.36)	0.015

* Simple linear regression

† Multiple linear regression

§ Adjusted regression coefficient

R² = 20%

Stepwise, multiple linear regression method applied.

Model assumptions are fulfilled

There were no interactions amongst independent variables.

No multicollinearity detected.

The prevalence of burnout in this study was 5.7%, which was a much lower figure compared to other research done in Taiwan (28%) and Sweden (36%) (6,9). A study about caregiver burden among nocturnal home hemodialysis patients done by Rioux et al. revealed a low burden score perceived by the caretakers, in which they postulated that it could be due to underestimation of overall burden (17). A local study done by Siti Aisyah showed similar prevalence rate (8.3%) among caretakers of children with chronic neurological illness (18). Majority of respondents were Malays and Muslims who were taught to accept their sick child as part of their faith and a way to make a person or family stronger (19). Religion plays a vital role as a coping mechanism. According to a study conducted in Iran, educational-spiritual intervention proved successful in reducing burnout (20).

Personal-related burnout had a higher score than the work-related and client-related domain in this study. A study by Lan Ping Lin revealed a similar finding, with personal burnout being higher than work-related burnout among institutional carers working with people with

intellectual and developmental disabilities (21). Study by Siti Aisyah that use the same questionnaire (CBI-M) among caretakers also revealed higher personal-related burnout score (18). The prevalence of work-related and client-related burnout was the same. Contrary to this, a study among workers in paediatric healthcare systems in United States revealed higher work-related burnout scores than personal burnout scores (22). Questions on work-related burnout were answered by caretaker in reference to the task of caring for their children. Due to this interpretation of 'work', sub-dimensions of work-related and client-related burnout were measuring similar domain of caring for their child. Questions in sub-dimension of client-related burnout were in regard to their interaction with their child. In sub-dimension of work-related burnout, questions were more focused on caretaker's perception of parental work. As majority of caretakers who were mothers and not working, the task of taking care of their child would give similar responds for both work and client-related.

This study showed there were associations between duration of initial diagnosis and total ward admission

with total burnout score. Patient with a longer period of diagnosis had 1.5 times higher total score of burnouts. During a quantitative examination of a study, it was demonstrated that as the disease progresses, new difficulties occur in the patient, and caregiver load necessarily increases over time, finally leading to burnout (24). Contrary to this, study by Siti Aisyah revealed no significant association between duration of illness with total of burnout score (18). This could be due to the nature of CKD differed from chronic neurological illness. Patient with CKD worsened with time, and this might cause stress or negative impact to family and patient. Increase total ward admission within six months was found to have 2.5 times higher total score of burnouts. Ward admission means patient and caretaker need to be away from home. Adjustments need to be made by caretakers such as taking leave from work and making arrangement for another adult to take care of other kids at home. This might contribute to higher burnout score. Further study needs to be done to evaluate and support this finding.

There were no associations between children's age, type of diagnosis, caretaker's age, marital status, education qualification and occupation with total burnout score. The univariable analysis showed a significant association between caretaker's and patient's age with total burnout score. However, this result was not significant in multiple linear regression analysis. This was consistent with a previous study that showed no association between parent's education and marital status with burnout (9). Interestingly, another study that comparing parental burnout among parents with child with special needs or without special needs revealed positive correlation between education level and emotional distancing for parents with children with no special needs (28). Forty two point eight percent of parents in the study were having educational background less than secondary level (28). Further study with larger sample size and multiple centre need to be done to further investigate on the risk factors that may contribute to burnout in caretakers.

Fourteen-point eight percent of caretakers had significant CSI score. CSI was used to assess potential caregiving concerns in 5 major domains: employment, financial, physical, social and time. In this study, the total score of burnouts had a positive and fair correlation with caretaker strain [$r=0.383$]. Hence, when caretaker feels more strain, burnout also increase. According to Shakya D's research, caregiver burden and depression have a significant positive correlation (23). Though the rate of burnout was lower in this study than in others, a higher CSI score indicated considerable caretaker worries, which could signal stress or worry that could lead to burnout in the future.

This study had several limitations. Convenience sampling method might cause bias and cannot be generalized to

the target population due to the possibility of under- or over-representation of the population. This study also was done at a single centre, in Kelantan, with most respondents were Malays. It might not be generalised to whole multi-cultural Kelantan population. This study did not examine protective factors as well as consequences of caretaker burnout.

In this study, caretaker burnout was indirectly measuring parental burnout. Parental burnout was a relatively new concept, as burnout usually used in context with the workplace (25). It was unclear whether current available tools were able to measure parental burnout properly like worker burnout. Furthermore, parental burnout is linked to marital strife and relationship estrangement, escape and suicidal ideation, child neglect, and child violence (25). Further question need to be ask in those who have burnout, it is really due to taking care of CKD children or due to other problem.

Despite the low prevalence of total burnout in this study, the personal burnout score was prominent. Frequent ward admission and longer duration of disease might contribute to burnout among caretakers of paediatric CKD patient. A high number of caretakers having significant strain score showed that there were concerns among caretakers, and there might lead to burnout later. Further research and intervention need to be done in the local context to ensure caretaker's well-being be taken care of as part of a patient's management as a whole.

CONCLUSION

The result of this study showed that frequent ward admission and longer duration of disease might contribute to burnout among caretakers of paediatric CKD patient. Though the prevalence of total burnout was low, personal burnout score was prominent. A higher number of caretakers having significant strain score showed that there were concerns among caretakers, and there might lead to burnout later. Further research and intervention need to be done in the local context to ensure caretaker's well-being be taken care of as part of a patient's management as a whole.

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