ORIGINAL ARTICLE

The Correlation of Burnout and Stressors among Caretakers of Children with Cancer

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ABSTRACT

Introduction: Caretakers are the vulnerable group to burnout and stressor. Identifying potential stressors in the caretakers of children with cancer might lead to an effective prevention strategy for caretaker burnout. This study aims to examine burnout and its correlation with stressors among the caretakers of children diagnosed with cancer. **Method:** A cross-sectional study was conducted on the caretakers of children under 18 years old, diagnosed with cancer, and receiving treatment at Hospital Universiti Sains Malaysia (Hospital USM) for over six months in 2018. Assessment of burnout was completed using the validated Malay version Copenhagen Burnout Inventory (CBI-M) and General Stressor Questionnaire (GSQ-M). **Results:** Seventy-eight caretakers participated in this study. Respondents mainly were mothers (64.9%) and medium to low social-economic group (81.8%). In our cohort, we found 30 (38.4%) of respondents showed personal, 12 (15.4%) for work-related, and 63 (80.7%) for client-related moderate to very severe burnout, respectively. In the moderate to severe stressors, 33 (43.2%) had a poor relationship with colleagues, 34 (44.7%) had a poor relationship with superior, 35 (45.3%) had work-family conflicts, 38 (48.7%) had bureaucratic constraints, 43 (54.5%) for family and 46 (59%) had performance pressure. Spearman's correlation analysis showed a significant correlation between GSQ stressor domains score and client-related burnout ($p < 0.05$). **Conclusion:** The prevalence of burnout was alarmingly high, especially in the client-related domain among the caretakers of children with cancer. Future studies are needed to devise an appropriate interventional strategy for this group.

Keywords: Burnout, Stressor, Caretakers, Children, Cancer

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INTRODUCTION

Cancer has been the leading cause of disease burden among the paediatric population globally. Paediatric oncology is undergoing rapid evolution and change to achieve optimal care and mortality reduction parallel to United Nations Sustainable Development Goals (SDGs) (1-4). According to the Malaysian Cancer Registry, 37 out of 100,000 Malaysian children are at risk of developing cancer. Due to improvement in treatment modalities and supportive care, cancer patients' survival outcomes and mortality rates have improved, resulting in a higher disease burden among survivors and caregivers (1, 2, 4-12).

Common issues faced by children with cancer are prolonged hospitalization, school absenteeism, multiple blood takings, intensive care admission, while some with poorer prognoses may need palliative care support. To facilitate compliance and accomplish optimal treatment goals, parents must provide support, understanding, and dedication. Burnout, emotional tiredness, poor performance, and depersonalization are common among caregivers of children with cancer (13). Stress is created by stressors at the expense of lifestyle and elements such as psychosocial status, emotional discomfort, family dynamics change, and poor quality of life, all of which have a direct impact on patient's care (3, 7, 8, 11, 14-17).

A filial commitment is a cultural norm in Malaysia, where extended family members volunteer to care for sick family members, particularly youngsters. This tradition

has become the bedrock for community support due to local circumstances, social connection, and moral obligation (18). However, family caregivers experience significant burdens that can disrupt their biopsychosocial integrity and indirectly impact their emotional, social, financial, physical, and spiritual functioning despite the subjectivity of caretakers' duty (19, 20). These caretakers become invisible patients as their needs are not recognized or identified and they have to function and care for their child in the community.

Burnout is taken into account when emotional and interpersonal stresses on work are protracted (21, 22). Parental burnout could be associated with the reaction to parental stress. Unfortunately, conceptualizing burnout as part of stress study is biased with the vagueness of the current definition. Burnout is frequently associated with a lack of sense of significance at work, according to a clinical study (21). Burnout personnel were shown to be more susceptible to symptoms than strain levels or maybe have a serious negative reaction from the symptoms. The previous study has found a direct effect of stress on resilience and burnout. Working in an environment that influences emotion could potentially influence burnout and indirectly affect the strength of the affected individuals (23).

Burnout, tiredness, and fatigue in personal life, work, and client service were measured using the Copenhagen Burnout Inventory (CBI-M) (24, 25). Compassion fatigue is a form of burnout. However, it addresses the condition's relational nature, whereas burnout is frequently associated with stressors (26, 27). Stress develops when the ability of a person to meet the demands of a circumstance is inconsistent. The stressor is a human or environmental stressful occurrence (26). It has a significant impact on mood, well-being, behaviour, and health (27). Studies have indicated that cancer-related causes such as sickness and invasive treatments such as aspiration of the bone marrow have led to parental stress, reduced exercise and bad living conditions (28). The General Stressor Questionnaire (GSQ), an excellent psychometric tool that has been translated into Malay, was used to assess stress. It has a reliable internal consistency to measure the prevalence of stressors (18). This study aimed to study burnout and stresses facing carers and associated factors of children with cancer.

MATERIALS AND METHODS

Study design

A cross-sectional study was conducted to assess burnout among the caretakers who had children with cancer. To ensure accurate study reporting, the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist was used. Participants were recruited via convenience sampling.

Study setting and participants

During the study period, the primary caretaker accompanying the child, either one of the parents or legal guardians, were invited to participate in this study. We included caregivers who had children with cancer under the age of 18 who were still receiving medical treatment or being followed up on at the Paediatric Oncology unit. Caretakers who have been working at the welfare home were excluded. Consent was obtained before study enrolment. Participants were given 20 minutes to complete the questionnaires. The study was conducted at the Hospital Universiti Sains Malaysia (Hospital USM) from May to October 2018.

Measurement Tools

We utilized the validated Malay version of CBI-M to measure burnout in our studied population. It has composite reliability values of the three factors ranged from 0.84 to 0.87, and the Cronbach's alpha values of the three factors ranged from 0.83 to 0.87 (26). Personal burnout (part A), work-related burnout (section B), and client-related burnout (section C) are the three domains, with "client" referring to students, inmates, and patients (19). Twelve questions were graded on a Likert scale of 0 (always), 1 (frequently), 2 (occasionally), 3 (rarely), and 4 (never/almost never). Another seven questions used the following descriptors: 0 = very high, 1 = high, 2 = somewhat, 3 = low, and 4 = very low. Reverse scoring was applied in positively worded items. Higher scores indicated a high level of burnout (20). The mean score was used for interpretation, with a mean score of 2 or higher indicating significant burnout (20).

To assess the stressor, we utilized General Stressor Questionnaire (30). The internal consistency for GSQ was 0.94. This tool contains 28 items divided into seven domains: family, performance pressure, work-family conflicts, bureaucratic constraints, poor relationship with superiors, poor relationship with colleagues, and poor job prospects. To indicate the severity of stress, five rating scales were supplied, with 0 indicating no stress, 1 indicating mild stress, 2 indicating moderate stress, 3 indicating high stress, and 4 indicating severe stress. The severity of stress is reflected by a mean score, which ranges from 0.00 to 1.00 for no to mild stress, 1.01-2.00 for mild to moderate stress, 2.01-3.00 for moderate to high stress, and 3.01-4.00 for severe stress (30).

Ethical Clearance

Ethical approval was obtained from Research and Ethical Committee, School of Medical Sciences, USM Health Campus (USM/JEPeM/18010072).

Data Analysis

The Statistical Package for Social Science Version (SPSS) version 24 was used to evaluate all quantitative data. The analysis comprised respondents who completed all

of the surveys. Descriptive analysis was used to describe the sociodemographic characteristics of the respondent. Spearman's correlation analysis was applied for correlation between burnout and stressors because of bivariate normal distribution assumption was violated. The sample size was calculated at 74 respondents by single proportion, with a 95% precision of 0.10 and a 20% non-response rate.

RESULTS

There were 78 eligible respondents recruited. Fifty (64.1%) of the respondents were mothers, while 23 (29.5%) were fathers. There were 62.3% of the respondents completed their education up to secondary school. The majority of the respondents (81.8%) were from the low social economic group with a monthly salary below RM 3000. Most caretakers were those who have their children being treated for childhood cancer from 2009 to 2018. Table I represents the descriptive data of the participated respondents.

Mean (SD) CBI-M subscale scores for this sample were 2.30 (0.62) (personal); 2.83 (0.28) (work-related) and 2.77 (0.26) (client-related). On the personal subscale, 38.4% (n=30) of the caretakers reported moderate to very high burnout, 15.4% (n=12) reported burnout in the work-related domain and 80.7% (n=63) in the client-related domain. The participants scored more than 2, indicating severe burnout outcomes (Table II and Table III).

Table I: Descriptive analysis on demographics of caretakers of children with cancer in Hospital USM (N = 78)

Demographic	Frequency, n (%)
Relationship with the child	
Father	23 (29.9)
Mother	50 (64.9)
Others	4 (5.2)
Missing	1 (1.3)
Marital Status	
Married	71 (91.0)
Single	3 (3.8)
Widowed	3 (3.8)
Divorced	1 (1.3)
Caretaker education level	
Secondary school	48 (62.3)
Certificate/Diploma	15 (19.5)
Degree/Postgraduate	14 (18.2)
Salary (RM)	
Not fixed	19 (27.1)
501 – 1000	18 (25.7)
1001 – 2000	13 (18.6)
2001 – 3000	8 (11.4)
3001 – 5000	10 (14.3)
> 5000	2 (2.9)
Number of family members living together	6 (7.8)
None	56 (72.7)
1 – 5	13 (16.9)
6 – 10	2 (2.6)
11 – 15	
Length of hospital stay	
1 – 7 days	32 (54.2)
2 – 4 weeks	22 (37.3)
1 – 3 months	4 (6.8)
Up to 6 months	1 (1.7)

The majority of caretakers scored in the normal to mild range on the family (Mean (SD)= 1.33 (0.62)), poor relationship with superior (Mean (SD) = 1.19 (0.41), bureaucratic constraints (Mean (SD)= 1.04 (0.37)), work-family conflicts (Mean (SD)= 1.22 (0.6)) and performance pressure (Mean (SD)= 1.16 (0.36)) of GSQ questionnaire (Table IV). In Table III shows the prevalence of caretakers with moderate to severe stressors with 43 (54.5%) for family, 34 (44.7%) had a poor relationship with superior, 38 (48.7%) had bureaucratic constraints, 35 (45.3%) had work-family conflicts, 33 (43.2%) had a poor relationship with colleagues and 46 (59%) had performance pressure. The prevalence of burnout for each subscale in the CBI revealed that all caregivers, 78 (100 percent), experienced personal burnout, 77 (98.8 percent) experienced work-related burnout, and 67 (85.9 percent) experienced significant client-related burnout.

With Spearman's rho correlations ranging from 0.23 to 0.42, the burnout CBI subscales were significantly correlated with the stressor, particularly client-related burnout ($p<0.05$). In addition, the link between customer-specific burnout scores and work-family conflict score, poor relationships with colleagues and performance pressure was found to be highly significant ($p<0.001$) (Table V).

DISCUSSION

This was a single-center study involving a tertiary centre located in the northeast of Peninsular Malaysia. The area is inhabited by the majority Malay race with a population of more than 1.5 million. Hospital USM is a 747 bedded university hospital functions as paediatric oncology referral in this area. Culturally, caretakers are those from close family members, and they are often willing to take time off to care for their children and becoming full-time caretakers.

A high prevalence of burnout among the caretakers of cancer children was found in our study with the highest domain in the client-related burnout. This was consistent with the previous studies (30). Burnout reduces the quality of care provided to patients and has a negative impact on the caregiver's personal life (31). This was an alarming finding as our cohort of caretakers were vulnerable to developing burnout as most of them come from poor psychosocial backgrounds.

These caretakers suffered from significant burnout due to prolonged exposure to chronic stressors leading to exhaustion, thus manifesting a different component of burnout. Caretakers perceive stress differently despite the prolonged exposure to the experience. They may

Table II: Responses of CBI-M from the caretakers of children with cancer

Item Personal scale	Mean (SD)	Response frequencies, n (%)				
		Always	Often	Sometimes	Seldom	Never
A1 How often do you feel tired?	1.83 (1.08)	9 (11.5)	21 (26.9)	27 (34.6)	16 (20.5)	5 (6.4)
A2 How often are you physically exhausted?	1.82 (0.98)	7 (9.0)	24 (30.8)	26 (33.3)	18 (23.1)	3 (3.8)
A3 How often are you emotionally exhausted?	1.69 (1.14)	15 (19.2)	19 (24.4)	21 (26.9)	21 (26.9)	2 (2.6)
A4 How often do you think: "I can't take it anymore"?	3.06 (1.31)	6 (7.7)	4 (5.1)	11 (14.1)	15 (19.2)	42 (53.8)
A5 How often do you feel worn out?	2.37 (1.13)	6 (7.7)	11 (14.1)	20 (25.6)	30 (38.5)	11 (14.1)
A6 How often do you feel weak and susceptible to illness?	3.05 (0.99)	1 (1.3)	4 (5.1)	15 (19.2)	28 (35.9)	30 (38.5)
Mean average score	**2.30 (0.62)**					
Work related scale		**To a very high degree**	**To a high degree**	**Somewhat**	**To a low degree**	**To a very low degree**
B1 Is your work emotionally exhausting?	2.59 (0.92)	2 (2.6)	13 (16.7)	14 (17.9)	35 (44.9)	14 (17.9)
B2 Do you feel burnt out because of your work?	2.88 (1.09)	3 (3.8)	7 (9.0)	12 (15.4)	30 (38.5)	26 (33.3)
B3 Does your work frustrate you?	3.31 (1.11)	3 (3.8)	4 (5.1)	5 (6.4)	21 (26.9)	45 (57.7)
B4 Do you feel worn out at the end of the working day?	2.82 (1.15)	5 (6.4)	6 (7.7)	11 (14.1)	32 (41.0)	24 (30.8)
B5 Are you exhausted in the morning at the thought of another day at work?	2.96 (1.06)	4 (5.1)	4 (5.1)	9 (11.5)	35 (44.9)	26 (33.3)
B6 Do you feel that every working hour is tiring for you?	2.86 (1.04)	2 (2.6)	9 (11.5)	9 (11.5)	36 (46.2)	22 (28.2)
B7 Do you have enough energy for family and friends during leisure time?	2.36 (1.21)	8 (10.3)	9 (11.5)	23 (29.5)	23 (29.5)	15 (19.2)
Mean average score	**2.83 (0.28)**					
Client related scale		**Always**	**Often**	**Sometimes**	**Seldom**	**Never**
C1 Do you find it hard to work with clients?	2.74 (1.17)	3 (3.8)	11(14.1)	15 (19.2)	23 (29.5)	26 (33.3)
C2 Do you find it frustrating to work with clients?	2.50 (1.26)	3 (3.8)	6 7.7)	15 (19.2)	17 (21.8)	37 (47.4)
C3 Does it drain your energy to work with clients?	2.60 (1.22)	3 (3.8)	7 (9.0)	4 (5.1)	28 (35.9)	36 (46.2)
C4 Do you feel that you give more than you get back when you work with clients?	2.73 (1.12)	4 (5.1)	8 (10.3)	17 (21.8)	25 (32.1)	24 (30.8)
C5 Are you tired of working with clients?	3.31 (1.04)	2 (2.6)	5 (6.4)	7 (9.0)	17 (21.8)	47 (60.3)
C6 Do you sometimes wonder how long you will be able to continue working with clients?	2.79 (1.07)	1 (1.3)	8 (10.3)	18 (23.1)	22 (28.2)	29 (37.2)
Mean average score	**2.77 (0.26)**					

Table III: Prevalence of burnout and stressors according to the domain of each tools

Copenhagen Burnout Inventory (CBI-M)				**General Stressor Questionnaire (GSQ-M)**			
Domain	**Level of burnout**	**Prevalence (%)**	**Subscale Cronbach's alpha**	**Domain**	**Level of stress**	**Prevalence (%)**	**Subscale Cronbach's alpha**
Personal	Moderate High Very high Total	34.6 3.8 0.0 38.4	.85	Family	Mild Moderate High Severe	45.5 36.4 13.0 5.1	.70
				Poor relationship with superior	Mild Moderate High Severe	55.3 32.9 7.9 3.9	.78
Work-related	Moderate High Very high Total	12.8 2.6 0.0 15.4	.87	Bureaucratic constraints	Mild Moderate High Severe	51.3 35.5 13.2 0.0	.66
				Work-Family Constraints	Mild Moderate High Severe	54.7 32.0 12.0 1.3	.69
Client-related	Moderate High Very high Total	6.4 16.7 57.7 80.8	.83	Poor relationship with colleagues	Mild Moderate High Severe	65.8 22.4 10.5 1.3	.78
				Performance Pressure	Mild Moderate High Severe	41.0 28.2 25.8 5.0	.72

Table IV: Responses of the GSQ from the caretakers of children with cancer

Item	Mean (SD)	Response frequencies, n (%)					
Family		**Missing, n (%)**	**Causing no stress at all**	**Causing mild stress**	**Causing moderate stress**	**Causing high stress**	**Causing severe stress**
1 Inadequate preparation for dealing with more difficult aspects of family matters	1.83 (1.14)	-	7 (9.0)	30 (38.5)	17 (21.8)	17 (21.8)	7 (9.0)
2 Insufficient knowledge in educating and building child/ children characters	1.36 (1.22)	1 (1.3)	23 (29.9)	23 (29.9)	16 (20.8)	10 (13.8)	5 (6.5)
3 Poor communication and relationship with family members	1.13 (1.29)	2 (2.6)	35 (46.1)	14 (18.4)	14 (18.4)	8 (10.5)	5 (6.6)
4 Poor relationship with spouse	1.01 (1.15)	1 (1.3)	35 (45.5)	19 (24.7)	12 (15.6)	9 (11.7)	2 (2.6)
Mean average score	1.33 (0.62)						
Poor relationship with superior							
5 Lack of support from superior	1.17 (1.28)	2 (2.6)	32 (42.1)	19 (25.0)	9 (11.3)	12 (15.8)	4 (5.3)
6 Difficulty in maintaining relationship with superior	0.97 (1.14)	1 (1.3)	37 (48.1)	16 (20.8)	15 (19.5)	7 (9.1)	2 (2.6)
7 My beliefs contradict with those of my superior	1.53 (1.29)	-	23 (29.5)	17 (21.8)	17 (21.3)	16 (20.5)	5 (6.4)
8 Unfair assessment from superior	1.09 (1.24)	1 (1.3)	36 (46.8)	15 (19.5)	11 (14.3)	13 (18.4)	2 (2.6)
Mean average score	1.19 (0.41)						
Bureaucratic constraints							
9 Lack of authority to carry out my job duties	0.78 (1.10)	-	44 (56.4)	17 (21.8)	10 (12.5)	4 (5.1)	3 (3.8)
10 Unable to make full use of my skills and ability	0.97 (1.11)	-	35 (44.9)	23 (29.5)	7 (9.0)	13 (16.7)	0 (0.0)
11 Cannot participate in decision making	1.31 (1.09)	-	21 (26.9)	26 (33.3)	19 (24.4)	10 (12.3)	2 (2.6)
12 Having to do work outside of my competence	1.08 (1.10)	1 (1.3)	28 (36.4)	28 (36.4)	10 (13.0)	9 (11.7)	2 (2.6)
Mean average score	1.04 (0.37)						
Work-Family Conflicts							
13 Work demands affect my personal/home life	1.62 (1.27)	-	20 (25.6)	18 (23.1)	17 (21.8)	18 (23.1)	5 (6.4)
14 Advancing a career at the expense of home/ personal life	0.96 (1.04)	1 (1.3)	32 (41.6)	24 (31.2)	14 (18.2)	6 (7.8)	1 (1.3)
15 My life is too centered on my work	1.53 (1.31)	-	22 (28.2)	21 (26.9)	13 (16.7)	16 (20.5)	6 (7.7)
16 Absence of emotional support from family	1.05 (1.06)	1 (1.3)	30 (39.0)	23 (29.9)	15 (19.5)	8 (10.4)	1 (1.3)
Mean average score	1.22 (0.6)						
Poor relationship with colleagues							
17 Working with uncooperative colleagues	0.70 (1.07)	2 (2.6)	46 (60.5)	16 (21.1)	8 (10.5)	3 (3.9)	3 (3.9)
18 Working with incompetence colleagues	0.79 (1.08)	1 (1.3)	42 (54.5)	19 (24.7)	8 (10.4)	6 (7.8)	2 (2.6)
19 Relationship problems with colleagues /subordinates	0.99 (1.11)	1 (1.3)	35 (45.5)	18 (23.4)	16 (20.8)	6 (7.8)	2 (2.6)
20 Competition among colleagues	0.97 (1.22)	1 (1.3)	39 (50.6)	16 (20.8)	11 (14.3)	7 (9.1)	4 (5.2)
Mean average score	0.86 (0.24)						
Performance pressure							
21 Time pressures and deadlines to meet	1.27 (1.40)	-	29 (37.2)	20 (25.6)	12 (15.4)	13 (16.7)	4 (5.1)
22 Work overloads	1.40 (1.13)	-	22 (28.2)	19 (24.4)	23 (29.5)	12 (15.4)	2 (2.6)
23 Fear of making mistakes that can lead to serious consequences	1.04 (1.22)	2 (2.6)	35 (46.1)	18 (23.7)	12 (15.8)	7 (9.2)	4 (5.3)
24 My work is mentally straining	0.91 (1.21)	2 (2.6)	42 (55.3)	13 (17.1)	10 (13.2)	8 (10.5)	3 (3.9)
Mean average score	1.16 (0.36)						
Poor job prospect							
25 Feeling insecure in this job	1.05 (1.22)	1 (1.3)	36 (46.8)	17 (22.1)	11 (14.3)	10 (13.0)	3 (3.9)
26 Society does not think highly of my profession	1.03 (1.22)	1 (1.3)	37 (48.1)	15 (19.5)	16 (20.8)	4 (5.2)	5 (6.5)
27 Lack of promotion prospects	0.79 (1.04)	1 (1.3)	41 (53.2)	19 (24.7)	11 (14.3)	4 95.2)	2 (2.6)
28 Feeling of being underpaid	1.08 (1.35)	1 (1.3)	39 (50.6)	13 (16.9)	12 (15.6)	6 (7.8)	7 (9.1)
Mean average score	0.99 (0.31)						

likely have developed tolerance towards stressors and built their resilience. The outcome for stressors was not anticipated as mild to moderate stress was only captured in our study. Anecdotal evidence previously suggests that burnout is not always associated with high stress level (21). Since the questionnaire possessed different domains of stressors, it is important to denote that the cohort of caretakers is from a lower socioeconomic group. Hence, relationships with superior or colleagues or performance pressure might not be relevant, thus showing minimal stressors in these domains. Burnout appears to have distinct antecedents, correlates, and consequences and may be considered a subcategory of stress (21).

Table V : Correlation between burnout and stressor among caretakers of children with cancer at Hospital USM.

Stressor	Burnout	Correlation coefficient[b]	*p*-value[a]
Family	Personal	0.07	0.57
	Work-related	0.00	0.97
	Client-related	0.23	**0.046**
Poor relationship with superior	Personal	0.10	0.37
	Work-related	0.00	0.99
	Client-related	0.36	**0.001**
Bureaucratic constraints	Personal	0.02	0.89
	Work-related	0.04	0.74
	Client-related	0.34	**0.003**
Work-family conflicts	Personal	0.08	0.48
	Work-related	0.11	0.36
	Client-related	0.42	**<0.001**
Poor relationship with colleagues	Personal	0.08	0.51
	Work-related	0.04	0.72
	Client-related	0.40	**<0.001**
Performance pressure	Personal	0.15	0.18
	Work-related	0.19	0.10
	Client-related	0.40	**<0.001**
Poor job prospect	Personal	0.09	0.46
	Work-related	0.15	0.18
	Client-related	0.34	**0.002**

[a] Bivariate normal distribution assumption violated; Spearman's correlation analysis was applied.
[b] Correlation coefficient: $r = 0.00 – 0.25$ (little or no correlattion), $r = 0.26 – 0.50$ (fair correlation), $r = 0.51 – 0.75$ (moderate to good correlation), $r = 0.76 – 1.00$ (very to perfect correlation)

A study has reported 30% of parents feeling like alone parents (32). These perceptions of being loneliness are a result of psychosocial dynamics when caring for their ill child. When focusing their care on cancer and sick children, lone parents have little time to interact with other family members. As a result, they may be predisposed to burnout and suffered a decline in relationship quality during this stressful period. Caregivers who did not share their caregiving burden were nearly three times more likely to become stressed (34). According to a Korean study, stress and burnout have a positive correlation, but burnout and active coping have a negative correlation (33). Our study captured mild to moderate stress only despite high burnout prevalence, especially in client-related domain. In an adult study, it was noted only 25% of caretakers experienced stress (34). In general, caretakers are expected to experience stress more due to factors such as constant worry, emotional tolls, and lack of control in their lives.

There are potential interventions needed to minimize burnout and promote resilience among this vulnerable group. Frequent counseling or support group meetings should be encouraged. Regular inquiry on the patient's progress and caretakers' health and mental status are important to identify and plan for the appropriate measure. Caretakers have to adapt to new roles once a cancer diagnosis is made as well as making appropriate arrangements for other personal related duties (35). Some of the novel interventions to support these caretakers include the presence of onsite psychologist with stress interventional module, the availability of social network support such as non-government organization to support family financial difficulty and also technological web application to smoothen the community and hospital care transition.

However, our study has some limitations. Firstly, this study was conducted in one center with a small sample size. Many participants were females and Muslims which might lead to different stress perceptions, taking into consideration that they might turn to religiosity as a coping mechanism (21). Most of the caretakers were unemployed and committed to caring for their sick child. This might not be applicable for some of the items in the questionnaire as the tools seem to be focusing on employed caretakers (29). There was also potential bias from the selection of caretakers in our center. Although it was mostly caregivers for children with cancer, the impact of cancer stage and type, caregiver co-morbidity, or relevant medical problems in the family should not be underestimated. Other limitations were short period, non-availability of other ethnic groups within the study period, hence a population bias, in which outcome might be different. Duration of illness and treatment might contribute to variable effects on the outcome.

CONCLUSION

A high prevalence of client-related burnout was observed among caretakers compared to personal burnout in this study. This has urged further assessment and interventional study for these caretakers. It is imperative for the Malaysian health care system to acknowledge the impending mental health issues among those who are caring for cancer children in Malaysia.

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