

## Parenting Stress in Childhood Leukaemia

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### ABSTRAK

Adalah lazim untuk seseorang ibubapa mengalami stres apabila menjalankan peranan sebagai seorang ibu/bapa (Hoekstra-Weebers et al. 1998). Terdapat pelbagai punca stres dan stres ini bergantung juga kepada fasa rawatan dan peringkat kemoterapi (Sawyer et al. 2000). Jika stres ini tidak ditangani dengan elok, maka ianya dapat mendatangkan kesan terhadap aspek emosi dan sosial seseorang kanak-kanak dalam menerima diagnosis kanser selain daripada penerimaan rawatan yang diberi (Sawyer et al. 1993). Kajian ini bertujuan untuk mengenalpasti tahap stres dikalangan ibubapa, faktor-faktor risiko yang berkaitan dengan tahap stres yang tinggi, disamping jenis mekanisme yang digunakan oleh ibubapa untuk menangani stres tersebut. Seramai 117 ibu/bapa terlibat didalam kajian keratan lintang ini yang telah dijalankan di Unit Pediatrik Hematologi/Onkologi di Pusat Perubatan Universiti Kebangsaan Malaysia (PPUKM) dalam jangkamasa dua tahun. Ibu/bapa kepada pesakit yang berusia 12 tahun ke bawah telah diminta menjawab dua jenis borang soal selidik, iaitu Parenting Stress Index/Short Form (PSI/SF) dan Coping Inventory for Stressful Situation (CISS). Keputusan menunjukkan bahawa purata jumlah skor PSI untuk tahap stres dikalangan ibu/bapa ini ialah  $91.5 \pm 21.1$  (95% CI). Sejumlah 27.3% daripada golongan ibu/bapa mencatat tahap jumlah skor PSI yang tinggi (definisi ialah jumlah skor PSI  $\geq 103$ , iaitu  $\geq$  julat ke-75). Majoriti daripada ibu/bapa menggunakan mekanisme 'task-oriented' untuk menangani stres yang dialami. Berdasarkan analisa multiple logistic regression, mekanisme emotion-oriented merupakan satu-satunya faktor risiko yang signifikan bagi tahap jumlah skor PSI yang tinggi. Seseorang ibu/bapa yang menggunakan mekanisme 'emotion-oriented' adalah 7.1 kali ganda lebih (julat keyakinan 95%: 1.2 hingga 41.4) berkemungkinan untuk mencatat jumlah skor PSI yang tinggi jika dibandingkan dengan mereka yang menggunakan mekanisme yang lain. Dengan mengenalpasti golongan ibubapa yang berisiko tinggi ini, kaunseling dan sokongan psikologi akan dapat diberikan lebih awal supaya tahap stres mereka akan dapat ditangani dengan lebih efektif.

**Kata kunci:** stres ibu bapa, leukemia kanak-kanak

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## ABSTRACT

Parenting stress is the stress level experienced within the role of a parent (Hoekstra-Weebers et al. 1998). The source of stressors is variable and dependent on the phase of disease and chemotherapy (Sawyer et al. 2000). Failure to cope with these stressors may in turn affect the child's emotional and social adjustment towards the diagnosis of cancer in addition to poor medical treatment adherence behaviour (Sawyer et al. 1993). The objectives of this study are to determine the level of parenting stress, the risk factors contributing to high parenting stress, and the coping mechanisms used to handle the stress. This single centred, cross-sectional study was done amongst 117 parents at the Paediatric Haematology and Oncology Unit, Universiti Kebangsaan Malaysia Medical Centre (UKMMC) over two years duration. Self-administered questionnaires comprising the Parenting Stress Index/Short Form (PSI/SF) and Coping Inventory for Stressful Situation (CISS) were distributed to parents of children who were 12 years old and below. The mean total parenting stress score amongst parents of children diagnosed with acute leukaemia was  $91.5 \pm 21.1$  (95% CI). A total of 27.3% of parents experienced a high total parenting stress score (defined as total PSI score  $\geq$  75<sup>th</sup> centile, ie  $\geq$  103). Task-oriented coping mechanism was used by the majority of parents. Emotion-oriented coping mechanism was the only identifiable risk factor for high parenting stress score following multiple logistic regression analysis. A parent who used emotion-oriented coping mechanism was 7.1 times (95% Confidence Interval 1.2 to 41.4) more likely to have a high parenting stress score compared to a parent who used other coping mechanisms. By identifying these at-risk parents, appropriate counselling and psychological support may be offered early to alleviate the stress as well as assist in the coping and adjustment mechanisms of these parents.

Keywords: parenting stress, childhood leukaemia

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## INTRODUCTION

Acute leukaemia is the commonest cancer in children representing a third of all childhood malignancies (Greaves 2002). In Malaysia, the incidence of leukaemia is 9.5 per 100 000 population for males aged between 0 to 14 years, and 6.4 per 100 000 population for females aged between 0 to 14 years (Lim & Halimah 2000; Ministry of Health 2000). Currently, the use of multi-drug regimens and central nervous system (CNS) prophylaxis is

largely responsible for the overall 85% chance of long term survival in this group of children (Pui 2000).

The life-threatening nature of acute leukaemia and its invasive treatment present both physical and emotional stress for parents. Parenting stress is defined as total stress that a parent experiences as a function of certain salient child characteristics, parent characteristics and situations, which are directly related to the role of being a parent (Hoekstra-Weebers et al. 1998). High levels of parenting stress have

been found in many studies during the time of diagnosis and throughout the early stage of treatment, which persist for more than a year (Sawyer et al. 1993; Kazak et al. 1995). However, in a 4-year prospective study of psychological adjustment of parents whose children were diagnosed with cancer, Sawyer et al. (2000) found no significant differences between the psychological problems reported by parents whose children had been diagnosed with cancer and a control group whose children were healthy (Sawyer et al. 2000).

Failure to cope and to deal adaptively with stress may result in mental and physical illness. Coping has been defined as “constantly changing cognitive and behavioural efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Pearlin & Schooler 1978; Lazarus & Folkman 1984). In general, people who rely more on approach-oriented and task-oriented coping mechanisms tend to adapt better to life stressors and experience fewer psychological problems (Folkman & Lazarus 1988). Conversely, avoidance and emotion-oriented coping strategies seem to be associated with psychological distress. These latter two strategies involve emotional responses, and their behaviour and thoughts tend to focus on depressive symptoms (Ray et al. 1982).

Attention to the psychosocial needs of families during cancer treatment, particularly with respect to parental anxiety, may help these families cope with the treatment process and

prevent them from dropping out from cancer treatment for childhood cancer. The purpose of this study was (i) to determine the level of parenting stress amongst parents of children who have been diagnosed with acute leukaemia; (ii) to determine risk factors associated with high parenting stress score and (iii) to determine the coping mechanism used by parents in relation to stress.

## **MATERIALS AND METHODS**

This was a single centre, cross-sectional study conducted in UKM Medical Centre. The study was conducted from August 2007 till July 2009. The patients and their parents were recruited from the paediatric haematology/oncology clinic, ward and day care centre. The sampling method was universal sampling. All children between the age of one month to 12 years old, diagnosed to have acute leukaemia (acute lymphoblastic leukaemia, ALL or acute myeloblastic leukaemia, AML) were included. These patients were either still receiving or had completed chemotherapy. Children with other co-existing chronic illnesses or secondary malignancies and non-Malaysian citizens were excluded from the study. For the purpose of this study, a child who is newly diagnosed is defined as a child on treatment within the first two months following diagnosis. This would include those on induction and consolidation phase of chemotherapy.

Written informed consent was obtained from the parents after explanation regarding the study was carried out. The questionnaires were distributed to the parent or both parents,

depending on their presence during the recruitment process; if both parents were present, the questionnaires were answered independently. The following questionnaires were distributed to each parent individually: Parenting Stress Index/Short Form (PSI/SF) and Coping Inventory for Stressful Situation (CISS). Both questionnaires were available in Bahasa Malaysia or English language and have been validated (Farah Inaz 2004; Salwina 2001). These self-administered questionnaires were collected immediately upon completion. If the parents were not able to complete the questionnaires immediately, pre-stamped envelopes were provided. If the forms were still not received within the next two weeks, a reminder telephone call was made.

The 36-item PSI/SF is a direct derivative of the full-length (120 item) PSI through a series of replicated factor analyses (Abidin 1995). The PSI/SF comprises three subscales: parental distress (PD), parent-children dysfunctional interaction (PCDI) and difficult child (DC). The PD subscale measures the distress directly related to parenting a sick child. The PCDI subscale focuses on the parents' perceptions that his/her child does not meet the parents' expectations and that the interactions with his/her child are not reinforcing to his/her parent.

Whereas the DC subscale represents basic behavioural characteristics of children that parents believe make them either easy or difficult to handle. Each of these subscales contains 12 items; the total score of the PSI/SF is obtained by adding the three subscales together; a 5 point Likert scale is used, ie from

'strongly agree' to 'strongly disagree'. The maximum score for each subscale is 60 and the maximum score for the entire PSI/SF is therefore 180; the higher the score, the higher the parenting stress. The total score for PSI is divided into centile range. In our study, high parenting stress score is defined as a total PSI score of more or equal to the 75<sup>th</sup> centile.

The CISS was designed to measure the mechanism of coping. It has a total of 48 items with statements on a five point Likert scale ranging from 'never' to 'very often'. The items are subdivided into three domains: emotion, avoidance, and task-oriented (Endler & Parker 1990). Task-oriented coping describes purposeful task-oriented efforts aimed at solving the problem and cognitively restructuring the problem; this includes attempts in seeking information and attempts to alter the situation. Emotion-oriented coping describes self-oriented emotional reactions which may actually increase the level of stress; these reactions include becoming emotional or feeling angry and tense in response to the situation. Avoidance-oriented coping describes activities and cognitive changes aimed at avoiding the stressful situation. Examples of this include denial, wishful thinking and withdrawal.

All data were analysed using the SPSS version 16.0. Chi square test was used for comparison of qualitative variables between the high parenting stress group and low parenting stress group. Unpaired t test was used for parametric analysis of risk factors that affect parenting stress. Mann Whitney U and Kruskal Wallis tests were used for non-parametric bivariate analysis

ANOVA was used for parametric bivariate analysis comparing two or more population means such as mean PSI and DC score in the various treatment phase. Post Hoc analysis was used to re-analyse risk factors that were found to be significant based on ANOVA. Logistic regression analysis was used to identify factors which affected parenting stress the most.

## RESULTS

There were 106 children with acute leukaemia who were on follow up at the Paediatric Haematology and Oncology Unit of UKMMC during the study duration. Eighty nine patients fulfilled the inclusion criteria. Seventeen patients did not meet the inclusion criteria and were excluded from the study: of these, 13 were beyond 12 years of age; two had parents who were not able to read nor write in both languages; one had secondary leukaemia and another was a non-citizen. From the 89 patients who fulfilled the inclusion criteria, 16 were missed during the recruitment process due to either infrequent clinic appointment or defaulted follow up. From the remaining 73 children who were eligible for the study, only 66 families responded to the questionnaires which comprised 56 fathers and 61 mothers.

The mean age of patients was  $7.9 \pm 2.8$ , years and slightly more males (56.1%). The majority were of Malay ethnicity (75.8%). Thirty patients (45.4%) were on maintenance chemotherapy and 26 patients (39.4%) had completed treatment. Eight patients (12.1%) were newly diagnosed and two

were on palliative treatment as they were not in remission despite receiving treatment. Table 1 summarises the socio-demographic characteristics of the parents. The majority (75.2%) had three or more children. Most of the parents (66.6%) received education till secondary school level. A total of 73 parents (62.4%) made mutual decision in relation to their child's treatment. The mean total parenting stress index (PSI) score was  $91.5 \pm 21.1$  (Table 2). The mean score for coping mechanism was highest for the task-oriented coping mechanism i.e. 59. Statistical analysis showed that there was no significant difference between the mean maternal and paternal PSI [i.e.  $91.3 (\pm 22.7)$  and  $91.6 (\pm 19.4)$  respectively], and CISS scores. Table 3 illustrates that there was no significant difference in the mean score for each of the PSI/SF subscales based on the various phase of treatment for acute leukaemia. Two parents whose children were on palliative care were omitted from this analysis.

Risk factors for high parenting stress scores were categorised into parental or patient-related factors. Parental risk factors associated with high parenting stress scores ( $\geq 75^{\text{th}}$  centile which correspond to a total score of 103) are shown in Table 4. Emotion-oriented coping mechanism was significantly associated with a high parenting stress score (p value 0.009); none of the other factors were statistically significant. There was no significant difference in total parenting stress score between parents who made mutual decisions as compared to those who did not (p value 0.9).

As for patient-related risk factors, none were statistically significant; these

included age, gender, race, religion and treatment phase. Multiple logistic regression analysis was performed to predict the probability of having a high total PSI score ( $\geq 75^{\text{th}}$  centile). Emotion-oriented coping mechanism was found to be significant with a

p value of 0.03. A parent who uses emotion-oriented coping mechanism was 7.1 (95% Confidence Interval 1.2 to 41.4) times more likely to have a high total PSI score as compared to a parent who uses other types of coping mechanisms.

Table 1: Socio-demographic characteristics of 117 parents of children with acute leukaemia

Characteristics	n	% (unless stated otherwise)
<b>Age (years: mean <math>\pm</math> SD)</b>		38.81 (6.15)
<b>Relation</b>		
Father	56	47.9
Mother	61	52.1
<b>Race</b>		
Malay	89	76.1
Chinese	14	12
Indian	10	8.5
Others	4	3.4
<b>Religion</b>		
Islam	92	78.6
Buddha	14	12
Hindu	8	6.8
Christian	3	2.6
<b>Number of children</b>		
1	9	7.7
2	20	17.1
3	88	75.2
<b>Monthly family income (RM)</b>		
Mean (IQR)		2096 (IQR : 1000-3912)
<b>Education level</b>		
Primary	11	9.9
Secondary	74	66.6
Tertiary	26	23.4
<b>Decision maker</b>		
Husband	12	10.3
Wife	31	26.5
Mutual	73	62.4
Others	1	0.9

IQR : Inter Quartile Range

Table 2: Mean PSI and CISS scores among 117 parents of children with acute leukaemia

Subscale	Mean Parental Scores (Mean $\pm$ SD)
<b>Total Parenting Stress Index (PSI)</b>	91.5 (21.1)
Parental Distress	31.4 (21.1)
Parent-Child Dysfunctional Interaction (PCDI)	28.3 (8.1)
Difficult Child (DC)	31.6 (8.4)
<b>CISS</b>	
Task-oriented	59 (11.5)
Emotion-oriented	38.3 (12.3)
Avoidance-oriented	39.4 (10.2)

PSI : Parenting Stress Index  
CISS : Coping Inventory for Stressful Situations

Table 3: Mean parenting stress scores for PSI/SF in various phase of treatment for acute leukaemia

Subscale	Newly diagnosed (n = 15)	Remission on maintenance (n = 55)	Completed treatment (n = 45)	p value
PSI	93.1(17.1)	93.3 (21.8)	89.8 (21.2)	0.69*
PD	67.3	58.4	54.3	0.42†
PCDI	53.7	60.1	56.7	0.76†
DC	33.2 (6.6)	32.3 (8.3)	30.9	0.57*

PSI : Total Parenting Stress Index, SF: Short Form, PD : Parental Distress, PCDI : Parent-Child Dysfunctional Interaction , DC : Difficult Child (DC)

†Kruskal Wallis test: Mean rank

\*ANOVA test: Mean  $\pm$ SD

## DISCUSSION

The diagnosis and subsequent treatment of childhood leukaemia is undeniably stressful for any family. A parent's ability to manage his or her distress during treatment of the child is vital as there may be potential impact on the well-being and long-term psychological adjustment of both parents and child.

The mean total PSI score in our study was 91.50 ( $\pm$ 21.12) which was lower when compared to the mean total PSI score amongst Malaysian mothers of children with epilepsy [97.8 ( $\pm$ 20.99)] (Farah Inaz 2004) and spina bifida

[92.4 ( $\pm$ 11.43)] (Norshireen Nazli 2005). In these two local studies, the control groups had a mean total PSI score of 85.07 ( $\pm$ 18.77) and 78.2 ( $\pm$ 21.14) respectively. Epilepsy and spina bifida are diseases in which treatment is largely symptomatic and non-curative. Spina bifida is also usually associated with physical disabilities in comparison to leukaemia; this may have contributed to a higher score within the PD and DC subscales of the PSI/SF.

In a study by Yeh amongst Taiwanese parents of children with cancer, the mean maternal and paternal scores

Table 4: Parental risk factors associated with high total parenting stress score

Risk factors	Total PSI score 75th centile n = 32 (% unless stated otherwise)	Total PSI score <75th centile n = 85 (% unless stated otherwise)	p value
Age (years: mean±SD)	39.8 (6.5)	38.4 (5.9)	0.25*
<b>Relation</b>			
Father	17 (30.4)	39 (69.6)	0.48 <sup>∞</sup>
Mother	15 (24.6)	46 (75.4)	
<b>Marital status</b>			
Married	31 (27)	84 (73)	1.00
Divorced	1 (50)	1 (50)	
<b>Race</b>			
Malay	24 (27)	65 (73)	0.72
Chinese	3 (21.4)	11 (78.6)	
Indian	3 (30)	7 (70)	
Others	2 (50)	2 (50)	
<b>Religion</b>			
Islam	27 (29.3)	65 (70.7)	0.20
Buddha	2 (14.3)	2 (85.7)	
Hindu	1 (12.5)	7 (87.5)	
Christian	2 (66.7)	1 (33.3)	
<b>Number of children</b>			
1	2 (22.2)	7 (77.8)	0.89
2	5 (25)	15 (75)	
3	20 (28.4)	63 (71.6)	
<b>Monthly family income (RM)</b>			
Mean (IQR)	3752.18 (IQR :2503-3911)	2509.83 (IQR:1802-3201)	0.08†
<b>Education level</b>			
Primary	4	8	0.89 <sup>∞</sup>
Secondary	24	52	
Tertiary	4	25	
<b>Type of coping mechanism</b>			
Task-oriented	55.4	60.35	0.48†
Emotion-oriented	72.4	53.94	0.009†
Avoidance- oriented	36.65 (7.4)	40.51 (10.92)	0.10*

PSI : Parenting Stress Index

IQR : Inter Quartile Range

\*t test : mean SD; Chi square test ; †Mann Whitney U test : Mean rank



were 124.1 ( $\pm 19.47$ ) and 125.86 ( $\pm 18.64$ ) respectively; there was no statistical difference based on parental gender (Yeh 2002). Although our study also revealed no significant difference between the gender of parents, the mean total PSI scores for their parental groups were much higher when compared to our results. Cross-cultural differences may have contributed to the higher parenting score in the Taiwanese population. The non-significant difference between maternal and paternal parenting scores probably infers that the overall responsibility and care of the child were shared equally by both parents. This is also reflected by the fact that decisions were mutually made by the majority of parents (62.4%) in our study. However, the non-significant difference between maternal and paternal parenting stress scores could also be explained by the possibility of both parents discussing the questions (of the research tools) and sharing their responses.

Only 27.3% of the parents from our study had a high total parenting stress score. Published studies have reported a variable prevalence of sub-clinical parenting stress related symptoms amongst parents caring for children with leukaemia which ranged from 20% to 95% (Kazak et al. 2001; Kazak et al. 2004; Manne et al. 1998). This was however based on other forms of assessment tools in determining parenting stress level. High level of parenting stress has been found in many studies both at the time of diagnosis and early stage of treatment which may persist for more than a year (Hoekstra-Weebers et al. 2001). Our study has

shown that there was no difference in the total PSI score throughout the various phase of treatment for leukaemia.

Several studies have reported a higher parenting stress level amongst parents with lower income group and lower educational level (Young et al. 2002). Our study however showed no significant difference in both these factors. The cost of chemotherapeutic treatment in our patients is significantly supported by our hospital in addition to financial support by various non-governmental organisations. The majority (66.6%) of parents in our study have an educational level of secondary school; this may have also contributed to better parental understanding, perception and acceptance of the child's disease and treatment.

The style or mechanism of coping plays an important role in individual well-being. In our study, task-oriented coping mechanism was used by the majority of parents. As mentioned before, task-oriented coping is a strategy involving problem solving and seeking information in order to alter the situation. This could probably explain why only 27.3% of parents in our study had a high total PSI score ( $\geq 75^{\text{th}}$  centile). Conversely, avoidance and emotion-oriented coping strategies seem to be associated with psychological distress. Interestingly, emotion-oriented coping mechanism was the only identifiable risk factor for high total PSI score following multiple logistic regression analysis in our study. Emotion-oriented coping mechanism is said to be bi-directional. In the short term, emotion-oriented coping may be beneficial as it allows

the parent to ventilate and express their emotions more freely. In the long run however, it can be maladaptive as it may result in more stress. Thus, parents who use emotion-oriented coping strategy should be identified early so that psychosocial support may be given to alleviate the stress.

There were several limitations to our study. As this was a cross-sectional study, the collection of data was only done at a particular point in time. As a result, evaluation of parenting experiences over the entire course of illness or treatment was not possible. A longitudinal study with repeated assessment of parenting stress and coping mechanisms at various point in time would have been a better option. The use of disease-specific measures of parenting stress, such as Pediatric Inventory for Parents and the Psychosocial Assessment Tool may have been beneficial and thus provided more accurate levels of parenting stress within the context of childhood illness than the more general measures of parenting stress (Streisand et al. 2001; Kazak et al. 2003). In addition to this, life stressors were also not assessed concurrently. Parental personality traits prior to the onset of the child's illness is another important aspect in the assessment of coping strategy and it is preferable to evaluate these traits when dealing with coping measures for future studies. Therefore, a prospective study, incorporating additional assessment tools such as life stressor and child behavioural checklist, is recommended for better understanding of parental stress over the entire course of treatment.

## CONCLUSION

The mean total parenting stress score amongst parents of children diagnosed with acute leukaemia was  $91.5 \pm 21.1$  which was lower than that reported by other studies involving cancer patients. Only 27.3% of these parents experienced a high total parenting stress score. Emotion-oriented coping mechanism was the only risk factor that was associated with a high PSI score; as such the CISS may be used as a screening tool to identify these at-risk parents so that psychosocial intervention may be offered.

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