CHILDREN WITH TRANSFUSION DEPENDENT THALASSAEMIA: THE STUDY OF PSYCHOLOGICAL DISTRESS AND COPING STRATEGIES AMONG CARETAKERS

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CHILDREN WITH TRANSFUSION DEPENDENT THALASSAEMIA: THE STUDY OF PSYCHOLOGICAL DISTRESS AND COPING STRATEGIES AMONG CARETAKERS

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Introduction: Hemoglobin E beta thalassaemia is prevalent in Malaysia. Knowing thalassaemia is a chronic disease it is a lifelong burdens not only to the patient but also to the parent and other caretakers. Psychological distress is manifested in multiple ways and at different level of severity. Therefore coping strategies are developed in order to reduce the stress hence ascertain a high quality of life.

Objectives: The aim of this study were to determine the mean psychological distress level and brief COPE of caretakers, to compare mean psychological distress level with brief COPE and income status and to identify the associated factors for psychological distress and brief COPE respectively.

Methodology: DASS 21 and brief COPE questionnaires.

Results: Depressive median score was (2.00, IQR 4.00). Anxiety mean score was (3.54, SD 3.54). Stress mean score was (4.25, SD 3.26). The highest mean score for brief COPE was religion (7.00, IQR 2.00). Depressive caretakers had significant score for substance use (4.50, IQR 3.00). Meanwhile anxious caretakers had significant score for denial (5.50, IQR 3.00), substance use (4.00, IQR 4.00) and behavior disengagement (4.00, IQR 3.00). There was no significant difference between psychological distress and income status. Age, gender, education, working and income status were identified to have association with brief COPE.

Conclusion: Majority of caretakers had utilized religion coping, meanwhile substance use, denial and behavioral disengagement were utilized by depressive and anxious caretakers. Scoring for DASS 21 showed no significant different between two groups of income. Brief COPE was associated with age, gender, education, working and income status.

Prof Madya Dr Norsarwany Mohamad: Supervisor

Prof Madya Dr Azizah Othman: Co-Supervisor

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LIST OF ABBREVIATIONS

DASS	Depression anxiety stress score
HKK	Hospital Kuala Krai
HRPZ II	Hospital Raja Perempuan Zainab II
HUSM	Hospital Universiti Sains Malaysia
IQR	Interquartile range
MLR	Multiple logistic regression
SD	Standard deviation
SLR	Simple logistic regression
TDT	Transfusion dependent thalasaemia

KANAK-KANAK TALASEMIA BERGANTUNG PADA TRANFUSI DARAH: KAJIAN MENGENAI TEKANAN PSIKOLOGI DAN STRATEGI DAYA TINDAK DI KALANGAN PENJAGA-PENJAGA

ABSTRAK

Talasemia merupakan gangguan autosom resesif pada sel darah merah di mana terdapat kecacatan dalam sintesis hemoglobin yang normal. Secara umum talasemia dibahagikan kepada alfa dan beta talasemia, bergantung kepada rantaian globin yang terlibat. Beta talasemia selanjutnya dibahagikan kepada tiga iaitu beta talasemia minor, intermedia dan major. Di samping itu hemoglobin E beta talasemia juga banyak terdapat di Malaysia. Biasanya kumpulan pesakit ini tergolong kepada bergantung pada transfusi darah dan tidak bergantung pada transfusi darah. Mengetahui talasemia adalah penyakit kronik ia adalah satu beban sepanjang hayat bukan sahaja kepada pesakit malahan juga kepada ibu bapa serta penjaga. Tekanan psikologi dimanifestasikan dalam pelbagai cara serta pada peringkat keterukan yang berbeza. Oleh itu strategi-strategi daya tindak disusun bagi mengurangkan stres tersebut lantas kualiti hidup yang tinggi dapat dilestarikan. Objektif utama kajian rentas ini adalah untuk mengenal pasti tahap tekanan psikologi dan strategi-strategi daya tindak yang diguna pakai oleh penjaga-penjaga kanak-kanak talasemia yang bergantung pada transfusi darah. Selain itu perbandingan antara dua perbezaan min juga sebahagian daripada objektif primer kajian ini. Ia melibatkan perbezaan min di antara strategi-strategi daya tindak yang diguna pakai oleh penjaga-penjaga kanak-kanak talasemia yang bergantung pada transfusi darah dan perbezaan tahap skor tekanan psikologi mereka serta perbezaan min di antara

tahap tekanan psikologi di kalangan penjaga-penjaga kanak-kanak talasemia yang bergantung pada transfusi darah dan perbezaan tahap status pendapatan mereka. Seterusnya faktor-faktor peramal yang melibatkan kedua-dua natijah dapat dikenal pasti. Soal selidik DASS 21 dan COPE ringkas telah digunakan dalam metodologi kajian ini. Hasil kajian mendedahkan skor median untuk item kemurungan adalah 2.00 dengan 4.00 julat antara kuartil (IQR). Min skor item kebimbangan adalah 3.54 dengan sisihan piawai 3.54 (SD). Sementara itu skor min bagi item tekanan adalah 4.25 dengan sisihan piawai 3.26 (SD). Lima daripada empat belas item COPE ringkas telah menunjukkan skor min melebihi 5.00 iaitu keagamaan (7.00 skor median dengan 2.00 julat antara kuartil), penerimaan (6.00 skor median dengan 3.00 julat antara kuartil), olahan positif (5.81 skor min dengan 1.80 sisihan piawai), daya tindak aktif (5.49 skor min dengan 1.82 sisihan piawai) dan merancang (5.25 skor min dengan 1.69 sisihan piawai). Penjaga-penjaga yang telah mengalami tekanan psikologi kemurungan didapati lebih tinggi skor median COPE ringkas secara signifikan bagi penggunaan bahan (4.50, IQR 3.00) berbanding penjaga-penjaga yang tidak tertekan (2.00, IQR 0.00). Sementara itu penjaga-penjaga yang telah mengalami tekanan psikologi kebimbangan didapati lebih tinggi skor median COPE ringkas bagi penafian (5.50, IQR 3.00), penggunaan bahan (4.00, IQR 4.00) dan pengunduran tingkah laku (4.00, IQR 3.00) berbanding penjaga-penjaga yang tidak tertekan (3.00, IQR 2.00), (2.00, IQR 0.00), (2.00, IQR 0.00) secara berurutan. Walaubagaimanapun tiada perbezaan min yang signifikan ditemui apabila analisa bandingan antara status pendapatan miskin dan tidak miskin dijalankan ke atas kumpulan kemurungan dan juga kebimbangan. Faktor-faktor peramal iaitu umur (belia), jantina (wanita), pendidikan (tinggi), status pekerjaan (bekerja) dan

status pendapatan (tidak miskin) telah dikenalpasti mempunyai talian dengan COPE ringkas. Kesimpulannya segelintir penjaga tertekan semasa menjaga kanak-kanak talasemia yang bergantung pada tranfusi darah dan majoriti daripada mereka telah menggunakan daya tindak menjurus keagamaan, penerimaan dan olahan positif bagi menanganinya. Sementara itu kumpulan penjaga yang murung dan bimbang didapati telah menggunakan COPE ringkas yang bersifat negatif dasarnya iaitu penggunaan bahan, penafian dan pengunduran tingkah laku. Skor bagi DASS 21 telah menunjukkan tiada perbezaan signifikan di antara dua kumpulan pendapatan. Faktor-faktor seperti umur, jantina, tahap pendidikan, status pekerjaan dan status pendapatan telah terbukti mempengaruhi hasil COPE ringkas di kalangan penjaga.

CHILDREN WITH TRANSFUSION DEPENDENT THALASSAEMIA: THE STUDY OF PSYCHOLOGICAL DISTRESS AND COPING STRATEGIES AMONG CARETAKERS

ABSTRACT

Thalassaemia is an autosomal recessive disorder of red blood cell whereby there is defect in synthesis of normal haemoglobin. In general thalassaemia is divided into alpha and beta thalassaemia, depending on which globin chain is involved. Beta thalassaemia can further be subdivided into three namely beta thalassaemia minor, intermedia and major. On top of that, hemoglobin E beta thalassaemia is also prevalent in Malaysia. This group of patient is usually classified into transfusion dependent and non-transfusion dependent. Knowing thalassaemia is a chronic disease it is a lifelong burdens not only to the patient but also to the parent and other caretakers. Psychological distress is manifested in multiple ways and at different level of severity. Therefore coping strategies are developed in order to reduce the stress hence ascertain a high quality of life. The main objective of this cross sectional study is to identify the psychological distress level and coping strategies utilized by caretakers of transfusion dependent thalassaemia children. Other than that comparing two means different also part of this study primary objectives. It involves mean different between coping strategies utilized by caretakers of transfusion dependent thalassaemia children and different level of their psychological distress score and mean different between psychological distress levels among caretakers of transfusion dependent thalassaemia and their different level of income status. Subsequently the predictors affecting both

outcomes were identified. DASS 21 and brief COPE questionnaires were used in the study methodology. This study revealed the median score for depressive item was 2.00 with 4.00 interquartile range (IQR). The mean score for anxiety item was 3.54 with 3.54 standard deviation (SD). Meanwhile the mean score for stress item was 4.25 with 3.26 standard deviation (SD). Five out of fourteen brief COPE items showed mean score of more than 5.00 which were religion (median score of 7.00 with 2.00 interquartile range), acceptance (median score of 6.00 with 3.00 interquartile range), positive reframing (mean score of 5.81 with 1.80 standard deviation), active coping (mean score of 5.49 with 1.82 standard deviation) and planning (mean score of 5.25 with 1.69 standard deviation). Depressive psychological distressed caretakers had significant higher median brief COPE score for substance use (4.50, IQR 3.00) then the non-distressed caretakers (2.00, IQR 0.00). Meanwhile anxious psychological distressed caretakers had significant higher median brief COPE score for denial (5.50, IQR 3.00), substance use (4.00, IQR 4.00) and behavior disengagement (4.00, IQR 3.00) then the non-distressed caretakers (3.00, IQR 2.00), (2.00, IQR 0.00), (2.00, IQR 0.00) respectively. However there was no significant difference found between poverty and non-poverty income status on depressive or anxiety group. Predictors namely age (young adulthood), gender (female), education (high), working status (working) and income status (non-poverty) were identified to have association with brief COPE. As a conclusion few caretakers were distressed in looking after transfusion dependent thalassaemia children and majority of them had utilized religion, acceptance and positive reframing to cope with it. Meanwhile depressive and anxious group caretakers were found to utilize brief COPE of negative in nature which were substance use, denial

and behavioral disengagement. Scoring for DASS 21 showed no significant different between two groups of income. Factors such as age, gender, education, working status and income status had been proven to affect the outcomes brief COPE among caretakers.

CHAPTER ONE

INTRODUCTION AND LITERTURE REVIEW

1.1 Epidemiology

Thalassaemia is an autosomal recessive disorder of red blood cell whereby there is defect in synthesis of normal haemoglobin. In general thalassaemia is divided into alpha and beta thalassaemia, depending on which globin chain is involved. Beta thalassaemia can further be subdivided into three namely beta thalassaemia minor, intermedia and major. On top of that, Hb E beta thalassaemia is also prevalent in Malaysia. This group of patient is classified into transfusion dependent and non-transfusion dependent.

It is estimated that 240 million people are heterozygous for beta thalassaemia and annually 200,000 affected homozygotes are born. Being one of the most common genetic diseases in the world, the prevalence is high in Mediterranean such as Italy, Greece and Cyprus, Asian countries like China and India and South East Asia countries involving Malaysia. According to Malaysian Thalassaemia Registry, for the year 2010 there were 4768 citizens who were registered as transfusion dependent thalassaemia. Latest statistics show that 1 in 20 Malaysians are carriers for beta thalassaemia trait. Malay and Chinese account for more than 70 % of thalassaemia patients in Malaysia where it encompasses 50.4% and 23.7% respectively.

There are different thalassaemia phenotypes in Malaysia for example among Malays majority are hemoglobin E beta thalassaemia meanwhile beta thalassaemia patients are more prevalent among Chinese and Kadazan. The numbers of thalassaemia patients were 309 in Kelantan. In this state Malays ethnicity account for more than 90% of the population.

1.2 Disease Burden

The management of thalassaemia is similar to other chronic illnesses that comprises of biopsychosocial and spiritual dimensions. As thalassaemia is a chronic disease it is a lifelong burdens not only to the patient per say but also to the surrounding entity especially the parent and other caretaker. Moreover Malaysia patient population cohort from year 2002 to 2010 showed shifting to the right. This means Malaysia has more surviving patients and presence of older patients. Thus the iron toxicity related diseases is another integral factor that will make a paradigm shift in near future.

Chronic illness such as thalassaemia often impose negative effects to psychological functioning of both patients and their family. Risk of psychological adjustment problems in children with chronic illness is 1.5 to 3 times as high as their healthy peers (Thompson and Gustafson, 1996).

Similar to other chronic disease, thalassaemia burdens not only the children but also the parents and the whole family (Wahab *et al*, 2011).

A focus group study that explored the concerns, beliefs and feelings about thalassaemia conducted on Malaysian children aged 8 to 22 and their parents indicated that concerns and adverse impact were related to poor grades in school, low self-image, limited employment opportunity, marriage, financial problems and difficulty to integrate in the society (Wahab *et al*, 2011).

A study on 150 parents of children with beta thalassaemia major in India indicated that 10 percent had adjustment disorder, 33.3 percent had depressive disorder, 10 percent had anxiety disorder and 11 percent had somatoform disorder. 95 percent of the parents of newly diagnosed children expressed feeling of dazed and shock, fear of death, hopelessness, separation anxiety and problems with their memory and concentration (Khairkar *et al*, 2010).

Disease related and demographic factors are the psychosocial circumstantial conditions that may mitigate or exacerbate the sufferings of the chronically ill children. Frequent hospitalization, a later onset of illness and children at a range of ages between 7 to 11 years old were found to report significantly higher psychological problems (Ashiq and Azizah, 2010).

1.3 Coping

Different individuals use different strategies for coping with negative affective state and associated life problems. Effective coping strategies are crucial to ascertain high quality of life. Strategies are developed to identify means to reduce stress. Psychological distress is manifested in multiple ways and at different level of severity.

1.4 Rationale of the study

Burden of psychological distress among caretakers of thalassaemia transfusion dependent group needs to be measured in objective manner using a psychological tool. Efforts from various counterparts had been made to look into this matters and Malaysia also need to stand up with some statistical figure at least.

The identified distress among the caretakers from this study later will require a psychological support from the experts and further strengthening their coping strategies in near future.

CHAPTER TWO

STUDY OBJECTIVES

2.1 Research Questions

i-What is the level of distress among caretakers of transfusion dependent thalassaemia children?

ii-What is the coping strategies utilized by caretakers of transfusion dependent thalassaemia children?

iii-Is there any significant difference in the mean of coping strategies between distressed and non-distressed caretakers of transfusion dependent thalassaemia children?

iv-Is there any significant difference in the mean of distressed between different income status of caretakers of transfusion dependent children?

v-Is there any significant associated factors affecting level of distress among caretakers of transfusion dependent thalassaemia children?

vi-Is there any significant associated factors affecting coping strategies utilized by caretakers of transfusion dependent thalassaemia children?

2.2 General Objectives

To identify the psychological distress level and coping strategies utilized by caretakers of transfusion dependent thalassaemia(TDT) children.

2.3 Primary Objectives

- To determine mean psychological distress level among caretakers of TDT children using DASS 21.
- To determine mean score of each coping strategies utilized by caretakers of TDT children using Brief COPE.
- To compare mean coping strategies utilized by caretakers of TDT children with different level of their psychological distress score.
- To compare mean psychological distress level among caretakers of TDT children with different level of their income status.

2.4 Secondary Objectives

- To identify the associated factors affecting psychological distress among caretakers of TDT children.
- To identify the associated factors affecting coping strategies utilized by caretakers of TDT children.

2.5 Research Hypotheses

i-There was a significant difference of mean score of coping strategies between distressed and non-distressed caretakers of TDT children.

ii-There was a significant difference of mean score of psychological distressed level with different level of income status among caretakers of TDT children.

iii-There were a significant associated factors affecting psychological distress level among caretakers of TDT children.

iv-There were a significant associated factors affecting coping strategies utilized by caretakers of TDT children.

CHAPTER THREE

METHODOLOGY

3.1 Study Design

This was a cross sectional study, conducted from April 2013 to April 2014 and extended to March 2016 in Day Care Center Unit, Department of Paediatrics Hospital Universiti Sains Malaysia (HUSM), Hospital Raja Perempuan Zainab II (HRPZ II) Kota Bharu and Hospital Kuala Krai (HKK).

3.2 Study Population

Caretakers of transfusion dependent thalassaemia (TDT) children in HUSM, HRPZ II and HKK including newly diagnosed patients within the study period.

- Inclusion criteria:
    - All TDT caretakers of HUSM, HRPZ II and HKK patients
- Exclusion criteria:
    - Cognitively incapable of understanding and completing the questionnaires and / or the interview
    - Any serious medical and psychiatric illnesses including substance abuse at time of answering question

Sample size calculation

The sample size determination was based on the study objectives. Single mean formula had been applied in order to determine the number of sample size for the first and second primary objectives. Meanwhile two means formula had been applied for the third and fourth primary objectives. The minimum requirement of sample size was 68, as derived from the formula calculation.

3.3 Variable/Operational Definitions

i-**Psychological distress**: undifferentiated combinations of symptoms ranging from depression and general anxiety symptoms to personality traits, functional disabilities and behavioural problems.

ii-**Coping**: behavioural and cognitive efforts made by individuals in attempting to deal with stressful situations.

iii-**Caretaker**: a person who gives physical or emotional care to transfusion dependent thalassaemia children.

iv-**Transfusion dependent thalassaemia (TDT)**: all thalassaemia patient who requires packed cell transfusion at least twice a year.

v-**Age**:

Young adult: age between 20 to 39 years old.

Middle adulthood: age between 40 to 64 years old.

vi-**Poverty status** (Based on "Penggunaan Pendapatan Garis Kemiskinan (PGK) " Jabatan Kebajikan Masyarakat Malaysia 2007)

Poverty: total house income RM 720 and below

Non – poverty: total house income more than RM 720

vii-**Education level**

High: having education at diploma level and above

Non high: up to secondary education

3.4 Measurement Tools

- Demographic Data
- Depression Anxiety and Stress Scale (DASS) 21 to measure caretaker's psychological stress level
- Brief COPE to identify the coping strategies utilized by the caretakers

The demographical data were obtained from the respected hospitals. Explanation given to the caretaker and subsequently the DASS 21 and brief COPE self-administered questionnaires were delivered to the participants once consented. After completion of the questionnaires they must immediately be submitted to the investigator. The variables taken for demographic data were: age, gender, race, income, education level, occupation and number of affected child under their care. For measurement tools, 2 sets of scoring system had been utilized. First the DASS 21 and subsequently the brief COPE.

DASS 21

DASS 21 is the short version of the original one which is known as DASS 42. DASS 42 was first developed by researchers at University of New South Wales, Australia namely Lovibond SH, Lovibond PF in year 1995. Then subsequent researchers, Antony, Bieling, Cox, Enns, and Swinson established a 21-item version of the DASS (DASS-21) with seven items per scale in year 1998. It is non-diagnostic questionnaires.

The DASS 21 consists of three self-report scales designed to provide relatively pure measures of the three related negative affective states of depression, anxiety and stress. Each of the three scales contains 7 items.

The depression scale assesses dysphoria, hopelessness, devaluation of life, self-deprecation, lack of interest or involvement, anhedonia and inertia.

The anxiety scale assesses autonomic arousal, skeletal muscle effects, situational anxiety and subjective experience of anxious affect.

The stress scale assesses difficulty relaxing, nervous arousal and being easily upset or agitated, irritable or over reactive and impatient.

Based on DASS 21 questionnaires, question 3, 5, 10, 13, 16, 17, 21 will assess depression domain, question 2, 4, 7, 9, 15, 19, 20 will assess anxiety domain and question 1, 6, 8, 11, 12, 14, 18 will assess stress domain.

Ramli Musa *et al* had validated DASS 21 into Bahasa Melayu and the Cronbach's alpha value for overall items was very good which was 0.90 (CI 95%).

The rating used Likert score which as follows:

0 : did not apply to me at all

1 : applied to me to some degree or some of the time

2 : applied to me to a considerable degree or a good part of time

3 : applied to me very much or most of the time

Furthermore the total scoring is illustrated by table beneath.

	Depression	Anxiety	Stress
Normal	0-9	0-7	0-14
Mild	10-13	8-9	15-18
Moderate	14-20	10-14	19-25
Severe	21-27	15-19	26-33
Extremely severe	28+	20+	34+

Brief COPE

On the other hand, the brief COPE scale was proposed to assess a broad scope of coping behavior among adults for all condition, illnesses or non-illnesses. It was originally developed by Carver in year 1997. In Malaysia the brief COPE scale was already validated, whereby the internal consistency (Cronbach's alpha) ranging from 0.25 to 1.00 and the scales were reliable and valid instruments which could be applied in Malaysian protocol (N.Yusoff *et al,* 2009).

In general it comprises of 28 items and is categorized into 14 subscales.

Items for brief COPE scale:

1. Self- distraction
2. Active coping
3. Denial
4. Substance use
5. Use of emotional support
6. Use of instrumental support
7. Behavioral disengagement
8. Venting
9. Positive Reframing
10. Planning
11. Humor
12. Acceptance
13. Religion
14. Self-blame

Based on brief COPE questionnaires, question 1 and 19 will assess self-distraction domain, question 2 and 7 will assess active coping domain, question 3 and 8 will assess denial domain, question 4 and 11 will assess substance use domain, question 5 and 15 will assess use of emotional support domain, question 10 and 23 will assess use of instrumental support domain, question 6 and 16 will assess use of behavioral disengagement domain, question 9 and 21 will assess venting domain, question 12 and 17 will assess positive reframing domain, question 14 and 25 will assess planning domain, question 18 and 28 will assess humor domain question 20 and 24 will assess acceptance domain, question 22 and 27 will assess religion domain, question 13 and 26 will assess self-blame domain.

The items are scored in 4 points Likert score. The higher score on each subscale indicates more use of that particular coping strategy and vice versa

1 : I haven't been doing this at all

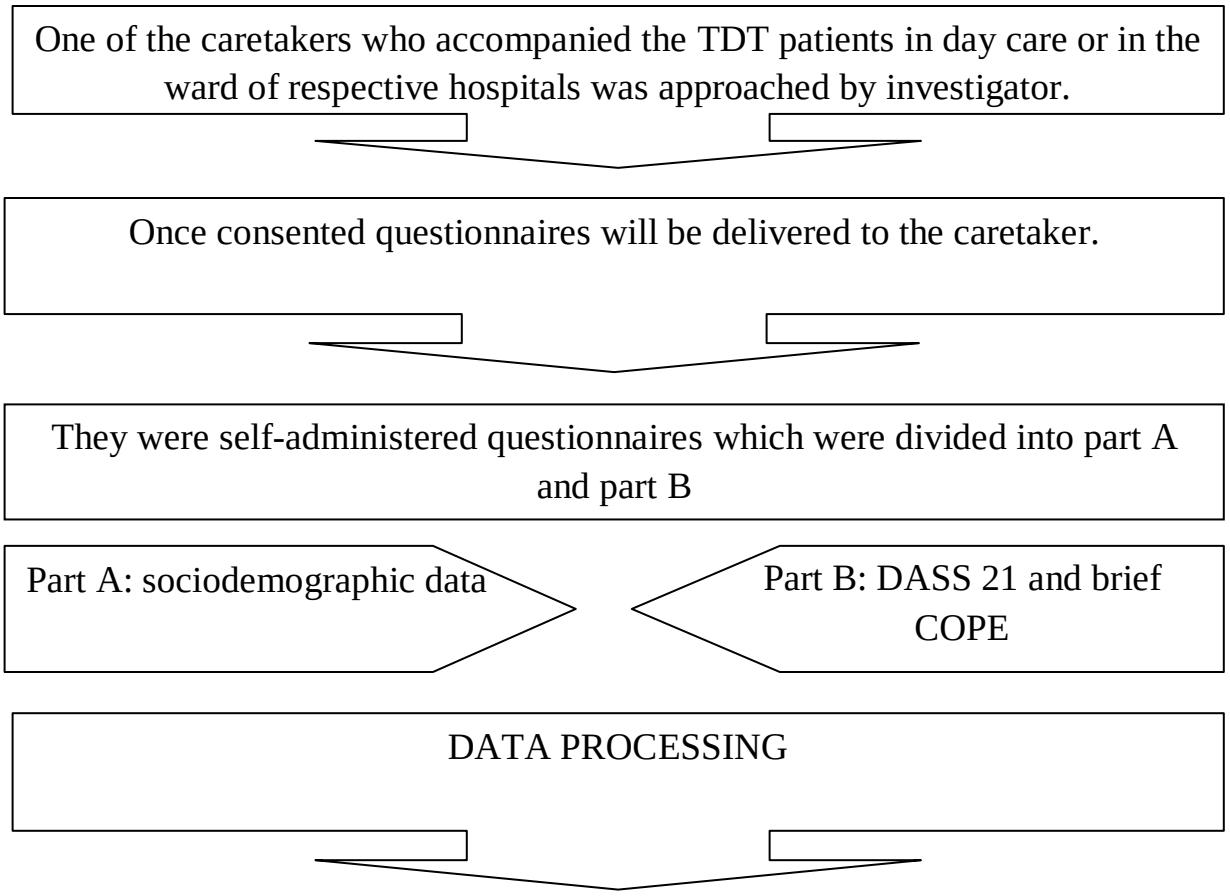
2 : I've been doing this a little bit

3 : I've been doing this a medium amount

4 : I've been doing this a lot

For each domain the higher score indicates more usage of that particular coping.

3.5 Flow chart



3.6 Statistical Analysis

Data was analyzed through SPSS -20.

i-Data Exploration and Cleaning

Data exploration and cleaning was run in order to obtain descriptive statistics for all the variables. Data cleaning was carried out to identify for any missing value and detection of error in the data entry. The descriptive analysis was performed for:

1-Sociodemographic data of caretakers

2-DASS 21 score

3-Brief COPE score

For categorized data, frequency and percentage (%) were presented in the result. For numerical data the result was presented as mean and standard deviation (SD) if the variables were normaly distributed and for skewed variables the data were presented as median and inter-quartile range (IQR). The normality of variables was checked using histogram with overlaid normal curve.

ii-Univariate analysis

Univariate analysis using the independent t test or Mann Whitney test was executed for 2 groups mean comparison. Independent t test was used for normaly distributed data and on the other hand Mann Whitney test was used for skewed data. Again the normality of the variables was checked using histogram with overlaid normal curve. The result was presented as mean and standard deviation (SD) if the variables were

normaly distributed and for skewed variables the data were presented as median and inter-quartile range (IQR).

iii-Multiple Logistic Regression

Multiple Logistic Regression was used in order to estimate the associated factors affecting DASS 21 and also coping strategies. The predictors of interest were:

1-Age

2-Gender

3-Working status

4-Income status

5-Education status

6-Number of TDT children under care

The study outcome was dichotomous binary categorical variable for both DASS 21 and brief COPE. In order to achieve final model, all the 6 steps in Multiple Logistic Regression were run as follows:

1-Data exploration and cleaning

2-Univariate analysis (Simple Logistic Regression)

3-Variable selection (Multiple Logistic Regression): preliminary main effect model

4-Checking multicollinearity and interaction: preliminary final model

5-Checking assumptions: final model

6-Interpretation and presentation

The result subsequently presented as OR (Odd ratio) and concluded as association.

3.7 Ethical issue

All subjects were thoroughly informed regarding the interview and written consent was obtained (Appendix A). The study protocol was approved by the Research and Ethics Committee, School of Medical Sciences, Universiti Sains Malaysia (Appendix B) and Medical Research and Ethics Committee, Kementerian Kesihatan Malaysia (Appendix C).

CHAPTER FOUR

RESULTS

4.1 Sociodemographic data

Total of 68 caretakers voluntarily took part in this study. Female were slightly higher compared to male respondents. The percentage of female caretakers were 55.9% (n=38) while the male caretakers were 44.1% (n= 30). Majority of the caretakers were in the middle adulthood age group which account for 64.7% (n=44) and the rest 35.3% (n=24) were in the young adult age group with mean age of 43 years. 98.5% (n=67) of them were Malays and only 1.5% (n=1) was Chinese. For educational status, non-higher education level outnumbered the higher education group by 38 respondents. The percentage were 77.9 % (n=53) for non-higher education level and 22.1% (n=15) for higher education level. Majority of caretakers who involved in this study were working. The percentage was 60.3 % (n=41) and for non-working caretakers the percentage were only 39.7% (n=27). From income status perspective, non-poverty group outnumbered the poverty group by 38.2% with gathered percentage of 69.1% (n=47) and 30.9% (n=21) respectively. Majority of the caretakers looking after only 1 affected TDT children with percentage of 79.4% (n=54) and the remaining 14 caretakers looking after 2 or more affected TDT children with percentage of 20.6%

Table 4.1: Sociodemographic data caretakers of TDT children, n=68

		Number	Percentage (%)
Hospital	HUSM	14	20.6
	HRPZ II	48	70.6
	HKK	6	8.8
Age	Young adult	24	35.3
	Middle adulthood	44	64.7
Gender	Male	30	44.1
	Female	38	55.9
Race	Malay	67	98.5
	Chinese	1	1.5

Table 4.1: Sociodemographic data caretakers of TDT children

		Number	Percentage (%)
Number of affected child under care	Less than 2	54	79.4
	2 or more	14	20.6
Job status	Working	41	60.3
	Not working	27	39.7
Poverty status	Poverty	21	30.9
	Non poverty	47	69.1
Education level	Higher	15	22.1
	Non higher	53	77.9

4.2 Prevalence of DASS 21

The most frequent answer for depressive and anxiety score was “did not apply at all (score =0)” with percentage for depressive item ranging from 55.9% (n=38) to 88.2% (n=60) and for anxiety item ranging from 47.1% (n=32) to 70.6% (n=48) except for question 2 answer “applied to some degree or some of the time (score=1)” had highest percentage which was 47.1% (n=32). However for stress score the answer “did not apply at all (score=0)” and “applied to some degree or some of the time (score=1)” account for highest percentage. 4 questions and 3 questions respectively. For answer “did not apply at all (score=0)” the percentage ranging from 63.2% (n=43) to 69.1% (n=47) meanwhile for answer “applied to some degree or some of the time (score=1)” the percentage ranging from 45.6% (n=31) to 57.4% (n=39).