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BURNOUT AND STRESSOR-RELATED FACTORS AMONG CARETAKER OF CHILDREN WITH CHRONIC NEUROLOGICAL ILLNESS

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ABSTRACT

Objective: Caring for children with neurological conditions is challenging. This study aimed to determine the prevalence of burnout and its associated factors among caretakers of children with chronic neurological illness. **Method:** This cross-sectional study involved 18 years or older caretakers of children with neurological illness for more than 3 months duration. They were recruited from Paediatric Neurology outpatient clinics over a period of 3 months from July to October 2019 at a general hospital in the state of Kelantan, Malaysia. Each caretaker was given a set of questionnaires that included General Stressor Questionnaire (GSQ) which was translated into Malay version 'Soal Selidik Umum (SSU)', Copenhagen Burnout Inventory-Malay version (CBI-M) and Demographic Information Form. **Results:** Overall, only 20 caretakers had mean score of 50 or higher in all component in CBI-M, making the prevalence of total burnout among the caretakers of 8.3% (95% CI = 5.2%, 12.6%). Personal burnout involved 78 caretakers (32.5%, 95% CI = 26.6%, 38.8%), 42 caretakers with client-related burnout (17.5%, 95% CI = 12.9%, 22.9%) and 11 caretakers had work-related burnout (4.6%, 95% CI = 2.3%, 8.1%). Most common stressors were performance pressure, work-family conflict and poor job prospects. Multiple logistic regression analyses showed that family stressors, types of children's neurological illness and number of household occupants were associated with personal burnout, client-related burnout and total burnout in their caretakers. **Conclusions:** Prevalence of total burnout among the caretakers was low, but personal burnout was prominent. Caretakers of children with genetic illness, cerebral palsy and autism had higher prevalence of burnout compared to other chronic neurological illness.

Keywords: Burnout, Stressor, Caretaker, Children, chronic neurological illness

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Introduction

Caring for children is a wonderful and rewarding experience. However, parents may be exposed to stress attempting to meet the challenges of caring for their own child. This is more profound in those caring for children with chronic neurological illness [1]. Burnout is originally described as a psychological syndrome emerging as a prolonged response to chronic stressors related to the workplace environment. Key dimensions are overwhelming exhaustion, feelings of cynicism and detachment from the

job, and a sense of ineffectiveness and lack of accomplishment [2].

The associations between physical and psychological health, and being an informal

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caregiver are well established [3]. Caring for children with chronic neurological illness may imposed higher burden physically and emotionally [1]. The act of caring might be accompanied by high levels of unpredictability and uncontrollability. As a consequence these factors may create secondary stress in multiple life domains, requiring high levels of vigilance and coping styles [1].

Burnout is a specific syndrome of exhaustion related to prolonged emotional imbalance, where the burden of perceived stress is overwhelming and exceeds coping strategies [4]. Burnout concept was first described in the mid-1970s as a syndrome specifically related to working environment, regarded as occupational hazard [2]. Recent studies showed evidence of exhaustion not only at the workplace, but also as a result of being a parent [5, 6]. Parental burnout is characterized by physical and emotional exhaustion, emotional distancing from one's child, and a sense of incompetency in parenting roles [7]. However, parental stress does not always lead to parental burnout [8].

Parental suffering in relation to children chronic illness is likely to occur at 3 main points. Prior to diagnosis, the family need to battle with disruption to ideal family life with child's recurrent ill health. Secondly, parents will experience a reaction to diagnosis of the condition, which may include complex feelings of loss, guilt, fear and even shame. In the end, parents may suffer in relation to period of adjustment, including challenges of disease management and supporting their child [9].

Caretakers may need to provide wide variety of assistance for their children [3]. Although care giving can be profoundly fulfilling, it can also cause physical and psychological disturbances [10, 11]. Caretakers of children with neurological illness such as cerebral palsy need to overcome the extra burden in dealing with their children's impairment or disabilities [11]. Children with disabilities are more likely to reside with caregivers with high levels of financial and psychological stress [12]. Burnout symptoms are more common to parents of children with chronic diseases as compared to those with normal children [13]. Parental burnout has larger associations with couple's conflict, escape and

suicidal ideation, child neglect and parental violence [7].

Many studies have been conducted internationally and locally to identify burnout in the medical workforce and formal caregivers. However, local data regarding burnout in caretakers of children with chronic illness are lacking. A local study found that 52% of mothers of children with developmental disabilities experienced psychological health problems with the highest prevalence exhibited by mothers of children with intellectual disability, autism and Down syndrome [14]. Another study in parents of children with Down Syndrome showed mean parenting stress was significantly higher among children with reported behavioral problems compared to others [15]. Recently the Copenhagen Burnout Inventory (CBI) was translated and validated into Malay version, CBI-M [16]. This provides an opportunity to study burnout in caretakers among the Malaysian population, using the Malay language as their first language.

The main objective of the study was to describe prevalence of burnout in caretakers of children with chronic neurological illness by utilizing Copenhagen Burnout Inventory-Malay version (CBI-M). It also investigated possible stressors among these caretakers as well as other socio-demographic factors associated with burnout.

Methods

Study design and participants

This was a cross-sectional study, recruiting caretakers from Paediatric Neurology Clinic over a period of three months. It was conducted in Hospital Raja Perempuan Zainab II, a tertiary hospital in the state of Kelantan, Malaysia. This study was approved by Medical Research and Ethics Committee, National Medical Research Register, Ministry of Health, Malaysia (NMRR-18-3689-45251) as well as The Human Research Ethics Committee of Universiti Sains Malaysia (Ethical approval code USM/JEPEM/19030191). This study was a part of Universiti Sains Malaysia Research University Grant.

Caretakers including parents or guardian of children aged less than 18 years old with chronic neurological illness were recruited via convenient sampling over a 3-month period from July 2019 to October 2019. Participants were approached

by principal investigator/trained research assistant during their children's regular scheduled follow-up at neurology outpatient clinic. Subjects were allowed sufficient time to consider their participation in the study. Written informed consent was obtained. Guided questionnaires including Copenhagen Burnout Inventory and General Stressors Questionnaires were used to identify burnout and associated stressors. Inclusion criteria were the main caretaker of children who were attending neurology clinic and the caretaker must be 18 years or older, caring for children with chronic neurological condition including cerebral palsy, attention-deficit hyperactive disorder (ADHD), autism, epilepsy and developmental delay for the duration of more than 3 months. The children under care were aged between 3 months to 18 years old. Exclusion criteria were caretakers who were not proficient in Malay language and did not give informed consent.

Sample size calculation was based on 95% confidence interval with power of study 80%. The main objective to determine the prevalence of burnout was used in the single proportion formula [17]. Prevalence of burnout of 56% was derived from a study looking at prevalence of psychological problems among caretakers of children with cerebral palsy [3]. Considering 20% non-response rate, the minimum required sample for caretakers was 232.

Research tools

Two validated questionnaires were used, which were General Stressor Questionnaire (GSQ) and CBI-M. GSQ was translated and validated into Malay language as "Soal Selidik Umum" (SSU) [18]. This Malay language version, SSU was used to identify common stressor among caregiver of children with chronic neurological condition. It comprised of 28 items with 7 domains (Family, Performance Pressure, Work-Family Conflicts, Bureaucratic Constraints, Poor Relationship with Superior, Poor Relationship with Colleagues and Poor Job Prospect). Each domain consisted of 4 questions. Each question used Likert-score 0 to 4 (0-causing no stress, 1-mild stress, 2-moderate stress, 3-high stress, 4-severe stress).

Family related stressors described as events occurring in family that can lead to person's emotional disturbances such as poor relationship

with the spouse, poor support from family members and having lack of skill in managing family [18, 19]. Performance pressure related stressors described as work demands that cause emotional disturbances to a person such as work overload, where any mistake can lead to disastrous consequences [18]. Work-family conflicts related stressors described as work events that compromise a person's personal and home life that lead to distress feelings such as advancing career at the expense of personal or home life [18, 20]. Bureaucratic constraints related stressors was described as organizational working environment that can cause distress feeling to a person such as lack of support from authority [18]. A poor relationship with the superior and colleagues related stressors described as interpersonal relationship events that can cause distress feelings to a person such as lack of support from superior and uncooperative colleagues [18]. The job prospect related stressors described as events related to reward and recognition such as feeling of being underpaid and lack of recognition to the job [18].

CBI-M were used for study of burnout in caretakers. It comprised of 3 sub-dimensions including personal burnout, work-related burnout, and client-related burnout. Personal burnout referred to degree of physical and psychological fatigue and exhaustion experienced by the person [21]. 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 [21]. Client-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 with their child [21].

Both tools were previously used in different populations. Burnout was previously well recognized as work-related entity [22]. At the beginning of this study, there were no standard tools available for measuring parental burnout. Thus, the CBI-M (validated tool for job burnout) was adapted into the current sample of caretakers, whereby caretakers were asked to consider taking care of their children as 'work'. The current study aimed at identifying burnout and stressor-related factors in caretakers of children with chronic neurological illness, including housewives and fathers who were

unemployed. Both tools were previously utilized in another study involving 78 caretakers of children with cancer, receiving treatment in Hospital Universiti Sains Malaysia in 2019. Overall reliability data was calculated with Cronbach's alpha for CBI-M and GSQ were 0.89 and 0.96, respectively [23].

Statistical analysis

Diseases were grouped into several sub-categories to facilitate data analysis including epilepsy, cerebral palsy, autism, attention-deficit hyperactive disorder, developmental delay, intellectual disability, genetic, metabolic and acquired neurological disorder. Genetic disorder included the neurological condition associated with gene abnormality, including Neurofibromatosis, Tuberous sclerosis, Joubert Syndrome and Dandy-Walker Malformation. Metabolic disorder was referring to neurological condition associated with metabolic disturbances including neurotransmitter disease, myasthenia, and mitochondrial myopathy, encephalopathy, lactic acidosis, and stroke (MELAS). Acquired neurological disorder were those not due to congenital malformation or genetic disorder and developed after birth following infection or trauma and contributed to neurological sequelae, including meningitis, encephalitis and acute disseminated encephalomyelitis (ADEM).

Data was entered and analysed using IBM SPSS version 24. Descriptive statistics were used to summarise socio-demographic characteristics of participants. Numerical data were presented as mean (SD). Categorical data was presented as frequency. Mean of total scores for each sub-dimensions of CBI-m calculated with scores of 50 or more considered as significant [21]. Scores were calculated according to specific domains in SSU. Final mean score of 2 or more was considered as significant stressors in the current study [18]. Factors associated with burnout were analysed using simple logistic regression and multiple logistic regressions. Dependent variables included personal burnout, work-related burnout and client-related burnout.

Results

The children's caretakers were identified and screened for eligibility during a 3 months period.

Two hundred and forty-five caretakers agreed to participate in the study. However, only 240 caretakers (98.0%) were analysed. The reasons for exclusion were missing data (4 caretakers, 1.6%) and patient over 18 years old (1 caretaker, 0.4%). Most of the caretakers were staying in Kota Bharu (43.3%). Majority of them were female (82.1%), Malay (94.6%) and Muslim (95.8%). Most of the participant owned their house (79.3%), had 3 rooms in the house (39.7%) and had total 5 occupants in their house (23.4%).

Most caretakers were high school graduates (47.7%), working full time (60.0%) and most were working in government sectors (51.0%). Thirty-seven percent of caretakers were housewives. Mean working-hour for those working full time was 8.08 hours (SD = 1.85) while for those working part-time was 6.50 hours (SD = 1.29). Those working in government sectors had mean working hour of 8.14 hours (SD = 1.13), while mean working hour for private sectors was 8.39 hours (SD = 1.91) and mean working hour for self-employed caretakers was 7.61 hours (SD = 2.63). Those working full time had higher median of salary with median of RM 2,000 (IQR = 2,900) as compared to those working part-time with median salary of RM 1,200 (IQR = 1,925). Those working in government sectors had the highest median salary with median salary of RM 3,000 (IQR = 2,861), as compared to private sectors with median salary of RM 1,400 (IQR = 1,175) and self-employed with median salary of RM 1,000 (IQR = 1,300).

Mean age of children with chronic neurological illness in this study was 7.19 years old (SD = 4.21), and most of them were male (60.8%) and already had the illness for more than 5 years (38.3%). Details were listed in Table 1.

Table 1: Demographic data of children with chronic neurological illness, (n = 240)

Patient's Demographic		n (%)
Age (year)		7.19 (4.21) ^a
Gender	Male	146 (60.8)
	Female	94 (39.2)
Types of Illness	Acquired neurological disorder	6 (2.5)
	ADHD	8 (3.3)
	Autism	24 (10.0)
	Cerebral Palsy	62 (25.8)
	Developmental Delay	53 (22.1)
	Epilepsy	69 (28.8)
	Genetic disorder	10 (4.2)
	Intellectual disability	5 (2.1)
	Metabolic disorder	3 (1.3)
Duration of Illness	less than 1 year	17 (7.1)
	1 to 2 years	66 (27.5)
	3 to 4 years	65 (27.1)
	more than 5 years	92 (38.3)
Disability Registration	Yes	128 (53.3)
	No	112 (46.7)

^a Mean (Standard Deviation)

From 240 caretakers included in the study, only 20 caretakers had mean score of 50 or higher in all components in CBI, making the prevalence of total burnout among the caretakers of 8.3% (95% CI = 5.2%, 12.6%). The prevalence of burnout differed for each specific domain. A total of 78 caretakers had personal burnout (32.5%, 95% CI = 26.6%, 38.8%), 42 had client-related burnout (17.5%, 95% CI = 12.9%, 22.9%) and 11 had work-

related burnout (4.6%, 95% CI = 2.3%, 8.1%). Out of 240 caretakers, 34 had combination of personal and client-related burnout (14.2%, 95% CI = 10.0%, 19.2%), 9 had personal and work-related burnout (3.8%, 95% CI = 1.7%, 7%), and 9 had both work-related and client-related burnout (3.8%, 95% CI = 1.7%, 7%). (Table 2)

Table 2: Prevalence of burnout among caretakers of children with chronic neurological illness (n = 240)

Burnout Subdomain*	Number of caretakers	Prevalence (95% CI)
Personal Burnout		
Yes (Mean Score ≥ 50)	78	32.5% (26.6%, 38.8%)
No (Mean Score < 50)	162	67.5% (61.2%, 73.4%)
Work Burnout		
Yes (Mean Score ≥ 50)	11	4.6% (2.3%, 8.1%)
No (Mean Score < 50)	229	95.4 (91.9, 97.7%)
Client Burnout		
Yes (Mean Score ≥ 50)	42	17.5% (12.9%, 22.9%)
No (Mean Score < 50)	198	82.5% (77.1%, 87.1%)
Total Burnout*		
Yes (Mean Score ≥ 50)	20	8.3% (5.2%, 12.6%)
No (Mean Score < 50)	220	91.7% (87.4%, 94.8%)

* Burnout = mean score for component in each specific subdomain ≥ 50

Total Burnout = mean score for all component ≥ 50

The prevalence of personal burnout among the caretakers of children with genetic illness was 60.0% (95% CI = 26.2%, 87.8%), followed by cerebral palsy (43.5%, 95% CI = 31.0%, 56.7%) and autism (37.5%, 95% CI = 18.8%, 59.4%). The highest prevalence of client-related burnout was among the caretakers of children with genetic illness (30.0%, 95% CI = 6.7%, 65.2%), followed by autism (29.2%, 95% CI = 12.6%, 51.1%) and cerebral palsy (27.4%, 95% CI = 16.9%, 40.2%). The highest prevalence of work burnout was among the caretakers of children with metabolic illness (33.3%, 95% CI = 0.8%, 90.6%), followed by intellectual disability (20.0%, 95% CI = 0.5%, 71.6%) and autism (12.5%, 95% CI = 2.7%, 32.4%). The highest prevalence of total burnout was among the caretakers of children with genetic illness (30.0%, 95% CI = 6.7%, 65.2%), followed by intellectual disability (20.0%, 95% CI = 0.5%, 71.6%) and autism (16.7%, 95% CI = 4.7%, 37.4%). Most common stressors were performance pressure stressor (11.3%), work-family conflict

stressor (6.7%) and poor job prospect stressor (5.8%).

Univariable analysis with simple logistic regression show that number of house occupant, type of illness, registration for people with disability with Welfare Department, number of siblings, family stressor, poor relationship with superior stressor, bureaucratic constraints stressor, work-family conflict stressor, performance pressure stressor and poor job prospect pressure stressor had significant association with personal burnout. Multiple logistic regression analyses showed that when adjusted to caretaker's gender, number of house occupant, type of the children's illness, family stressor, performance pressure stressor and poor job prospect stressor, it was found that all the variables had significant association with personal burnout among caretakers of children with chronic neurological illness (Table 3).

Table 3: Factors associated with personal burnout among caretakers of children with chronic neurological illness (n = 240)

Variable		Simple Logistic Regression			Multiple Logistic Regression		
		Crude β	Crude OR (95% CI)	p-value	Adj. β	Adj. OR (95% CI)	p-value
Caretaker's Age (years)	30 and below	0	1				
	31 – 35	- 0.47	0.63 (0.27, 1.47)	0.284			
	36 – 40	- 0.26	0.86 (0.37, 1.96)	0.710			
	41 – 45	- 0.47	0.62 (0.25, 1.55)	0.309			
	46 and above	- 0.83	0.44 (0.17, 1.13)	0.087			
Caretaker's Gender	Male	0	1			1	
	Female	0.71	2.04 (0.92, 4.49)	0.078	0.94	2.55 (1.01, 6.47)	0.049
No of occupant	4 occupants or less	0	1		0	1	
	5 or 6 occupants	0.91	2.48 (1.23, 5.00)	0.011	1.42	4.15 (1.77, 9.72)	0.001
	7 or more occupants	0.50	1.66 (0.78, 3.53)	0.191	0.76	2.13 (0.87, 5.23)	0.100
OKU Registration	No	0	1				
	Yes	0.57	1.78 (1.02, 3.09)	0.042			
Type of Illness	Epilepsy	0	1		0	1	
	Metabolic	- 20.01	-	0.999	- 20.37	-	0.999
	Acquired	- 0.41	0.66 (0.07, 6.09)	0.716	- 0.08	0.92 (0.09, 9.36)	0.944
	Dev. Delay	0.36	1.43 (0.64, 3.22)	0.385	0.68	1.97 (0.80, 4.89)	0.142
	ADHD	0.10	1.10 (0.20, 6.02)	0.909	0.04	1.05 (0.13, 8.71)	0.967
	ID	- 0.19	0.83 (0.09, 7.95)	0.870	- 1.37	0.26 (0.01, 5.61)	0.386
	Cerebral Palsy	0.94	2.56 (1.21, 5.42)	0.014	1.06	2.89 (1.25, 6.68)	0.013
	Autism	0.69	1.99 (0.73, 5.39)	0.177	0.23	1.26 (0.34, 4.59)	0.728
	Genetic	1.61	4.97 (1.25, 19.81)	0.023	1.94	6.96 (1.42, 34.03)	0.017
No of siblings	1 sibling	0	1				
	2 siblings	1.01	2.74 (0.97, 7.77)	0.057			
	3 siblings	1.42	4.13 (1.49, 11.47)	0.007			
	4 siblings	1.05	2.86 (0.98, 8.36)	0.055			
	5 siblings or more	0.80	2.22 (0.77, 6.41)	0.140			

Table 3, continued.

Variable		Simple Logistic Regression			Multiple Logistic Regression		
		Crude β	Crude OR (95% CI)	p-value	Adj. β	Adj. OR (95% CI)	p-value
Family	Not significant	0	1		0	1	
	Significant Stressor	3.27	26.43 (3.35, 208.82)	0.002	3.22	24.94 (2.46, 253.15)	0.007
Poor relationship with superior	Not significant	0	1				
	Significant Stressor	1.46	4.42 (1.07, 18.16)	0.039			
Bureaucratic constraints	Not significant	0	1				
	Significant Stressor	1.80	6.06 (1.56, 23.51)	0.009			
Work-family conflicts	Not significant	0	1				
	Significant Stressor	1.64	5.16 (1.72, 15.41)	0.003			
Poor relationship with colleagues	Not significant	0	1				
	Significant Stressor	1.86	6.44 (0.66, 62.94)	0.109			
Performance pressure	Not significant	0	1		0	1	
	Significant Stressor	1.63	5.10 (2.17, 11.98)	< 0.001	1.39	4.02 (1.41, 11.45)	0.009
Poor job prospect	Not significant	0	1		0	1	
	Significant Stressor	1.76	5.81 (1.76, 19.17)	0.004	1.73	5.65 (1.27, 25.07)	0.023

As compared to the male caretaker, the female caretaker has the higher odds of having personal burnout (OR = 2.55, 95% CI = 1.01, 6.47, $p = 0.049$), when adjusted to number of house occupant, child's type of illness, family stressor, performance pressure stressor and poor job prospect stressor. As compared to those who had four or less occupants in the house, the odd ratio of having personal burnout among those who had seven or more occupants higher (OR = 4.15, 95% CI = 1.77, 9.72, $p = 0.001$) when adjusted to the caretaker's gender, child's type of illness, family stressor, performance pressure stressor

and poor job prospect stressor. Caretakers of children with cerebral palsy have a higher odds of experiencing personal burnout, as compared to those taking care of children with epilepsy (OR = 2.89, 95% CI = 1.25, 6.68, $p = 0.013$), and this was also higher for those taking care of children with genetic illness (OR = 6.96, 95% CI = 1.42, 34.03, $p = 0.017$).

Discussion

The mean age of caretakers in this study was 38.12 years old. Majority of them were female, Malay ethnicity, Muslim, mothers, married and healthy. Mean age of children in this study was 7.19 years old, and most of them were male, had 3 siblings and already had the illness for more than 5 years. Another study done in parents of children with type 1 diabetes and inflammatory bowel disease also showed higher response rate in mothers as compared to fathers and included children with mean duration of disease of 5 years [24]. Parenting was often regarded as important domain in mothers as compared to fathers [13]. This can partly explain the higher participation of mothers in the current study. Some fathers refused to participate in this study, claiming that care giving was mainly done by mothers. The other possible explanation was most of the time fathers were at work. Therefore, care taking was left for the mothers. Unfortunately, this data was not captured during the study period.

The current study included caretakers of children with chronic neurological illnesses. Only 53% of children were registered as people with disability. According to Laws of Malaysia (Persons with Disabilities Act 2008), registration for people with disabilities in Malaysia was voluntary. However, it will be mandatory for entry into early intervention program or Integrated Special Education Program later. Privileges may not be well-informed to parents. Therefore, it was deemed unnecessary to register. Some parents may still be in the state of denial regarding their child's diagnosis and refused to register. Children with epilepsy wouldn't qualify for disability card if the condition did not result in neurological sequelae or delayed development.

There were no associations between children's gender, age, duration of illness and caretaker's marital status and burnout. This was consistent with previous study that showed no association between demographic factors, parent's education and marital status with burnout [24].

Among all caretakers, the most common burnout was personal burnout. Those taking care of children with genetic illness, cerebral palsy and autism had a higher prevalence of personal burnout compared to overall participants. A study done in Iran on caregiver burden of children with

chronic diseases also found that maximum care giving burden was observed in those caring for children with cerebral palsy [25]. It was also noted in the study that prolonged duration of disease were associated with higher caregiver burden, as well as poorer quality of life and mental health of their parents [25]. Prevalence of personal burnout in caretakers of children with genetic illness was as high as 60% in the current study. However, only 10 caretakers had children with genetic illnesses (including Neurofibromatosis Type 1, Tuberous sclerosis, Joubert syndrome and Dandy Walker). Therefore, further study with larger samples was needed to find the true effect of this association. When looking at chronicity of disease, this result was consistent with a study done in Sweden that showed parents of chronically ill children with type 1 diabetes and inflammatory bowel disease had significantly more burnout symptoms than parents of healthy children [13].

The highest prevalence of client-related burnout in this study was among caretakers of children with genetic illness, followed by autism and cerebral palsy. Dealing with different types of chronic neurological illness imposed different levels of caregiver burden [26] leading to varying degree of stress. Another study done in 2014 showed mothers of children affected by Neurofibromatosis type 1 reported higher mean parenting stress than the mothers of typically developing children [27]. It was noted in the current study that those caring for more than one child were more likely to have client-related burnout, caring for 3 children increased the likelihood of having client-related burnout by 5 times. In the current study, as compared to those who had four or less occupants in the house, the likelihood of having client-related burnout among those who had five or six occupants was 5.69 times higher. This was consistent with other studies that showed good social support provided by extended families decreased caregiver burden, responsibilities and stressors [25, 28, 29].

The highest prevalence of work-related burnout was among the caretakers of children with metabolic illness, followed by those with intellectual disability and autism, while none of the caretakers of children with acquired neurological illness and genetic illness had work-

related burnout. However, the overall prevalence of work-related burnout in this study was very low, 4.6%. This was lower than average prevalence of 14% parental burnout in the context of typically developing children [30, 31]. Questions on work-related burnout were answered in relation to a task of caring for their own children. Due to this interpretation of 'work', sub-dimensions of work-related burnout and client-related burnout measured similar domain of caring for their own child. Questions in sub-dimension of work-related burnout were asking regarding caretaker's perception of parental work. In sub-dimension of client-related burnout, questions were more focusing on their interaction with their child.

It was interesting to find that only 4.6% of caretakers were having work-related burnout as compared to 17.5% experiencing client-related burnout. Majority of participants were Malays. Most Malays were Muslims who were taught to accept their sick child or disabled child as part of their faith and a way to make a person or family stronger [31]. Religion plays an important role as coping mechanism. A study done on burnout of parents of school age children with cancer found that educational-spiritual intervention was effective on reduction of burnout [32]. On the other hand, a study conducted in 2013 on caregivers of children with cerebral palsy showed having a disabled child was causing interference with quality of life for caregivers and higher burnout levels compared to control group. The same study also showed functional limitations of children were correlated with poorer caretakers' quality of life, mental health and burnout [11].

In the 11th Revision of the International Classification of Diseases (ICD-11), burnout was included as an occupational phenomenon. It was defined as a syndrome conceptualised as resulting from chronic workplace stress that has not been managed successfully [33]. This was characterised by 3 dimensions, feelings of energy depletion or exhaustion; increased mental distance from one's job, or feelings of negativism or cynicism related to one's job; and reduced professional efficacy [33]. In the current study, caretaker burnout was indirectly measuring parental burnout. Parental burnout was a relatively new concept [8]. It was unclear whether current available tools were accurate measures of

parental burnout [34]. Parental burnout has a larger association with couples' conflicts and partner estrangement, escape and suicidal ideation, child neglect and child violence [7].

Burnout experience had been postulated to occur following interaction between multiple sources of stressors that were uncompensated over a period of time. Parental burnout resulted from chronic imbalance of risks over resources available in the parenting domain [8]. In the current study, the most common stressors were performance pressure, work-family conflict and poor job prospects. Multiple logistic regression analyses showed that family stressor, types of child's neurological illness and number of household occupants were associated with parental burnout. GSQ family domain consisted of questions asking about family dynamics [18].

In the current study, caretakers with significant family stressors were 24 times more likely to have personal burnout, 12 times more likely to have total burnout and 17 times more likely to have client-related burnout. This was consistent with a study involving 372 French parents where it showed having many children at home were risk factor for both emotional distancing and loss of sense of achievement [35]. Another study showed severity of functional limitation of children with cerebral palsy had a significant association with mental health and wellbeing of caregivers [11].

Findings in this study emphasised the importance of exploring social circumstances surrounding children and their caretaker. Caretakers with significant family stressors need to be identified and referred for further assistance and respite care because they were at higher risk of experiencing burnout.

Limitations

This study had several limitations. This was a cross-sectional study done at a single centre, in the capital of Kelantan. Most of the participants were Malays. It might not be generalised to whole multi-cultural Kelantan population. It was unable to determine cause and effect relationships with main findings were only possible associations. This study did not examine protective factors as well as consequences of caretaker burnout. Furthermore, CBI-M and GSQ were adapted from

the job-related constructs. Some of the questions in CBI-M were redundant when participants were asked to consider 'work' as taking care of their children and 'client' also was referring to their child. Questions in most domains of GSQ were related to working with peers or superior. Therefore, some of these questions were somewhat non-applicable to this current study.

Conclusion

This study showed that caretakers of children with chronic neurological illness had higher levels of burnout than those caring for normally developing children. Prevalence of total burnout among the caretakers of children with chronic neurological illness was low, but personal burnout was prominent. Associated factors for personal burnout were being a female, having 5-6 occupants in the house and caring for children with cerebral palsy or genetic disorder. Significant stressors identified were family stressors, performance pressure and poor job prospect.

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