

Stress Among Parents With Acutely Ill Children

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Summary

Objectives: A child's admission into intensive care is a major cause of stress for parents. However among Malaysian parents, data concerning the perception of stress are virtually absent. Therefore we conducted a study to measure the reliability of the Malay version of Parental Stressor Scale: Pediatric Intensive Care Unit (PSS: PICU) in identifying sources of stress and to study factors that might influence their stress response.

Methods: Over a six-month period, one hundred and twelve parents were requested to answer the questionnaires twice either in Malay or English, a week apart. Spearman's correlation and Cronbach's alpha coefficient was used to assess the repeatability and internal consistency of the questionnaires.

Results: Ninety-four (83.9%) and seventy-one (75.3%) parents responded to the first and second administration of questionnaire respectively. All answered in the Malay language except for three. The correlation ranged from 0.50 to 0.71 with a total score of 0.76. The Cronbach's alpha coefficient ranged from 0.75 to 0.93, with total a score of 0.95.

Alteration in parental roles was the most stressful source of stress. Fathers, parents of children with higher PRISM score and parents with no previous admission into intensive care unit scored significantly higher in staff's communication.

Conclusion: The Malay version of PSS: PICU is reliable in identifying sources of stress. Alteration in parental roles was the most stressful source of stress. Parents' gender, previous experience and severity of the child illness may influence their stress responses.

Key Words: Paediatric Intensive Care Unit (PICU), Paediatric High Dependency Unit (PHDU), Parental Stressor Scale: Paediatric Intensive Care Unit (PSS: PICU), Paediatric Risk Mortality Scale (PRISM)

Introduction

A child's admission into the intensive care unit could result in a significant threat to the stability of the family. In this strange environment, the family might experience fear, anger, mistrust, helplessness or hopelessness. Then in combination with the lack of knowledge about their child's future, they might exhibit the worst kinds of behaviour¹. Carter and Miles divided stresses experienced by parents into personal, situational and environmental².

A study in the paediatric intensive care unit at Yale-New Haven Hospital showed that parents went into various stages of stress responses³. Initially they experienced shock or denial followed by anticipatory waiting and subsequently mourning or elation depending on their children's condition. Huckabay and Tilem-Kessler showed that parent's anxiety levels were higher than expected, reaching near panic on the first day of admission⁴.

Among Malaysian parents, data concerning the perception of stress is virtually absent. All the available information was based from the western study. In view of this, we conducted a study to measure the reliability of the Malay version of PSS: PICU in identifying sources of stress and to study factors that might influence their stress responses.

Materials and Methods

This is a cross-sectional study conducted in the Paediatric Intensive Care Unit (PICU) and Paediatric High Dependency Unit (PHDU) of Institut Pediatrik, Hospital Kuala Lumpur over a period of five months from December 1999 to April 2000. The study population was parents or primary caregivers whose children were admitted to PICU and PHDU.

The inclusion criteria were i) parents whose children had been admitted to PICU or PHDU for at least 48 hours as emergency cases either with

medical or surgical conditions, ii) they had visited their children at least twice and were able to respond to the questionnaire either in the Malay or English version. The exclusion criteria were i) parents whose children were admitted to PICU or PHDU as a pre-planned admission, ii) their children died or were discharged within 48 hours of admission and iii) parents of non-Malaysian citizens.

The Questionnaire

The Parental Stressor Scale: Pediatric Intensive Care Unit (PSS: PICU), was designed to study the source of stress for parents when their children were admitted to the paediatric intensive care unit. It was developed by Miles and Carter in 1983. It was based on their research, Selye's theory on stress, Lazarus's cognitive-phenomenological theory on stress, Roy's adaptation model of nursing, and Moos's theory on coping with illness⁵. The PSS: PICU is made up of seven dimensions (Table 1). Each dimension contains multiple items. Each item is scored on a five-point Likert-type scale, with "5" indicating the event as 'extremely stressful' and "1" as 'not stressful'. Internal consistency of the subscales ranged from 0.72 to 0.99; with the total instrument's alpha coefficient was 0.95. Validity coefficient for all dimensions were significant at $p < 0.01$. The PSS: PICU has been translated into Spanish and was shown to be reliable in assessing Hispanic parents' perception of stress in PICU⁶.

With written permission from the author, the original version of PSS: PICU was translated into a Malay version (Appendix 1). In order to retain the meaning of the original version as well as maintaining correct grammar in simple language, the English version of PSS: PICU was translated into the Malay version with the assistance of the Linguistic Department of University Malaya.

Eligible parents were invited to participate in the study after forty-eight hours of admission. It was anticipated that parents would have been more settled into PICU or PHDU environment after

Table I
Sources of Parental Stress as Measured by the PSS: PICU

Subscales	Examples
Painful procedures conducted on the child	Cannulations, suctioning, physiotherapy
Sights and sounds of intensive care	Alarms, equipment, other sick children
Child's behavioural and emotional responses	Crying, demanding, frightening, restless, rebellious
Child's appearance	Puffiness or change in colour
Alteration in parenting role	Not being able to see, visit, hold, help or care child
Staff's communication	Use of jargon, giving inconsistent or insufficient information to parents
Staff's behaviour	Laughing, joking, talking too much or not enough

forty-eight hours. They were given explanations regarding the aims of the study, and confidentiality was strictly observed. They were requested to answer the questionnaires in the presence of the investigator in their preferred language twice, a week apart. When both parents were available they were requested to answer the questionnaires separately without any discussion. It took approximately 20 to 30 minutes to complete the questionnaire.

Parents were also requested to respond to two open-ended questions (a) their most liked and (b) their most disliked aspects of PICU or PHDU.

Data Analysis

Mean and standard deviations were calculated for each subscale of the PSS: PICU. The mean subscale or total score for each subject was computed by dividing the sum of the subscale or total scores by the number of items rated "1" or above. The group means were then calculated from the individual mean scores⁵.

An independent t-test was used to compare the mean score of the seven subscales and the total scores between various variables. The differences in characteristics of children and parents in PICU and PHDU were analysed by either Pearson's chi-square test or independent t-test.

Non-parametric Spearman's correlation was used to measure the repeatability of the Malay version of PSS: PICU over time. Cronbach's alpha coefficients, which measure the internal consistency, were calculated from parents who had completed the first administration of the Malay version PSS: PICU.

Spearman's correlation coefficients were used to determine the correlation between various variables and parent's score. Subsequently linear logistic regression was used to determine the predictive factor for parental score on each subscale of PSS: PICU. The confidence interval with p value < 0.05 was considered significant.

Results

Ninety-four (83.9%) and seventy-one (75.3%) parents responded to the first and second administration of the questionnaires respectively. All answered in Malay except for three. The mean age of parents were 31.7 (SD=6.0) years. Fifty-six (59.6%) responders were mothers. The majority of the parents were Malays (53) followed by Chinese (6), Indians (3) and others (4). Eleven parents did not complete the study due to excessive stress (6), and death of the children (8) or non response for no obvious reason (8). There was no difference between the characteristics of

Table II
Characteristics of the children admitted to the Paediatric Intensive Care Unit (PICU) and Paediatric High Dependency Unit (PHDU)

Variables (n=43)	PICU (n=19)	PHDU	p
Mean Age (months)	20.0 ± 31.5	36.3 ± 78.3	0.25
Duration of hospitalisation (days ± SD)	29.95 ± 29.59	13.61 ± 10.10	0.02
Duration in the unit (days ± SD)	10.35 ± 6.85	5.17 ± 2.62	0.01
Duration of ventilation(days ± SD)	10.58 ± 10.1	0	0.01
Mean PRISM score	11.8 ± 8.1	-	
Therapeutic Intervention score	23.6 ± 8.7	-	
No. Ventilation	43	0	0.01
Previous ventilation	19	4	0.24
Outcome - Alive	28	19	0.01
Died	15	0	

Table III
Group Means for the Seven Subscales and Total PSS: PICU (n=93)

Subscales	n ^a	Mean	Range	SD
Parental roles	90	3.34	1.00 - 5.00	1.12
Child's behaviour and emotional response	92	3.08	1.00 - 4.90	0.96
Sight and Sound	90	3.04	1.00 - 5.00	1.15
Child's Appearance	90	2.97	1.00 - 5.00	1.08
Procedure	93	2.81	1.00 - 4.83	0.93
Staff's Communication	81	2.76	1.00 - 4.90	1.24
Staff's Behaviour	86	2.04	1.00 - 5.00	1.04
Total Score	93	2.84	1.00 - 4.67	0.79

^aDiffering ns reflect the number of items rated "0" (not experienced)

parents of children admitted to PICU or PHDU. There were sixty-two children involved in the study with a median age of 4.9 [Q1 3, Q3 30] months. The characteristics of the children admitted to these units were summarized in Table II. Diseases of the respiratory and the nervous system were the main reasons for admission i.e. 35.3% and 25.8% respectively.

The Cronbach's alpha coefficients ranged from 0.75 to 0.93, with a total of 0.95 and Spearman's correlation coefficient ranged from 0.50 to 0.71 with a total score of 0.76. The means, ranges, and standard deviations of the subscales and total score of the Malay version of PSS: PICU are shown in descending orders in Table III. Alteration in parental roles were the most stressful source of stress with a mean of 3.34 (SD=1.12).

There was no significance difference of the means score between parents of these two units. However fathers scored significantly higher in staff's communication than mothers (3.15 vs. 2.50, $p=0.017$, 95% CI [1.17,0.11]). Parents whose children were not ventilated prior to the study scored significantly higher in staff's communication subscales than parents whose children had been ventilated prior to the study (2.94 vs. 2.36, $p=0.05$, 95% CI [0.0001,1.1]).

There was a significant association between PRISM score and child's appearance subscales ($r=0.26$, $p=0.03$), PRISM score and staff's communication subscales ($r=0.25$, $p=0.04$), PRISM score and total score of PSS: PICU ($r=0.26$, $p=0.03$), duration of hospitalisation and staff's communication subscales ($r=0.21$, $p=0.04$), duration of hospitalisation and staff's behaviour ($r=0.28$, $p<0.01$) and parental income and procedure subscales (0.28, $p=0.02$).

Using linear logistic regression, the PRISM score was the only predictive factors for parents score on child's appearance, staff's communication and total score of PSS: PICU with $p<0.05$. There were one hundred and twelve comments on the positive aspects of intensive care from parents. Forty-seven (38.5%) were on the medical and nursing care, forty-one (33.5%) were on staff's behaviour and twenty one (17.2%) on intensive care environment. They liked the good services, and found staff to be fast, efficient, caring, disciplined and responsible. However there were fifty-eight comments on the negative aspects of intensive care unit. Sixteen (27.6%) parents were not happy with the staff behaviour such as joking, ten (17.2%) were not satisfied with the nursing care, and eight parents (13.8%) felt that the staff did not communicate adequately with them.

Discussions

Our first objective was to analyse the reliability and repeatability of the Malay version of PSS: PICU. Using test-retest technique the correlation coefficient for the Malay version of PSS: PICU was

moderate i.e. between 0.4 to 0.7 and was good for the overall questionnaire i.e. more than 0.7. This is in contrast with the English version of PSS: PICU of which good correlation in all subscales except for sight and sound subscales were obtained. However they only tested seventeen parents twenty-four hour apart⁷. This might explain the differences. Apart from that the test - retest technique has a few disadvantages. Bias might be introduced in the second set of answers or respondents might be unwilling or unable to answer the questionnaires for the second time. This was shown in our study, as 25% did not answer the second time.

Cronbach' alpha was used to measure the internal consistency of the Malay version of PSS: PICU. An alpha coefficient of more than 0.7 is considered good. Responses to a reliable questionnaire would differ because respondents had different opinions and not to confusing questionnaires. Our study showed that the alpha coefficient for all subscales and total score were more than 0.7. This finding correlated with the English version of PSS: PICU. Therefore, this result supports the reliability of the Malay version of PSS: PICU in identifying sources of stress among Malaysian parents.

The second objective of our study was to identify sources of stress for Malaysian parents when their children were admitted either to PICU or PHDU as well as to identify factors that might affect their reaction. This study showed that alteration of parental roles, child's behavior and emotional response were the most stressful sources of stress. Inability to take care of their children, not being able to see or visit their children whenever they like, not being able to be with their crying child, and not being able to hold their children were the main causes of stress for parents. These were important roles for parents. These finding are consistent with other studies conducted in the western country^{8,9,10,11,12,13} and with studies conducted in NICU¹⁴. This responsibility was universal for all parents across all boundaries of race and religion.

Even though there were significant differences in child's characteristics between PICU and PHDU, our results showed that there was no significant difference in the mean score of both parents. Whether their child was ventilated or not, they felt that alteration in parental roles as a major source of stress. However this finding contradicted with the study by Haines which showed that painful procedures were the greatest source of stress among parents whose children were ventilated¹¹. Her study also showed that parents of non-intubated children felt more stress on staff behavior. These differences might be due to the small number in her study (i.e. only thirteen parents in the non-intubated group).

Many researchers have studied perception of stress between mothers and fathers. Some studies showed no difference between the two groups and some showed that fathers felt more stress¹⁵. There was no significant difference in our study except on staff's communication subscales. Fathers felt more stressful on staff's communication than mothers. Detailed review of communication subscales showed that fathers felt that not being informed of the diagnosis and progress of their children was the most stressful source of stress. Observations in the hospital showed that mothers had major roles in the care of the children. They stayed with their children during the illness and spent more time in the hospital. During this long stay in the unit they had greater opportunity to ask or discuss with the staff. As the mother was always available, most of the information was given to them. This might explain why fathers felt the communication subscale more stressful than mothers.

Parents without any previous experience felt more stress on staff's communication than parents who had previous admission to intensive care unit. This is explained easily as parents with previous admission to intensive care unit were

used to the environment and had been well informed regarding the child's condition on the intensive care unit. Apart from that, it could mean that we did not explain enough to them. Another explanation is that during the first three days of admission, parents experienced high levels of stress and were in a denial stage. At this time their concern was more on their child's illness. Therefore the explanation given during the first three days of admission should be repeated many times.

Parents were affected by their child's appearance and staff's communication as their child become more ill. Patients might look puffy, pale or cyanosed when they become more ill. These were the main items of the child's appearance subscales. This might explain why parents scored higher in these subscales.

Using linear logistic regression, PRISM scores on the day of admission is the only factor for predicting parent's score on staff's communication, child's appearance and overall score of PSS: PICU. In other words, the higher the PRISM score on the day of admission, the higher they were the scores on staff's communication, child's appearance and overall score of PSS: PICU.

Conclusions

The Malay version of PSS: PICU is reliable in identifying sources of stress for Malaysian parents when their children are admitted to the intensive care unit. Alteration in parental roles, child's behavior and emotional response were the most stressful sources of stress for them. Fathers, previous experiences, type and severity of disease are important predictors of reactions. The PRISM score is useful for predicting parent's score on staff's communication, child's appearance and overall score of PSS: PICU.

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