

**COMPASSION FATIGUE: BURNOUT AND  
STRESSORS AMONG CARETAKERS OF  
CHILDREN WITH CANCER AT UNIVERSITI  
SAINS MALAYSIA.**

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**THESIS PROPOSAL**



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### **Abbreviations**

<b>CBI</b>	<b>CopenhagenBurnout Inventory</b>
<b>GSQ</b>	<b>General Stressor Questionnaire</b>
<b>HUSM</b>	<b>Hospital Universiti Sains Malaysia</b>
<b>SSU</b>	<b>Soalselidik Stressor Umum (Malay version of GSQ)</b>
<b>CBI-M</b>	<b>Copenhagen Burnout Inventory(Malay version)</b>
<b>SPSS</b>	<b>Statistical Package for the Social Science</b>

## **1)Introduction:**

This study is to determine the relationship between burnout and stressors, among caretakers of children with cancer at Pediatric Oncology Department of Hospital Universiti Sains Malaysia, Kelantan.

Burnout, was first described by Herbert Freudenberger in 1974.

Burnout has potentially serious consequences on healthcare providers either at personal or professional level such as erosion of empathy, suboptimal patient care, suicidal ideation and unprofessional behaviours<sup>i</sup>

Several studies with oncology staff have shown a high prevalence of burnout with or without significant anxiety or depression (Barni, Mondin, Nazzani, & Archili, 1995; Herschbach, 1992; Ramirez, et al., 1995; Taylor, Graham, Potts, Richards, & Ramirez, 2005; Ullrich & FitzGerald, 1990; Whippen & Canellos, 1991) when dealing with patients and relatives, especially patient deaths cited as major sources of stress (Delvaux, Razavi, & Farvacques, 1988; Razavi & Delvaux, 1997).

Stressors, have a major influence upon mood, our sense of well-being, behavior, and health. Acute stress responses in young, healthy individuals may be adaptive and typically do not impose a health burden.<sup>ii</sup>

Stress occurs when there is a mismatch between the demands of a situation and the person's ability to cope with it (Edwards, Caplan, & Van Harrison, 1998; Edwards & Cooper, 1990; Van Harrison, 1978). It is known that prolonged distress will lead to burnout syndrome that has been described as a prolonged response to chronic emotional and interpersonal stressors on the job, determined by the dimensions of exhaustion, cynicism, and inefficacy (Maslach, Jackson, & Leiter, 1996; Schaufeli, Leiter, & Maslach, 2009).

Cancer most commonly suffered by children here are Acute myeloid leukemia, Acute lymphoblastic leukemia, Lymphoma, Retinoblastoma, Osteosarcoma, Ewing sarcoma, Rhabdomyosarcoma, Wilm's tumor, Neuroblastoma, Nephroblastoma, Hepatoblastoma, Primitive neuroectodermal tumor, Langerhans cell histiocytosis and many other malignancies.

Most of children with cancer require frequent hospitalization and some with prolong hospital stay and intensive care or prolonged ventilation, while some frequently visit daycare and specialist clinics for follow ups to undergo chemotherapy, radiotherapy and cytotoxic drugs, also require frequent investigation and monitoring involving some extensive procedure for blood, bone marrow and cerebral spinal fluid, biopsy sometimes even involve minor or major

procedure and surgical intervention and radiological imaging . Some children who have diagnosed with poorer prognosis will receive palliative care. Along with this, caretakers of children with cancer are identified as vulnerable group to suffer burnout and stress due to stressors.

Thus, this study is mainly focused on caretakers of children with cancer, which includes parents or legal guardians of children who have been diagnosed with cancer, under follow up as inpatient and outpatient, as such study has not been conducted on our local population.

## **2)Problem Statement and Rationale**

- 1)To conducted on our local settings, as no similar studies conducted in Malaysia
- 2)To assist in optimizing patient's treatment and care, also caretaker's health
- 3)To anticipate long term commitment in effective and capability of care, as caretakers are vulnerable group
- 4)To introduce better interventions or coping methods, to provide support and better potential strategies tailored according to individualized family needs and psychosocial family dynamics.
- 5) To minimize burnout and stressor among caretakers of children with cancer

## **3) Objectives**

### **3.1)General Objective**

To investigate burnout and stressor among caretakers of children with cancer at Hospital Universiti Sains Malaysia, Kelantan.

### **3.2)Specific Objectives**

- i)To study the prevalence of burnout among caretakers of children with cancer at Hospital Universiti Sains Malaysia, Kelantan.
- ii)To study the prevalence of stressor among caretakers of children with cancer at Hospital Universiti Sains Malaysia, Kelantan.
- ii)To study the correlation between burnout and stressor

#### **4)Research Hypothesis**

- i) The prevalence of burnout and stressor among caretakers of children with cancer is high.
- ii) There is a positive correlation between burnout and stressor

#### **5) Research design**

Cross-sectional study by purposive sampling method

#### **6)Study area**

Pediatric Oncology Department of Hospital Universiti Sains Malaysia (inpatient - Pediatric oncology ward, High Dependency Unit and Intensive Care Unit &and outpatient- Pediatric Oncology Clinic and Daycare)

#### **7) Study population**

Caretakers of children with cancer, receiving treatment at Hospital University Sains Malaysia, Kelantan or under follow up, both as inpatient and outpatient. Caretakers of children diagnosed with cancer below the age of 18 years old and still alive, who are the parents or legal guardian of this child will be considered to be enrolled in this study, once consent has been obtained. Preferably, the main caregiver or both parents or at least one of any legal guardian with proper identification documentation will be sampled once comply to criteria and written consent obtained. As for the cancer patient list, children below the age of 18 years old will be identified and labeled as an individual unit with number coding list, for privacy and patient information security to be ensured , who is still alive and still under follow ups, under investigation or receiving treatment as inpatient and outpatient at Pediatric-Oncology Department at Hospital Universiti Sains Malaysia, Kelantan. These children will be identified from the Pediatric –Oncology ward registry and Pediatric-Oncology clinic registry. All eligible participant will then be required to answer in private, at Hopsital Universiti Sains Malaysia, Kelantan premise, the questionnaires provided , as self reported during one setting , after simple briefing by investigator , within given duration of approximately 20 minutes and once completed, questionnaire will be collected immediately. All data obtained, will only be used for study purpose and not revealed unnecessarily to maintain the intergrity of data and participant. Malay version questionnaire will be used for those participant who has good language command In Bahasa Melayu , while English version will be used in those who have good English language command.

## **8)Study Criteria**

### **1) Inclusion Criteria**

- i) You are a parent or caretaker or legal guardian to a child with cancer
- ii) Your child, diagnosed with cancer and must be receiving treatment or under follow up, or under further investigation and monitoring, at Pediatric – Oncology Department of Hospital Universiti Sains Malaysia, Kelantan.
- iii) Your child diagnosed with cancer who is below the age of 18 years old

### **2) Exclusion Criteria**

- i) Parents or caretaker who are a welfare home worker
- ii) Parents or caretakers who has a deceased child who suffered from cancer

### **3)Withdrawal criteria**

- i) Eligible participants are allowed to withdraw at any point of this study , once he/ she informs the investigator and all data concerning this individual will not be used in this study and he/ she will immediately be terminated from study No penalty will be imposed on this individual as this is a voluntary based. Reasons if provided can be useful to anticipate or identify potential problems in relation to this study.
- ii) if a participant is to be terminated from this study, investigator will explain reasons

## **9) Research tool**

There will self reported questionnaires in English language and also available in Bahasa Melayu translation, with likert score to be filled up, within a given time . The questionnaire comprises of three sections :-

### **i) Personal data on socio-demographics**

### **ii)Copenhagen Burnout Inventory: -**

This Questionnaire will be used for burnout .In Copenhagen Burnout Inventory, there are primarily 3 domains, which include personal burnout, work-related burnout as well as client burnout. 2 types of Likerts scale are used. The questions on personal burnout were formulated in a way so that all human beings can answer them (a truly generic scale). The work-related burnout questions assume that the respondent has paid work of some kind. Finally, the client-related burnout questions include the term “client” (or a similar term when appropriate such as patient, students, inmate, etc.. There are 12 questions were rated by the Likerts scale ranged from “Always (0)”, “Often (1)”, “Sometimes (2)”, “Seldom (3)”, “Never/Almost never (4)”; while there are 7 questions were rated by the Likerts scale ranged from “To a very high degree (0)”, “To a high degree (1)”, “Somewhat (2)”, “To a low degree (3)”, “To a very low degree (4)”. Reverse scoring was applied in positively worded items. High scores indicated high level of burnout. Mean score was used for interpretation purposes where by a mean score of 2 or more signified significant burnout.<sup>iii</sup>

### **iii)General Stressor Questionnaire:-**

This is a good psychometric value, valid and reliable instrument. There will be 28 questions , consisting of 7 domains , which are family, poor relationship with superior, bureaucratic constraints , work-family conflicts, poor relationship with colleagues, performance pressure and poor job prospect. In which every one domain has four questions (items). There will also be 5 likert scores , which are (0)=causing no stress at all , (1)=causing mild stress, (2)=causing moderate stress, (3)=causing high stress and (4)=causing severe stress. Higher scores reveals higher level of stress, indicating intensity of stress, which are 0.00-1.00= causing none to mild stress, 1.01-2.00 =causing mild to moderate stress, 2.01 -3.00 = causinh moderate to high stress and 3.01-4.0 causing high to severe stress.



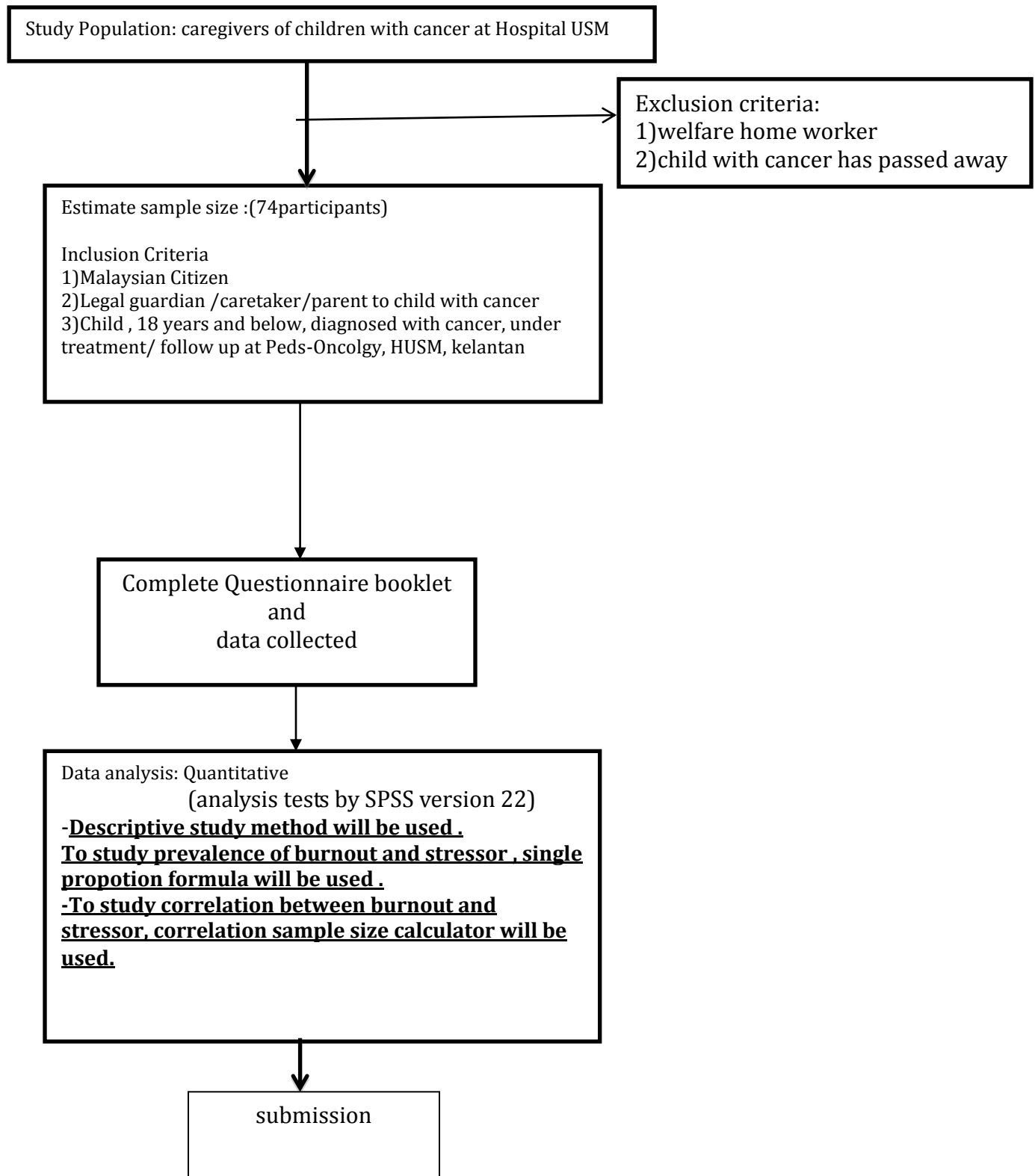
## **10) Data collection method**

This is a cross sectional study with purposive sampling method.

A list of children under the age of 18 years , who are diagnosed with cancer and receiving treatment , follow ups and investigation as inpatient or outpatient registered under Pediatric-Oncology department of Hospital Universiti Sains Malaysia, Kelantan will be identified and listed. This date will be obtained from the registry available at Pediatric-Oncology clinic and ward. Admission book will be screened to exclude number of child with repeated visits , all individual will be labeled as one unit despite repeated visits. This individual will be labeled with a number coding and listed separately to maintain integrity of data. Original list with names will be kept in a secured place and only available to investigator. This listed individual's parents, caretakers or legal guardian with appropriate identification documents will then be met and given briefing regarding this study, once these participant met the criteria and willingly gives consent, he or she will be recruited in this study. Preferably, the main caregiver or both parents or at least one of any legal guardian with proper identification documentation will be sampled once comply to criteria and written consent obtained. All eligible participant will then be required to answer in private, at Hopsital Universiti Sains Malaysia, Kelantan premise, the questionnaires provided , as self reported during one setting , after simple briefing by investigator , within given duration of approximately 20 minutes and once completed, questionnaire will be collected immediately. Malay version questionnaire will be used for those participant who has good language command In Bahasa Melayu, while English version will be used in those who have good English language command. All data obtained, will only be used for study purpose and not revealed unnecessarily to maintain the integrity of data and participant. All information gained in this study will remain private and confidential.

Data will be analyzed by using SPSS version 22. Descriptive study method will be used . To study prevalence of burnout and stressor, single propotion formula will be used .As for correlation study between burnout and stressor, correlation sample size calculator will be used.

## 11)Flow Chart



## **Sample Size**

Estimated active cancer children receiving treatment and regular follow ups over six months at Paediatric-Oncology Department of Hospital Universiti Sains Malaysia, Kelantan , are around 50-60 children (excluded those who have recurrent visits).

### **The sample size of this study was calculated by research objectives :**

<b><u>Objective (formula)</u></b>	<b><u>Parameter</u></b>	<b><u>Estimated Sample Size</u></b>
Prevalence of burnout among caretakers of children with cancer <sup>iv</sup>	<b><u>Prevalence: 67.9%</u></b> <b><u><math>\alpha = 0.05</math></u></b> <b><u>CI = 95%</u></b> <b><u>Precision = 0.10</u></b>	<b><u>52</u></b>
<b><u>Prevalence of stressor by caretakers of children with cancer</u></b>  <b><u>(calculation for single propotion formula)<sup>v</sup></u></b>	<b><u>Prevalence: 80%(estimated)</u></b> <b><u><math>\alpha = 0.05</math></u></b> <b><u>CI = 95%</u></b> <b><u>Precision = 0.10</u></b>	<b><u>62</u></b>
<b><u>Correlation study between burnout and stressor</u></b>  <b><u>(correlation sample size)</u></b>	<b><u>Total sample size =</u></b> <b><u><math>N = [(Z_{\alpha} + Z_{\beta}) / C]^2 + 3</math></u></b>  <b><u>*(minimum accepted correlation cefficient is 0.4)</u></b>	<b><u>52</u></b>

Adjusted after considering 20% non-response rate

The sample size of this study was calculated by research objectives using Sample size calculator.\*

**Reference:** Hulley SB, Cummings SR, Browner WS, Grady D, Newman TB. Designing clinical research : an epidemiologic approach. 4th ed. Philadelphia, PA: Lippincott Williams & Wilkins; 2013. Appendix 6C, page 79.

### 13)Gantt Chart

[illegible]

#### **14) Ethical consideration :**

- 1) Caretakers who children are receiving treatment and under follow up of Pediatric Oncology Department of Hospital Universiti Sains Malaysia, who are under the care of some doctors involved in this study , will still be given full freedom to participate or not without affecting their child's medical condition , management and care, while data received during this study will not be used for any achievement and decision related to work
- 2) Privacy and confidentiality will be ensured , as all forms are anonymous and will be entered into SPSS software and not for easy access of anyone , also not revealing personal identity during presentation
- 3) Consent will be taken from each participant, at the same time having the freedom to withdraw from study.
- 4) If during this study , any participant noticed to any medical problems or was triggered to have
- 5) The approval from the Research Ethics Committee (Human) Universiti Sains Malaysia will be obtained.
- 6) Any medical problems or sensitive issues triggered to participant during this study, will be adreesed appropriatly and attended to , also to reffer to department concerned if indicated.
- 7) To minimize bias, participants will be explained on ways to answer the questionnaire by trained personnel , without further explanation or elaboration and not interfering in participant's response.
- 8) Permission to use both questionnaire and translated into Bahasa Melayu copies has been granted by author , as author is also a co-researcher in this study.
- 9) There may be conflict of interest in this study , as co- researcher is an Oncologist , however there will not be any personal benefit, measures will be taken to avoid bias results , while patients care will not be disrupted under any circumstances.

### **15)Benefit of study**

Given the fact that caretakers of children with cancer are vulnerable to burnout , hence this study will provide potential strategies or intervention to improve and to provide better care , while minimizing burnout among caretakers .

### **16)Funding:**

This study has not been funded by any grant

### **17)Honorarium and incentives**

Token of appreciation will be given to every participant and their child.

## **18)Appendix**

(Questionnaire Enclosed)

\*Permission to use Questionnaire has been granted as author is involved in this study , as a co-researcher.

1)Demographic data / Personal Data

\*All personal information are kept confidential and only for research purpose.  
Names will be recorded separately , represented by identification code.

Example of personal data form :-

Identification Code:		
My Card Number :	Age:	Date of birth:
Gender: M/ F		
Ethnicity:		
Child's Diagnosis:		
Occupation :	Salary:	Number of family member Under your care :
Marital Status: Single/Married/divorced/ widow /wodower		
Number of family members to care for:		
Relationship of you to this child(patient):		
When was this child (patient ) under your care diagnosed with cancer:		
How frequent do you need to visit hospital/ clinic:		
If required admission, what is the frequency and duration of hospital stay:		

2) General Stressor Questionnaire (GSQ)-in English and Malay

3)Copenhagen Burnout Inventory (CBI)-in English and Malay

## **Appendix**

### **19)References**

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- <sup>i</sup>Dyrbye L, Shanafelt T. A narrative review on burnout experienced by medical students and residents. *Medical education*. 2016;50(1):132-149.
- <sup>ii</sup>Annu Rev Clin Psychol. Author manuscript; available in PMC 2008 Oct 16.
- <sup>iii</sup>Kristensen TS, Borritz M, Villadsen E, Christensen KB. The Copenhagen Burnout Inventory: A new tool for the assessment of burnout. *Work & Stress*. 2005;19(3):192-207
- <sup>iv</sup>Sample Size Precision and Power Calculator [computer program]. Version 1.0. Malaysia: Arunodaya Barman; 2009.
- <sup>v</sup> Hulley SB, Cummings SR, Browner WS, Grady D, Newman TB. Designing clinical research : an epidemiologic approach. 4th ed. Philadelphia, PA: Lippincott Williams & Wilkins; 2013. Appendix 6C, page 79.

### **Related References**

- Andrew Chin, R. W., Chua, Y. Y., Chu, M. N., Mahadi, N. F., Yusoff, M. S. B., Wong, M. S., et al. (in press). Prevalence of Burnout Among Universiti Sains Malaysia Medical Students *Education in Medicine Journal*, 8(3).
- Andrew Chin, R. W., Chua, Y. Y., Chu, M. N., Mahadi, N. F., Yusoff, M. S. B., Wong, M. S., et al. (unpublished). Investigating Validity Evidence of the Malay Translation Validation of of Copenhagen Burnout Inventory.
- Yusoff, M. S. B., Abdul Rahim, A. F., Baba, A. A., Ismail, S. B., Mat Pa, M. N., & Esa, A. R. (2013). Prevalence and associated factors of stress, anxiety and depression among prospective medical students. *Asian Journal of Psychiatry*, 6(2), 128-133.
- Yusoff, M. S. B., Abdul Rahim, A. F., Baba, A. A., Ismail, S. B., Mat Pa, M. N., & Esa, A. R. (2013). The impact of medical education on psychological health of students: A cohort study. *Psychology, Health & Medicine*.
- Yusoff, M. S. B., Ying Jie, T., & Esa, A. R. (2011). Stress, Stressors And Coping Strategies Among House Officers In A Malaysian Hospital. *ASEAN Journal of Psychiatry*, 12(1).



## **2 : THE TEXT**

## **2.1 DOCUMENTS SUBMITTED FOR ETHICAL APPROVAL**

### **2.2.1 THESIS PROPOSAL**

### **2.1.2 ETHICAL APPROVAL LETTER**

**2.2 :  
MANUSCRIPT FOR SUBMISSION**

**Burnout and stressors among caretakers of children with cancer at Hospital Universiti Sains Malaysia.**

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## **2. THE TEXT**

### **2.2.1: Introduction**

## **Compassion fatigue: Burnout and stressors among caretakers of children with cancer at Hospital Universiti Sains Malaysia.**

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### **Introduction**

Cancer has become a leading disease burden among pediatric population globally. Pediatric oncology in this current era is undergoing rapid evolvement in order to achieve optimal care and to reduce mortality and morbidity among patients, in keeping with sustainable development goals (SDG), as aspired by United Nations.<sup>1-4</sup> On the International Childhood Cancer day in 2018, WHO announced that more than 300,000 children from birth till 19 years old were diagnosed with cancer. The Malaysian Cancer Registry also reported that there were 37 in 100,000 children, have risk of cancer. Advanced treatment modalities and supportive care have increase survival rate and reduce mortality rate, which may contribute to more morbidity, hence higher disease burden among survivors and caretakers.<sup>1, 2, 4-12</sup>

Majority of children with cancer require frequent and prolonged hospitalization, prolonged school absenteeism, frequent investigations, intensive care or prolonged ventilator support, while some children with poorer prognosis received palliative care. Parental support, understanding and commitment are important to enable compliance and to



achieve optimal treatment goals. Caretakers of children with cancer are identified as vulnerable group to suffer burnout, a concept described as emotional exhaustion, reduced performance and depersonalization.<sup>13</sup> Stress due to stressors at the expense of lifestyle, psychosocial status, emotional distress and family dynamics modification, poor quality of life, which affected patient care.<sup>3, 7, 8, 11, 14-17</sup>

Validated, Malay version Copenhagen Burnout Inventory (CBI-M), was chosen in this study as it is the newest tool to measure burnout, with good psychometric, freely and easily available in many languages. In addition, the tool can be used to assess exhaustion and fatigue pertaining to personal life, work and service to clients.<sup>18, 19</sup> The concept of compassion fatigue is closely related or said to be a form of burnout, however it addresses the relational nature of condition, while burnout often related to stressors.<sup>20, 21</sup>

Stress occurs when there is a mismatch between the ability of a person to cope with the demands of a situation. Stressor is resulted from personal or environmental event that causes stress.<sup>22</sup> It has a major influence upon mood, sense of wellbeing, behavior and health.<sup>23</sup> Studies have shown that cancer related factors, such as disease itself and invasive procedure such as bone marrow aspiration have contributed to parenting stress leading to limitation of their activity and contributing to poor quality of life.<sup>8</sup> A study also showed differences in culture imposed different responses to stress, as in Chinese group showed lower emotional distress as compared to Caucasians.<sup>11, 24</sup> Parenting stress needs to be tackled for future intervention. Stressor was measured using General Stressor Questionnaire (GSQ), a good psychometric tool, translated to Malay language. It is a reliable and validated tool to measure the prevalence of stressor.<sup>25</sup>

The purpose of this study is to determine the prevalence of burnout and stressor among caretakers of children with cancer and the correlation between burnout and stressors.

This study was conducted in the interest as to, studies in this field is limited, the outcome of this study may enable holistic care and to explore other stressors faced by local population that may not be sensitive to the current tools used. The outcome of the qualitative data may contribute in implementing a more sensitive tool for our local community.

## **Materials and Methods**

### *Study design*

A mixed quantitative and qualitative cross-sectional methodology was conducted on caretakers who had children suffered from cancer. This is a single centre study conducted over a 6 months period in 2018 at Hospital Universiti Sains Malaysia.

Parents or legal guardian who were the caretakers accompanying or staying with the child during the period of the study were approached. Inclusion criteria were parents or caretaker to children with cancer below 18 years of age and receiving treatment or under follow-ups from both inpatient and outpatient of Paediatric Oncology unit in Hospital Universiti Sains Malaysia. Exclusion criteria were caretakers who worked at welfare home. Consent was obtained from eligible participants. Self-administered guided questionnaire booklet consisting Copenhagen Burnout Inventory-Malay version (CBI-M) and General Stressor Questionnaire – Malay version (GSQ-M) were distributed during a face-to-face session. Participants were given 20 minutes to complete and was collected immediately upon completion.

### *Measurement Tools*

#### 1) Quantitative

##### ii) Copenhagen Burnout Inventory –Malay version

The Malay translated and validated version of Copenhagen Burnout Inventory version was used to measure burnout as it is a reliable validated tool with good psychometric properties.<sup>18</sup> It consist of three domains, which are personal burnout (section A), work related burnout (section B) and client related burnout (section c), “client” is a similar term when appropriate as students, inmates and patients.<sup>19</sup> Twelve questions used Likert scales from [0] always, [1] often, [2] sometimes, [3] seldom, [4] never / almost never. Another seven questions used [0] to a very high degree, [1] to a high degree, [2] somewhat, [3] to a low degree and [4] to a very low degree. Reverse scoring was applied in positively worded items. High levels of burnout were represented by high scores.<sup>18</sup> Mean score was used for interpretation purpose where by a mean score of 2 or more represented significant burnout.<sup>18</sup>

##### iii) General Stressor Questionnaire-Malay version

To study stressor, Malay version of General Stressor Questionnaire was translated and validated by *Yusoff et.al* the developer of this questionnaire. He is a co-researcher of this study and his publication is in progress.<sup>25</sup> Internal reliability for GSQ-M using Cronbach’s alpha on 78 participant resulted 0.95. This tool has twenty-eight items with seven domains, which are family, performance pressure, work-family conflicts, bureaucratic constraints, poor relationship with superior, poor relationship with colleagues and poor job prospect. Five rating scales of response were provided to signify severity of stress which

are, [0] causing no stress at all, [1] causing mild stress, [2] causing moderate stress, [3] causing high stress and [4] causing severe stress. Intensity of stress is represented by mean score, which are 0.00 – 1.00= causing none to mild stress, 1.01-2.00=causing mild to moderate stress, 2.01-3.00=causing moderate to high stress and 3.01-4.00= causing high to severe stress.<sup>25</sup>

## 2) Qualitative

Eligible participants were given a set of questionnaire booklet, which included an open-ended question for free text response in order to trigger more discussion and expression, while related stressors were identified. The question was, *“You are required to write on your experience, feelings, thoughts or problems faced during the period of caring for you child who is suffering from cancer.”* Data from each participant in Malay language was transcribed in excel format. Each transcript was given a code. Thematic analysis was applied on response transcripts. Several discussion and peer debriefing were held to review and confirm themes and subthemes. Questionnaire booklet is enclosed in the appendix.

## **Ethical approval**

Ethical approval was obtained from Research and Ethical Committee, School of Medical Sciences, USM Health Campus on 24<sup>th</sup> April 2018 (ethical code approval:USM/JEPem/ 18010072 ).

## **Data Analysis**

The quantitative data was analysed using Statistical Package for Social Science Version 24. For correlation between burnout and stressor, Spearman's correlation analysis was applied in view of bivariate normal distribution assumption violated. Sample size was estimated as 74 respondents by single proportion formula with 95% precision of 0.10 and considering 20% non-response rate.

As for qualitative study, data was analysed in excel program simultaneously as it was being collected. While quotations were transcribed, coding, theme and subthemes were organized. Transcripts were read and frequently appeared codes were listed. It was also translated to English language, once open coding identified, homogenous conditions with similar context were identified. The relationship that connected subcategories with core categories were identified and constructed. Serial supervisors' discussion and peer debriefing and related article were reviewed.

## **Results**

### *Quantitative Analysis*

There were 78 eligible respondents recruited. All were Malays, as no other ethnicities were available during study period. There were 50 (64.9%) mothers, 27 were, employed and 20 unemployed, while 23 (29.9%) were fathers, whereby 21 were employed and 2 unemployed and 4 others included 1 elder brother, 2 elder sisters and 1 stepmother. There were 62.3%

who received secondary school education. 81.8%, were represented by B40 category as they received RM 3000 and below as monthly salary. This study included caretakers of child being diagnosed with cancer since year 2009 till 2018. Table 1 represents the descriptive analysis on demographics. Cronbach's alpha on 75 respondents resulted 0.95, showing high internal reliability. 78 (100%) caretakers suffered personal burnout, while 77(98.8%) suffered work-related burnout and 67(85.9%) responded as significant burnout to client-related domain. Figure 1 describes the prevalence of burnout.

The results showed at seven stressors domains contributed to burnout, however they mostly scored none to mild stress level with a mean range of 0 to 1.00, which was followed by mild to moderate level with mean range of 1.01 to 2.00. Overall was seen that respondents were prevalent to work related stressors. Results are represented by figure 2. Sub analysis on employed mothers among newly diagnosed and old cases. The pattern seen in this outcome is that employed mothers developed higher stress with longer duration of illness as across all domains for newly diagnosed cases, majority were none significant, while for older cases, showed prevalence of significant stress to performance pressure, work-family and family related domains. Unemployed mothers had reflected significant stress to family related domains and bureaucratic constraints. Results shown in table 2. Sub analysis on employed fathers of old cases suffered significant stress level towards poor relationship with superior with 64.7%, bureaucratic constraints, 70.6% and 70.6% suffered from performance pressure stressor. Spearman's correlation analysis shows a significant correlation between stressor domains' score and client-related burnout. Highly significant correlation ( $p < 0.001$ ) was found between client-related burnout score and the score for work-family conflicts, poor relationship with colleagues and performance pressure. Significant correlation between burnout and stressors, as high significant correlation was

found between client-related burnout score with work-family conflicts, poor relationship with colleagues and performance pressure. Table 3 below shows the correlation between burnout and stressor.

### *Qualitative*

From the open-ended, free text question, we have at least obtained five themes, which are i) stressor, ii) emotion, iii) coping mechanism, iv) effective healthcare and v) failure of health care. It requires to be further studied on, as it has generated many unexpected themes and subthemes.

The theme “stressors”, discussed here as it is related to this study. Eight subthemes were generated, each further represented by some categories and examples of quotation written by caretakers. These results represent stressors that are faced by our local community in practicality. It is strongly proposed that based on this outcome, a new, more suitable questionnaire or tool to measure stressor can be developed for caretakers of our local community. Some of these stressors could be similarly describe however may represent a slightly different dimension or domains<sup>26</sup>. Below are some of the examples of themes, subthemes and the quotations by the respondents.

#### *Theme 1: work*

This theme consists of nine categories:

##### i) Unemployed

Participant (001M) who expressed the problem of unemployment along with other problems faced, who said:

*[...]Initially felt unbelievable, scared, mixed feelings, feeling empty. Was just faced with death of a child due to fever and unable to accept it. Moved to Kelantan – felt family support, feeling strengthened, left with no place to stay, unemployed, financial problem.(001M)*

##### ii) Problem with employer



Participant (004F) had concern with employer due to his commitment involve in the care of his sick child and the change evolving around him and his child, his sharing was as follow:

*[...]in the beginning of diagnosing his child with ALL, he was sad, depressed, self blaming. After 1 month of treatment, I accepted the fact, after mingling with other caretakers and watching the progress of their children. Problems related to logistics and financial during follow-ups were faced as we stayed in a different state. Had mental stress as a result of altered emotions of the child from time to time , difficulties in caring for the child's diet and environment. Having problems with employer, had to take unpaid leaves to accompany child to hospital.(004F)*

iii) Leave issues

*[...]felt sad in the beginning, scared to surrender child for chemotherapy. Felt very pressured. Expenditure, child's behavioural problems, forced to take unpaid leave, problems with work.(015F)*

separately concerns were echoed by participant (007M) and participant (025M), as follows:

*[...]hospital admission required during chemotherapy, needing long leave request.(007M)*

*[...]plenty of patience needed in patient care, there is increase financial need, forced to take frequent leaves during treatment.(025M)*

iv) Work performance

Most participants expressed their work performance has been affected

*[...] difficulties to work, faced problems from family and finances (009F)*

*[...] difficult experience and shocking, feeling sad, feeling haunted. Total change in family live routine. Problem with work commitment, complication in managing other children at home. Faced adjustment disorder in the beginning, had frequent*

*leave application(021M)*

similarly participant (027M ) echoed by saying:

*[...] faced with some problems , as felt tired emotionally, physically and spiritually, felt sad and disappointed during the frequent treatment follow-ups and getting to know the disease in depth while faced with work matters.(027M)*

## Theme 2: Family

It is learnt that family dynamics are affected during this process of caring for sick member. Many commonly shared on this aspect.

### i) Family problems

It was described as one of the most commonly contributing stressor besides work and financial constraints. Participant (009F) stated:

*[...] family problem, problems to work and financial problem.(009F)*

### ii) change in family routine / dynamics

participant (021M),(026M) and (038M) have expressed their challenges as follows:

*[...] difficulties in managing other kids at home(021M)*

*[...] difficulties in taking turns to care for child as mother is pregnant, facing financial constraints as there is no permanent income.(026M)*

*[...]I was overwhelmed by sadness when my child was diagnosed with cancer, but I had to strengthen myself for the sake of my child, even though I had to be separated from my 8 month old child who was still breastfeeding.(038M)*

similarly described by participant (068M)

*[...]sad because of the sick child, had to be separated or distant from other family members at home. Faced with financial problems in daily expenditure.(068M)*

### iii) Neglect of care

Participant (062M) has brought to attention, the possible neglect of care over other children under her care, as below:

*[...] initially I was in denial when my child was certified to have cancer, as the child was very active and cheerful individual. After many days of reflection, I accepted it as a bitter most trial. I spend more time with my sick child as compared to the other children who were most of the time neglected.(062M)*

### Theme 3:Financial

#### i) Financial constraints

participant (005F) and (025M) has expressed financial constraints as below, in addition I was observed that majority caretakers have raised this stressor repeatedly.

*[...] my patience was tested, I have accepted this condition, however need to work on the recovery. Need to manage time more efficiently as there are other children at home who are young and schooling. Having financial problems as cost of expenditure is high. Need to make good financial planning(005F).*

*[...] need full patience in caring for the patient, in need of more money. Forced to take frequent leaves during treatment.(025M)*

#### ii) High medical cost

it was also learnt that some are faced with high financial burden from the medical bills, as said by participant (029M)

*[...]high medical bill, life changes with child's health status, faced with emotional stress during each admission, worries on child's health progress.(029M)*

#### iii) Unpaid leaves

unpaid leaves also contributes to financial burden , participant (042M) has described as below:

*[...] some stress contributed by pregnancy, urged to take unpaid leaves, while money is required for treatment, and other young children at home(042M)*

#### Theme 4: Psychosocial support

##### i) Logistic problem

there was one participant (004F) who shared this :

*[...]in the beginning of diagnosing his child with ALL, he was sad, depressed, self blaming. After 1 month of treatment, I accepted the fact, after mingling with other caretakers and watching the progress of their children. Problems related to logistics and financial during follow-ups were faced as we stayed in a different state. Had mental stress as a result of altered emotions of the child from time to time , difficulties in caring for the child's diet and environment. Having problems with employer, had to take unpaid leaves to accompany child to hospital.(004F)*

##### ii) Adaptation disorder

some do suffer from adjustment disorder, it also reflects on how people perceive stress, and it may vary from individuals. Below is the shared statement participant (036F) and (021M)

*[...]initially got stress frequently, during each counselling sessions, felt to burdened, felt stress from family, it was requested that time be given for adaptation to this new situation.(036F)*

*[...]problem with work commitment, complication in managing other children at home, adjustment was one of the problems faced initially and need for frequent leave applications.(021M)*

*[...] difficulties faced in terms of logistics (004F)*

##### iii) Child's emotional behaviour disorder

*[...]difficulties to adapt to schooling , since refusal to socialized and assumed that people may not understand child's condition. Faced with risk of infection. Steroids resulting mood swings in child, caretakers has to play along and persuade child in taking medications.(061M)*

similarly described by participant (013M) and (045M), as below:

*[...]stress in dealing with behavioural changes of ill child(013M)*

*[...] in the beginning feeling shocked and emotional, noticed during Dexamethasone medication child has good oral intake, however his behaviour transformed to be aggressive.(045M)*

#### iv) Mentally stressed

*[...]emotional stress is faced due to emotional changes in sick child and problems during care of sick child at home(004F)*

### Theme 5: Personal

#### i) Afraid to face treatment

*[...] shocked as never thought about cancer. Difficult to accept the fact. Scared to face treatment. Acceptance and feeling fortunate to draw strength from God.(011F)*

#### ii) Pregnancy

*[...] difficulties in taking turns to care for sick child as mother is pregnant (026F)*

#### iii) Negative thoughts

some maybe overwhelmed by negative feelings or thoughts during lowest point of life , below are as described by participant (053M) similarly by (072M)

*[...] always having negative thoughts on child falling ill, feeling fear that this will*

*lead to death and fear of other siblings getting ill as well.(053M)*

*[...] stress while taking care of sick child during pregnancy, with limited finances and thinking about other children at home (072M)*

iv) Lack of sleep

respondent (073M) had expressed lack of sleep

*[...] difficulties in understanding situation as child is still young, difficulties to get enough sleep(073M)*

#### Theme 6 : Inadequate knowledge in patient care

i) Need to learn about chemotherapy

*[...] was very sad and shocked initially. Needed more patience with patient, need to give more attention. Get worried when child is unwell, need frequent communication with doctors and nurses, need to learn about chemo drugs given to patient. (035F)*

ii) Misconception or inter and intrapersonal

this theme was similarly described in a previous study.

respondent (056M) shared that

*[...] bone marrow aspiration could worsened child's condition and always had argument with husband due to misunderstandings.(056M)*

iii) Lack of information on diet

*[...] treatment is costly, felt people at school could not understand patient, exposed to risk of infection, had to face mood swings due to steroids. Having lack of knowledge on diet to comply(061M)*

### Theme 7: Time

It was noticed that time factor was described as one of common stressors in other studies as well and maybe related in a slightly different dimension<sup>25</sup>. Respondent (005F), (059M) and (063F) have described time as a stressor but expressed differently.

#### i) Time management

*[...] in need of good time management to care for schooling children at home and to care for ill child(005F)*

*[...] problem arises when it involved prolonged hospital stay, as I have another baby who requires care but I am unable too, but to ask for assistance from my relatives.(059M)*

*[...] felt sad, felt like loosing my child. Work has been disturbed, required to give full attention to child(063F)*

### Theme 8: Religiosity and spirituality

Recently religiosity and spirituality have been identified as an important contributing stressor, specially in Asian countries and its impact may to be higher among multiracial community. It was described in a study that it is a part of holistic approach, whereby patients anticipate healthcare providers to address this issue that could contribute to better treatment outcome or in end of life care<sup>27, 28</sup>. This is an interesting area to explore in future studies.

#### i) difficulties in performing religious rights

There were two respondents, (019M) and (027M) expressed as below,

[...] difficulties in praying if patient is unwell and wants to be accompanied at all times. Taking too long to take medication.(019M)

[...] frequency of treatment, work matters, got to know disease better. Feeling tired spiritually and physically, felt extremely sad and disappointed. (027M)