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

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TABLE OF CONTENTS

1.0 Preliminaries **Page**

2.0 Text

Chapter 3 Manuscript (ready for submission)

3.0 Appendices

LIST OF TABLES

LIST OF FIGURES

ABBREVIATIONS

ADHD	Attention deficit hyperactive disorder
CBI	Copenhagen Burnout Inventory
CBI-M	Copenhagen Burnout Inventory-Malay version
CI	Confidence interval
GHQ	General Health Questionnaire
GSQ	General Stressor Questionnaire
IBM	International Business Machines Corporation
ICD-11	International Classification of Diseases, Eleventh Revision
ID	Intellectual disability
IQR	Interquartile range
JEPeM	JawatankuasaEtikaPenyelidikan (Manusia) USM, The Human Research Ethics Committee of USM
MREC	Medical Research & Ethics Committee
NMMR	National Medical Research Register
PSS	Parental Stress Scale
QoL	Quality of life
RUI	Research University Grant
SD	Standard deviation
SMBQ	Shirom-Melamed Burnout Questionnaire
SPSS	The Statistical Package for the Social Sciences
SSU	SoalSelidikUmum
USM	UniversitiSains Malaysia

OPERATIONAL DEFINITION

Burnout	Psychological syndrome emerging as a prolonged response to chronic interpersonal stressors on the job (taking care of children with chronic neurological illness). Caretaker burnout defines as mean score of 50 or more in each dimension of CBI-M (Copenhagen Burnout Inventory-Malay)[1]
Stressors	Event that triggers stress response
Neurological disorder	Any condition that is caused by a dysfunction in part of the brain, or nervous system, resulting in physical and/or psychological symptoms
Acquired neurological disorder	Neurological disorder not due to congenital malformation or genetic disorder, it developed after birth due to infection or trauma and contribute to neurological sequelae eg. meningitis, encephalitis, acute disseminated encephalomyelitis (ADEM)
Genetic disorder	Neurological condition associated with gene abnormality eg. Neurofibromatosis, Tuberous sclerosis
Metabolic disorder	Neurological condition associated with metabolic disturbances egneurotransmitter disease, myasthenia, MELAS (mitochondrial myopathy, encephalopathy, lactic acidosis, and stroke)

Disability	Limited or prevented in any way in their ability to do things most children of the same age could do, due to a medical condition or had any emotional, developmental, or behavioural problems which needed treatment or counselling
Chronic illness	Health problem lasted 3 months or more, affecting child's normal activities, and requires frequent hospitalisations, home health care and/or medical care[2]
Primary caregiver/caretaker	Person who takes primary responsibility for someone who cannot fully care for him/herself

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ABSTRAK

Objektif:Penjagaankanak-kanak yang menghidapipenyakitsarafkronikadalahmencabar. Kajian inibertujuanuntukmenentukanprevalenlesuupaya dan faktorpenyebabtekanan yang berkaitan di dalamkalanganpenjagakanak-kanak yang menghidapipenyakitsarafkronik.

Kaedah:Iniadalahkajianrentasyang melibatkanibubapaataupenjagaberumur 18 tahunkeatasyang telahmenjagakanak-kanakberpenyakitsarafkronikmelebihijangkamasa 3 bulan. MerekatelahdirekrutdariKlinikPakarNeurologiKanak-kanakdalamtempoh 3 bulanbermuladariJulaihinggaOktober2019disebuah hospital besar di negeri Kelantan, Malaysia. Setiappesertadiberi set soalselidik yang merangkumi General Stressor Questionnaire (GSQ) yang telahdialihkeversi Bahasa Melayu ‘SoalSelidikUmum’ (SSU),versi Bahasa MelayuCopenhagen Burnout Inventory(CBI-M)dan Boranginformasidemografi.

Keputusan:Duaratusempatpuluhorang penjagakanak-kanakberpenyakitsarafkroniktelahmenyertaikajianini.

Purataumurpesertadalamkajianiniialah 38.12 tahun (SD = 7.74). Majoritiadalahwanita (82.1%), kaummelayu (94.6%) dan beragamaislam (95.8%). Purataumurkanak-kanakberpenyakitsarafkronikdalamkajianiniialah 7.19 tahun (SD = 4.21), dan kebanyakannyaadalahlelaki (60.8%) dan sudahmenghidapipenyakitsarafkroniklebihdaripada 5 tahun (38.3%).

Secarakeseluruhanhanya 20 orang penjagakanak-kanakmendapatmarkahpurata50 ataulebihdalamsemuakomponen CBI-M, menjadikanprevalenlesuupayaglobal dalamkalanganpenjagasebanyak8.3% (95% CI = 5.2%, 12.6%). Prevalenlesuupayaadalahberbezamengikutsetiapdomain. Lesuupayaperibadimelibatkan 78 orang penjaga(32.5%, 95% CI = 26.6%, 38.8%), 42 penjagamengalamilesuupayaberkaitandenganpesakit (17.5%, 95% CI = 12.9%, 22.9%) dan 11 penjagamengalamilesuupayakerja(4.65%, 95% CI = 2.3%, 8.1%).

Prevalenlesuupayaperibaditertinggiadalah di dalamkalanganpenjagakanak-kanakdenganpenyakitgenetik (60.0%, 95% CI = 26.2%, 87.8%), diikuti oleh PalsiSerebral (43.5%, 95% CI = 31.0%, 56.7%) dan autisme (37.5 %, 95% CI = 18.8%, 59.4%). Prevalenslesuupaya global tertinggiadalahdi dalamkalanganpenjagakanak-kanakyang mengalamipenyakitgenetik (30.0%, 95% CI = 6.7%, 65.2%), diikutidenganketidakupayaanintelektual (20.0%, 95% CI = 0.5%, 71.6%) dan autisme (16.7 %, 95% CI = 4.7%, 37.4%).

Punca-puncatekananyang utamaadalahtekananprestasi, konflikkeluarga-kerja dan prospekkerja yang rendah. Analisis ‘multiple logistic regression’ menunjukkanbahawatekanankeluarga, jenispenyakitsarafkanak-kanak dan bilanganpenghunirumahadalahdikaitkandenganlesuupayaperibadi, lesuupayaberkaitandenganpesakit dan juga lesuupaya globaldalamkalanganpenjaga.

Kesimpulan: Prevalenslesuupaya global dalamkalanganpenjagaadalahrendah, tetapilesuupayaperibadiadalahketara.Penjagakanak-kanakdenganpenyakit genetic, palsiserebral dan autism mempunyaiprevalenslesuupaya yang lebihtinggiberbandingdenganpenyakitsarafkroniklain.

Kata kunci: lesu upaya, stres, kanak-kanak, penyakit neurologi kronik

ABSTRACT

***Objective**:* Caring for children with neurological condition is challenging. This study aimed to determine the prevalence of burnout and its associated factors in caretakers of children with chronic neurological illness.

Methods:Thiscross-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 inthe state of Kelantan, Malaysia. Each caretaker was given a set of questionnaires, that included General Stressor Questionnaire (GSQ) which was translated into Malay version 'SoalSelidikUmum (SSU)', Copenhagen Burnout Inventory-Malay version (CBI-M) and Demographic Information Form.

Results: Two hundred and forty caretakers of children with chronic neurological illness participated in the study. The mean age of caretaker was 38.12 years old (SD = 7.74). Majority of them were female (82.1%), Malay (94.6%) and Muslim (95.8%). Mean age of children with chronic neurological illness was 7.19 years old (SD = 4.21), and most of them were male (60.8%) and had the illness for more than 5 years (38.3%).

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%). The prevalence of burnout differs for each domain. 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%).

The highest prevalence of personal burnout was among caretakers of children with genetic illness (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 total burnout was among caretaker 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, work-family conflict and poor job prospect. Multiple logistic regression analysis showed that family stressor, 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 were low, but personal burnout was prominent. Caretakers of children with genetic disorder, cerebral palsy and autism had higher prevalence of burnout compared to other chronic neurological illness.

Keywords: burnout, stressor, children, chronic neurological illness

CHAPTER 1: INTRODUCTION

Caring for children is a wonderful experience. All parents may be exposed to stress attempting to meet challenges of caring for their own child. This is more profound in those caring for children with chronic neurological illness.[1]Burnout is previously described as psychological syndrome in response to prolonged interpersonal stressors at workplace. 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 caregiver are well established.[3]Children with chronic neurological illness imposed more burden to their caretakers.[1]The act of caring might be accompanied by high levels of unpredictability and uncontrollability.[4] All these factors has the ability to create secondary stress, and frequently requires high levels of mindfulness and coping strategies.[1]

Burnout is a specific syndrome of exhaustion related to prolonged situations of emotional imbalance, where the burden of perceived stress is overwhelming and exceeds personal resources or coping strategies.[5]It was first described in the mid-1970s as a syndrome specifically related to workplace[2], regarded as a source of occupational hazard. Recently these exhaustions were also noted in relation to caring for children at home. Parental burnout is a relatively new entity.[6] Parental burnout is characterized by physical and emotional exhaustion, emotional distancing from one’s child, and a sense of incompetency inparenting role.[7] Parental stress does not necessarily always lead to parental burnout.[8]

Caretakers may provide wide variety of assistance with activities of daily living.[4]Although caregiving can be rewarding and pleasurable, it can also cause physical and psychological deterioration.[9, 10] Caretakers of children with neurological illness such as cerebral palsy need to overcome the extra burden from their children’s impairments.[10] Children with disability were twice as likely to reside with caregivers with high levels of financial stress and almost three and a half times as likely to reside with caregivers with high levels of psychological stress.[4] Burnout symptoms are more common in parents of children with chronic disease as compared to those with normal children.[11]Parental burnout may lead to child neglect and violent behavior towards children, as well as escape and suicidal ideations.[7]

Many studies have been conducted internationally and locally to identify burnout in medical workforce and formal caregivers. However local data regarding burnout in caretakers of children with chronic illness are lacking. Recently the Copenhagen Burnout Inventory (CBI) was translated into Malay version, CBI-M.[12] This provides an opportunity to study burnout in caretakers among Malaysian populations, using Malay language as their first language.

This study aims to describe prevalence of burnout among caretakers of children with chronic neurological illness by utilising Copenhagen Burnout Inventory-Malay version (CBI-M). It also investigated possible stressors and other socio-demographic factors associated with burnout.

CHAPTER 2: STUDY PROTOCOL

Title

A study of burnout and stressor-related factors among caretaker of children with chronic neurological illness

Literature review

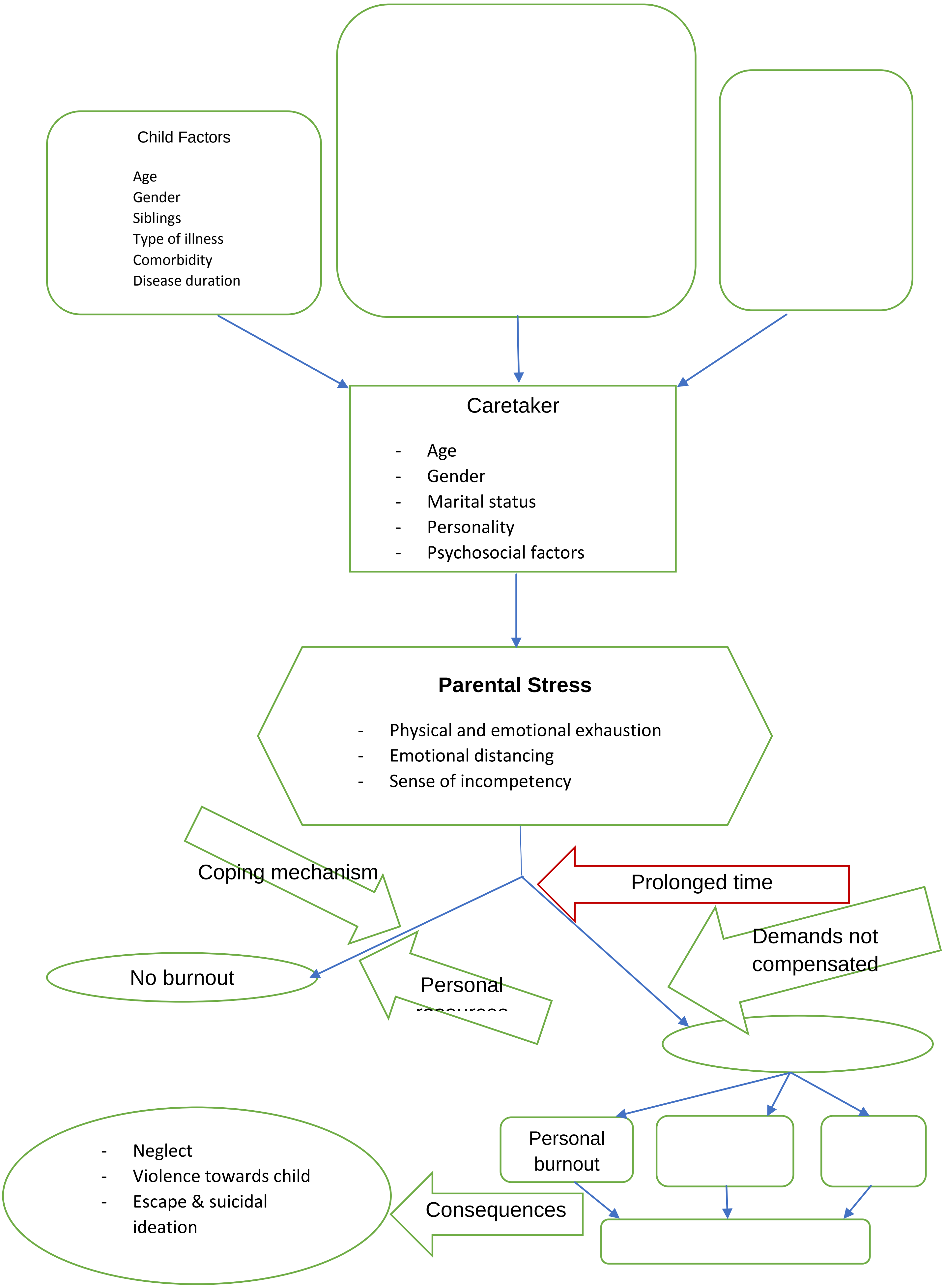
The term burnout was first described in relation to professional burnout, thought to be a syndrome of exhaustion related to working environment.[5] However more recent studies were showing evidence of exhaustionas a result of being physically and emotionally overwhelmed byparental role.[8, 11] First measure of parental exhaustion, the Parental Burnout Inventory (PBI) recently been created and validated in French,[8]examining sociodemographic, child-related, parent-related, parenting and family-functioning correlation with parental burnout. Parental burnout may potentially affect up to 14% of parents.[8]

Parental burnout are over-represented in parents of children with chronic disease compared to typically developing children.[11]Caregivers of patient with cerebral palsy had poorer quality of life, worse mental health and higher burnout levels.[13] Disabilities and impairment of children under care were correlated with caretakers depression score and poor quality of life .[10]

Fifty-six percent of caregivers had General Health Questionnaire (GHQ) scores above the cut off threshold for psychological disorders and the strongest predictor for psychological problems was high level of caregiver burden. Other predictors include lower educational level of caregiver, younger age of children, the use of more treatment type and not seeking support for care giving.[3] In a study of 354 parents of children with type I diabetes mellitus, 37.5% of parents (44.4% mothers and 28.4% fathers) scored for clinical burnout usingthe Shirom-Melamed Burnout Questionnaire (SMBQ).[14] There were no association between demographic factors including child's gender and age, parent's education, marital status and clinical burnout in parents.[8, 11] These associations were more prominent for mothers than for fathers as well as those with certain personality trait such as the need for a high degree of control in their life.[14]

Parental suffering in relation to children's chronic illness is likely to occur at 3 main points.[15] Prior to diagnosis, the family need to battle with disruption to ideal family lifewith 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.Sleep disruption is a well-known factors associated with burnout.[7]Parental burnout has larger associations with couple's conflict, escape and suicidal ideation, child neglect and parental violence.[6]

Conceptual framework



Problem statement & Study rationale

The study aims to describe prevalence of burnout in caretaker of children with chronic illness, specifically neurological diseases. This study will also investigate possible stressors and factors associated with burnout.

Many studies have been conducted internationally and locally to identify burnout in medical workforce and informal caregivers. However local data regarding burnout in caretakers of children with chronic illness are lacking. Recently the Copenhagen Burnout Inventory was translated into Malay version. This provides an opportunity to study burnout in caretakers among Malaysian populations, using Malay language as their first language.

Research Question (s)

1. Does caretaker of children with chronic neurological illness suffer from burnout more often than the general population?
2. Do children with chronic neurological illness more likely to live in households with caretakers who experienced many stressors than in households where caregivers experienced little or no stress?

General objective

To study the prevalence of burnout and its associated factors in caretakers of children with chronic neurological condition

Specific objective

1. To describe the prevalence of burnout in caretakers of children with chronic neurological illness using Copenhagen Burnout Inventory- Malay (CBI-M)

2. To describe common stressors among caretakers of children with chronic neurological illness using General Stressor Questionnaire (GSQ)

3. To determine factors associated with burnout in caretakers of children with chronic neurological illness

Methodology

Study design

This is a cross sectional study. Participants will be recruited from Paediatric Neurology clinics over a period of 3 month. Each participant will be given a set of questionnaires, divided into 3 subheadings. Participant will spend maximum of 30 minutes answering these questions.

Study location and duration

This study will be conducted in Hospital Raja Perempuan Zainab II, a tertiary hospital in the state of Kelantan, Malaysia. Participants will be recruited from August 2019 until October 2019.

Study population and sample

Caretakers including parents or guardian of children aged less than 18 years old with chronic neurological illness will be recruited via convenient sampling over a period of 3 months.

Sampling technique

All caretakers of patients who fulfill inclusion criteria, accompanying children to neurology clinic will be included in the study. Patient information sheets will be givento caretakers and informed consent obtained. Subjects will be approached by principal investigator/co-investigator/trained research assistant during theirscheduled follow-up date at neurology outpatient clinic. Information regarding the study, risk of burnout, and potential stressors will be given to potential subjects. Subjects will be allowed sufficienttime to consider their participation in the study.Questionnaires will be used to identify stressors and burnout. Baseline demographic data will be recorded.

Inclusion criterias are primary caretaker of children who are attending neurology clinics, must be 18 years or older and caring for children aged 3 months to 18 years. The children under their care must be diagnosed with chronic neurological disorder including cerebral palsy, epilepsy,attention-deficit hyperactive disorder and autism.

This study will exclude caretakers who are not proficient in Malay language, newly diagnosed children less than 3 months duration and those caring for children with epilepsy who are not on medication.

Sample size calculation

Using 95% confidence interval with, power of study 80%. Sample size calculation using the first objective: To determine the level of burnout and stress using single proportion formula:

$$n = \frac{Z^2 p(1-p)}{\Delta^2}$$

n = minimum required sample

Z = value of standard normal distribution = 1.96

Δ^2 = precision = 7%

p = 56% (the prevalence of psychological problems among caregivers of children with cerebral palsy)[3]

$$n = \frac{1.96^2 \times 0.56 \times (1-0.56)}{0.07^2}$$

$$= 193$$

Considering 20% non-response rate, the minimum required sample for caretakers [193+39(20% non-response)] is 232.

Research tool

Two validated questionnaires will be used, the General Stressor Questionnaire (GSQ) and the Copenhagen Burnout Inventory (CBI).

The GSQ was translated and validated in Malay language-SoalselidikStresorUmum (SSU). SSU were derived from a review of literature on the subject and a discussion with experts in the field. It measures stressors in a group of

House Officers. SSU will be adapted in this study to identify common stressor among caregiver of children with chronic neurological condition.[16]

The Copenhagen Burn out Inventory-Malay version, CBI-M[12] will be used for study of burnout in the caretakers. It comprises of 3 sub-dimensions including personal burnout, work-related burnout, and client-related burnout. Personal burnout refers to degree of physical and psychological fatigue and exhaustion experienced by the person. Work-related burnout refers to degree of physical and psychological fatigue and exhaustion that is perceived by the person as related to his or her work. Client-related burnout refers to degree of physical and psychological fatigue and exhaustion that is perceived by the person as related to his or her work with clients.[12]

A reliability and validity study for SSU was done in 2009 among house officers in UniversitiSains Malaysia Hospital[16]. Another study was done later in 2017 by the same author, investigating validity evidence of Malay translation of the CBI.[12] The study aimed to translate CBI into Malay language and to validate the translated version among a group of medical students in the same hospital. Both tools used in this study previously used in different population, burnout is a concept previously recognized as work-related entity. The current study aims at identifying burnout and stressor-related factors among caretakers of children with neurological illness, including housewives and fathers who are unemployed. A ‘pilot’ study was done using both tools in 78 caretakers of children with cancer, receiving treatment in Hospital UniversitiSains Malaysia.[17] Reliability data was calculated from this study.

Scoring for CBI[18]

CBI has 3 sub-dimensions:personal burnout, work-related burnout, and client-related burnout. Personal burnout domain are generic questions that can be answered by all participants. Work-related burnout assumes respondent has a paid job. Client-related burnout includes the term ‘client’,in this study, referring to child with chronic neurological illness.

CBI SCORING

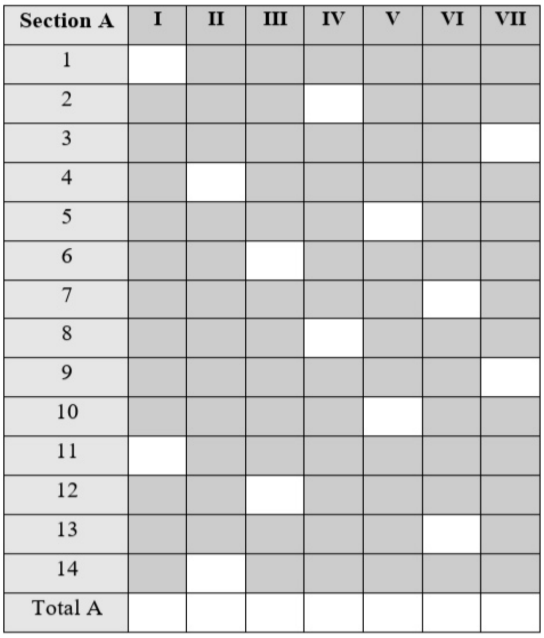
RESPONSE CATEGORIES: ALWAYS, OFTEN, SOMETIMES, SELDOM, NEVER/ALMOST NEVER

SCORING: ALWAYS:100. OFTEN:75. SOMETIMES:50. SELDOM:25. NEVER/ALMOST NEVER:0

Mean of total scores for each sub-dimension will be calculated. Mean scores of 50 more will be considered as significant.[18]

Scoring for SSU[16]

SSU has 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).



Section A	I	II	III	IV	V	VI	VII
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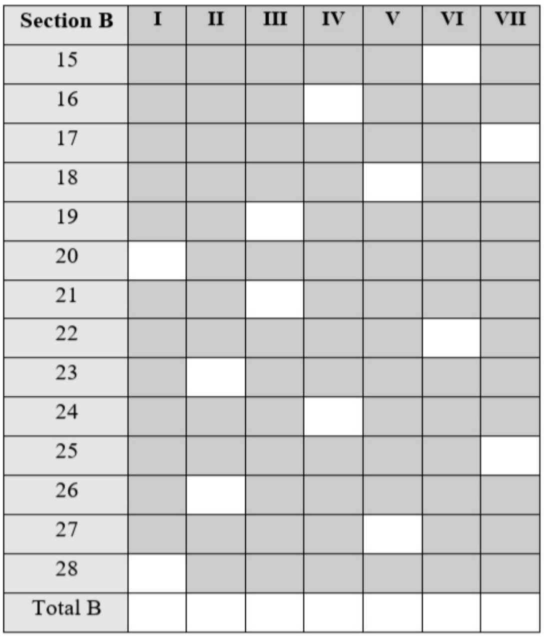

Section B	I	II	III	IV	V	VI	VII
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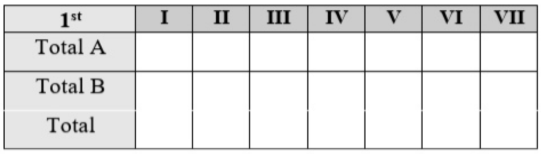
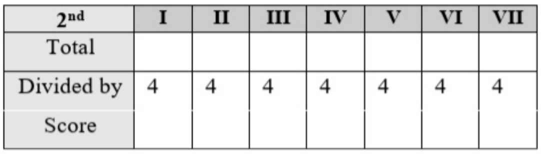


1st	I	II	III	IV	V	VI	VII
Total A							
Total B							
Total							



2nd	I	II	III	IV	V	VI	VII
Total							
Divided by	4	4	4	4	4	4	4
Score							

Scores will be calculated from these tables. Final score of >2 will be considered as significant stressor in the current study.

Operational definition

Burnout	Psychological syndrome emerging as a prolonged response to chronic interpersonal stressors on the job (taking care of children with chronic neurological illness). Caretaker burnout defines as mean score of 50 or more in each dimension of CBI-M (Copenhagen Burnout Inventory-Malay)[12]
Stressors	Event that triggers stress response
Neurological disorder	Any condition that is caused by a dysfunction in part of the brain, or nervous system, resulting in physical and/or psychological symptoms
Acquired neurological disorder	Neurological disorder not due to congenital malformation or genetic disorder, it developed after birth due to infection or trauma and contribute to neurological sequelae eg. meningitis, encephalitis, acute disseminated encephalomyelitis (ADEM)
Genetic disorder	Neurological condition associated with gene abnormality eg. Neurofibromatosis, Tuberous sclerosis
Metabolic disorder	Neurological condition associated with metabolic disturbances eg. neurotransmitter disease, myasthenia, MELAS (mitochondrial myopathy, encephalopathy, lactic acidosis, and stroke)

Disability	Limited or prevented in any way in their ability to do things most children of the same age could do, due to a medical condition or had any emotional, developmental, or behavioural problems which needed treatment or counselling
Chronic illness	Health problem lasted 3 months or more, affecting child’s normal activities, and requires frequent hospitalisations, home health care and/or medical care[19]
Primary caregiver/caretaker	Person who takes primary responsibility for someone who cannot fully care for him/herself

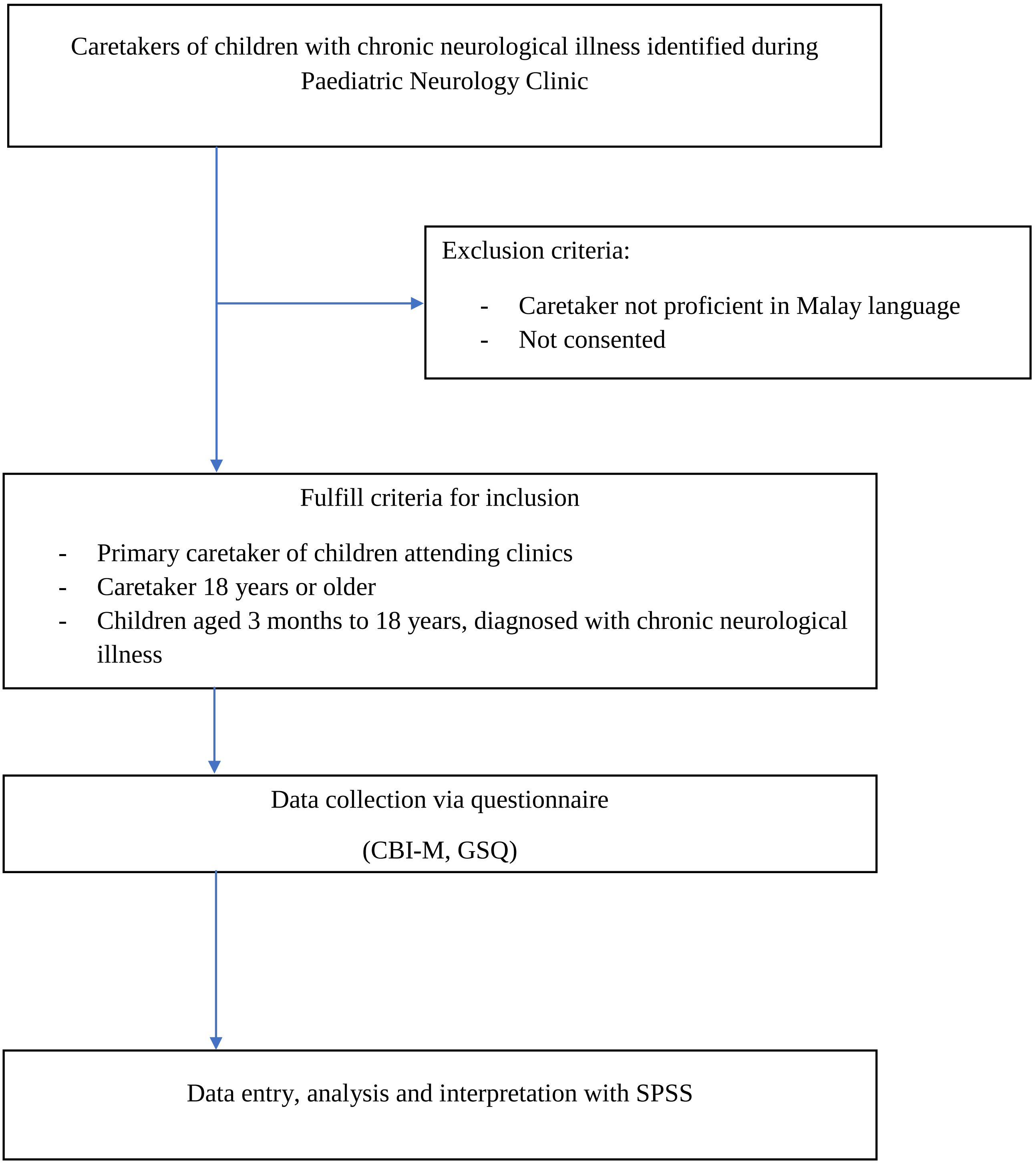


Figure 1 Study Flowchart

Statistical analysis

Data will be entered and analyse using SPSS version 24. Descriptive statistics will be used to summarise socio-demographic characteristics of participants. Numerical data will be presented as mean (SD). Categorical data will be presented as frequency.

Statistical analysis includes:

Objective 1: Describe prevalence of burnout (%) and 95% confidence interval

Objective 2: Describe percentage of different stressors in caretakers of children with chronic neurological illness

Objective 3: Simple logistic regression and multiple logistic regression

Expected results

Objective 1: To describe the prevalence of burnout in caretakers of patients with chronic neurological illness

Burnout	**N (%)**	**95% CI**
Yes		
No		

Objective 2: To describe common stressors present in caretakers of patients with chronic neurological illness

Type of stressors	**Mean (SD)**
Family	
Poor relationship with superior	
Bureaucratic constraints	
Work-family conflicts	
Poor relationship with colleagues	
Performance pressure	
Poor job prospect	

Objective 3: To determine factors associated with burnout in caretakers of children with chronic neurological illness

Using simple logistic regression and multiple logistic regression

Characteristics (Caretakers)	Crude OR (95% CI)	P value	Adjusted OR (95% CI)	P value
Age				
Gender				
-Male				
-Female				
Ethnic background				
-Malay				
-Chinese				
-Indian				
-Others				
Relationship to children				
-Father				
-Mother				
-Others				
Education level				
-Less than high school				
-High school grad				
-College				
-Bachelors degree and more				
Income				

Characteristics (Caretakers)	Crude OR (95% CI)	P value	Adjusted OR (95% CI)	P value
Religion				
-Muslim				
-Christian				
-Hindu				
-Buddhist				
Living condition				
-Own home				
-Rented				
-Number of rooms				
Occupation				
-Fulltime				
-Part-time				
-Unemployed				
-Housewife				
Types of work				
-Government				
-Private				
-Self-employed				
-Housewife				
Medical illness				
-Yes				
-No				

Characteristics (Children)	Crude OR (95% CI)	P value	Adjusted OR (95% CI)	P value
Age				
Duration of diagnosis				
<1 year				
1-2 years				
3-4 years				
>5 years				
Gender				
-Male				
-Female				
Age at diagnosis				
Types of disability				
-Learning				
-Physical				
-Multiple				
Comorbidities				
-Yes				
-No				
Registration with JKM				
-Yes				
-No				

Gantt chart & milestones

Activity	06/19	07/19	08/19	09/19	10/19	11/19
Data collection	X	X	X			
Data analysis		X	X	X		
Presentation and submission of report			X	X	X	
Report writing			X	X	X	
Project completion				X	X	
Submission					X	X