

# Coping Styles of Mothers with Disabled Children at Rural Community Rehabilitation Centres in Muar, Malaysia

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## Summary

Chronic disability in children imposes great strains on a family. The responsibility of mothering disabled children may be detrimental to the well-being of mothers. This study aims to assess the different types of coping styles of mothers with disabled children and its influencing factors. It is a cross-sectional study using Coping Inventory Stressful Situation (CISS) scale to determine the mothers' coping styles. A sample of 81 mothers with disabled children attending two rural Community Rehabilitation Centres, were included in the study. Overall, the mothers were using a mixture of coping strategies. However, they scored more in the task-oriented (mean T score =52.88) and emotion-oriented (mean T score = 50.52) coping styles, while the other subscales of coping styles, namely avoidance, distraction and social diversion were below average (mean T score < 50). Divorced mothers ( $p=0.04$ ) and those with low educational level ( $p=0.00$ ) were more inclined to use emotion-oriented coping strategies while mothers with younger children (< 5 years old) used more avoidance coping strategies ( $p=0.01$ ). There were no significant difference of coping styles in association with the mothers' age, ethnicity, duration of marriage, number of siblings, child's birth order or gender. By understanding the mothers' coping styles, health care workers would be able to educate the mothers with effective coping strategies and consequently reduce their psychological distress.

**Key Words:** Community rehabilitation centres, Coping styles, CISS scale, Disabled children, Mother, Rural

## Introduction

Children with chronic disability impose great strains on a family. Although a disabled child has the same basic needs as a normal child, it is often quite difficult for parents to meet them. This is because daily care of disabled children often depletes parents' energy and time, causing withdrawal from social and cultural activities. There is evidence of increased marital tension and parent-child conflict among families caring

for disabled children<sup>1,2</sup>. However, there is also evidence that some families cope very well and remain cohesive<sup>2</sup>. Mothers, traditionally, are the primary caretakers of children. The responsibility for mothering a disabled child will confine them to domestic role and deprive them from employment gratification. Some studies have indicated the responsibility may be detrimental to the health as well as happiness of the mothers and the mother's mental health was described as being in constant jeopardy<sup>1</sup>.

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Coping is defined as the effort we make to manage situations we have appraised as being potentially harmful or stressful<sup>3</sup>. There are several coping styles which are commonly used, namely; task or problem-focused, emotion-focused, avoiding, distraction and social diversion<sup>4</sup>. Some people may have particular preferred coping styles or patterns in their responses to different stressful situations. However, the more effective coping styles are characterized by thoughtfulness, problem-solving and self-confidence<sup>5</sup>.

In this study, the coping strategies of mothers with disabled children are assessed as it is believed that effective coping positively influences morale, social function and health while ineffective coping has equally powerful negative effects. By understanding the mothers' coping styles, it would help the health professionals, especially the family practitioners and the community health workers, to approach the mothers more effectively and guide the mothers on how to develop effective coping skills in managing their children at home.

The objectives of this study were:

1. To assess the coping styles of mothers with disabled children.
2. To determine the association between the coping styles and the mothers' demographic characteristics.
3. To determine the association between the mothers' coping styles and the birth order of the child, age of the child and the number of children in the family.
4. To find out the proportion of mothers who have resources for reference or group discussion for their children's problems.

## Materials and Methods

This was a cross-sectional study carried out between July to October, 2001. All mothers whose children were attending the Community Rehabilitation Centres in the district of Muar, Johor (a state in Malaysia) were included in the study. There were two rural Community Rehabilitation Centres, namely Serom 3 Community Rehabilitation Centre and Tangkak Community Rehabilitation Centre. These centres are under the administration of the Social Welfare Department. There were 83 children registered at these two centres. Mothers who refuse to participate in the study and those who were illiterate were excluded from the study.

A set of guided questionnaire was used to obtain the mothers' socio-demographic data and information regarding the affected child. 'Coping Inventory for Stressful Situation (CISS)' was used to assess the mothers' coping style. CISS was designed for measuring multidimensional coping styles. It consists of 48 self-rated questions on various aspects of coping that had been typically used in coping with stressful situation. Responses are via a 5-point Likert scale. Five sub-tests that describe the types of coping strategy would be derived upon scoring. The coping strategies are task-oriented, emotion-oriented, avoidance, distraction and social diversion. T-scores are standardized scores which permit the interpreter to directly compare the score on one scale to another scale. It has a useful feature as the T-score for each scale has the same mean and standard deviation. The T-scores have a mean score of 50 and a standard deviation of 10. The scale has a favourable internal reliability of 0.72 - 0.92 and has a test-retest reliability of between 0.60 - 0.72 over a period of six weeks<sup>6</sup>.

Analysis was done using the Statistical Package for Social Sciences (SPSS) and statistical significance was determined by analysis of variance (ANOVA) test. Statistical significance was accepted at a confidence interval of 95% and a p value of < 0.05.

## Results

A total of 81 mothers of disabled children participated in this study. Thirty-three (40.7%) were from Serom 3 Community Rehabilitation Centre and 48 (59.3%) were from Tangkak Community Rehabilitation Centre. The mean age of the mothers was 41 years old and the age range was between 25 to 63 years old. Majority of the mothers were Malays (63%), followed by Chinese (33.3%) and Indians (3.7%). More than half of the mothers (56.8%) were housewives. All except one had some formal education either primary school (44.4%), secondary school (49.4%) or tertiary education. Majority of the mothers had been married for more than 10 years (85.9%). Only 3 mothers (3.7%) were divorced while the rest (96.3%) were still married. The mothers, mostly, had five or less number of children (76.5%) (Table I).

The mean age of the disabled children was 10.5 years and the age ranged between one to eighteen years old. Fifty-three percent (53.1%) were boys and 46.9% were girls. Only 35.8% of them were the eldest children in the family. The rest were the younger siblings of the

family. The mean duration of diagnosis was 9.7 years (range: 1 year – 18 years).

Overall, the mothers were using a mixture of coping strategies. However, the mothers were more inclined to use task-oriented (Mean T score = 52.8) and emotion-oriented (Mean T score= 50.52) while the other coping strategies were scored below average (Mean T score < 50) (Table II). Task-oriented coping are described as efforts aimed at solving the problem, cognitively restructuring the problem or attempts to alter the situation<sup>45</sup>. Emotion-oriented coping describes emotional reactions that are self-oriented. Reactions include emotional responses such as blaming oneself for being too emotional, gets angry, becomes tense or self-preoccupation. In some situations, the reaction actually increases stress<sup>45</sup>. Avoidance coping describes activities and cognitive changes aimed at avoiding the stressful situation. These include

distracting oneself with other situations or tasks, or via social diversion as means of alleviating stress<sup>5</sup>.

It was shown that mothers with lower educational level scored significantly higher in the emotion domain of the CISS scales (Table III). Similar finding was also shown among mothers who were divorced (Table IV). Mothers with disabled children aged 5 years or below scored significantly higher in the avoidance domain of CISS scales (Table V). There were no significant differences of coping strategies in association with age of mother, occupational status, duration of marriage, birth order of the affected child, number of children in the family or gender of the disabled child.

None of the mothers in the study had ever joined any discussion group, support group or sought other resources to obtain information regarding their disabled children's problems.

**Table I: Socio demographic Characteristics of the Mothers of Disabled Children ( N = 81 )**

Characteristics		n	%
Ethnic	Malay	51	63.0
	Chinese	27	33.3
	Indian	3	3.7
Age	< 30 years	8	9.9
	30-39 years	32	39.5
	40-49 years	29	35.8
	> 50 years	12	14.8
Education	No formal education	1	1.2
	Primary	36	44.4
	Secondary	40	49.4
	Tertiary	4	4.9
Occupation	Housewives	46	56.8
	Working : Professional	2	2.5
	Intermediate	12	14.8
	Manual	21	25.9
Marital status	Married	78	96.3
	Divorced	3	3.7
Duration of Marriage	<5 years	3	3.8
	5 – 10 years	8	10.3
	>10 years	67	85.9
Number of Children	<5	62	76.5
	>5	19	23.5

**Table II : Mean T-score for each subscale of CISS ( coping styles)**

CISS scale	n	Mean T-score + SD
Task	81	52.88 ± 8.42
Emotion	81	50.52 ± 8.57
Avoidance	81	44.06 ± 7.55
Distraction	81	42.86 ± 7.18
Social Diversion	81	41.07 ± 10.66

**Table III : Association between the mothers' coping styles and their educational level**

CISS scale	Lower education (Mean T-score ± SD)	Higher education (Mean T-score ± SD)	p value
Task	48.57 ± 7.64	52.16 ± 9.04	0.06
<b>Emotion</b>	<b>54.97 ± 7.19</b>	<b>51.11 ± 9.04</b>	<b>0.04</b>
Avoidance	44.43 ± 7.99	43.75 ± 7.24	0.69
Distraction	42.89 ± 7.23	42.84 ± 7.22	0.98
Social Diversion	40.35 ± 11.84	41.68 ± 9.64	0.58

Lower education indicates primary education level.

Higher education indicates secondary and tertiary education level.

**Table IV : Association between the mothers' coping styles and marital status.**

CISS scale	Divorced (Mean T-score ± SD)	Married (Mean T-score ± SD)	p value
Task	50.67 ± 2.89	50.51 ± 8.72	0.98
<b>Emotion</b>	<b>67.00 ± 3.60</b>	<b>52.35 ± 6.13</b>	<b>0.00</b>
Avoidance	52.00 ± 7.00	43.76 ± 7.45	0.06
Distraction	50.00 ± 3.61	42.59 ± 7.16	0.07
Social Diversion	44.33 ± 26.65	40.95 ± 9.95	0.8

**Table V : Association between the mothers' coping styles and age of affected child.**

CISS scale	< 5 years old (Mean T-score ± SD)	> 5 years old (Mean T-score ± SD)	p value
Task	49.33 ± 12.19	50.61 ± 8.32	0.73
Emotion	55.83 ± 6.79	52.64 ± 8.53	0.38
Avoidance	51.50 ± 8.22	43.67 ± 7.23	0.01
Distraction	47.50 ± 8.07	42.49 ± 7.04	0.10
Social Diversion	48.33 ± 10.61	40.49 ± 10.51	0.08

## Discussion

This study had included a wide age range of disabled children, from infants to adolescence, and children with various disabilities. As there is evidence indicating that the type of parenting stress faced by the family changes as the child progresses from infancy to young adulthood, the type of coping strategies might also differ among mothers of younger children with disabilities compare to mothers with adolescents with disabilities<sup>6,7</sup>.

Overall, the mothers in this study were using a mixture of coping strategies. However, they scored more in the task-oriented (Mean T score =52.88) and emotion-oriented (Mean T score = 50.52) coping styles, while the other subscales of coping styles, namely avoidance, distraction and social diversion were slightly below average (Mean T score<50). Each mother is characterized by a different set of strengths and vulnerabilities that can account for important differences in the way she copes when her child has an ongoing disability<sup>3</sup>. Life events are not equally stressful to all people, and it appears that some combination of the environmental stresses or demands that people face and the resources they have available together affect their way of coping<sup>3</sup>. The mothers most probably used different coping styles for different situations, thus, the mixture of coping styles and their coping strategies might change as their children grow older.

Since the mothers scored highest in the task-orientated coping style, it indicates that the mothers in this study group seemed to be quite resigned to the fact that their children are having disabilities. Mothers are confronted more regularly with emotionally distressing situations as they are more involved directly in childcare. Such constant involvement with the child is likely to concomitantly offer time for rumination. Thus, there is tendency of a gradual resignation to the child's condition with time<sup>8</sup>. In addition, the study was done in a rural area, where people are still strongly bonded to their religious and spiritual values. Being religious is associated with better psychological adjustment and has been shown to be an effective coping strategy for a variety of stressful circumstances<sup>9</sup>. Using task-oriented coping styles, the mothers attempt to solve the problems, cognitively restructuring the problems or alter the stressful situation. These are constructive and effective coping strategies which should be encouraged by health professionals working with mothers with disabled children.

In this study, mothers who are single (divorced) were shown to have significantly higher emotion-oriented coping strategy. Divorce or marital separation is an extremely stressful event and involves a complex series of changes that often affect every aspect of family functioning, which include parent-child relationships, parenting effectiveness, family income and social relationship<sup>10</sup>. These changes may produce both short-term crises and long term effects which influence the coping ability of the mothers. It is reported that single mothers suffer from low self-esteem, loneliness and isolation<sup>11</sup>. They often present to physicians with complaint of fatigue, depression and general somatic complaints, which are signs of difficulty in coping with the family changes<sup>11</sup>. Having a disabled child further enhance the burden of these single mothers. Thus, it is important that health professionals recognize the problems faced by single mothers and educate them on better coping strategies which are more problem-oriented.

Another significant finding in this study is that mothers with lower level of education are more inclined to use emotion-oriented coping strategies as compared to those with higher level of education. Maternal education empowers the mother with job opportunities, financial resources and access to socio-educational and medical resources, all of which may alleviate the strain of having to care for a disabled child and further lead to a good coping strategy. This may be particularly relevant in developing countries where medical, educational and social services for the disabled are not provided by legislation and information on disability is often lacking<sup>13,14</sup>. Furthermore, various studies have documented the association between low level of parental education with negative attitude, poor coping strategies and psychosocial problems in families with disabled children<sup>3,9,12,15</sup>. These mothers should be encouraged to use more effective coping strategies in caring for their children and managing other stressful events.

It was also shown that mothers with disabled children aged five years old or less used higher avoidance coping strategy compared to mothers with older children. This could be due to the fact that parents of infants and preschool children face more intense stress during the period of initial adjustment to the child's disability<sup>6</sup>. These mothers are usually preoccupied with the feeling of fear about the course of the child's illness and doubts about their future. There may be self-blame and guilt over perhaps having been the

cause of the illness. This would lead to avoidance discussing the subject of the illness and later withdrawing from the outside world due to being overwhelmed by fear of what other people's reactions might be to their disabled child<sup>6</sup>. These mothers may not have been adequately prepared resulting in poor coping strategies. Health professionals play an important role in explaining and preparing mothers who have been identified to have disabled children. The mothers should be encouraged to discuss about their child's illness and learn to deal with it more effectively.

None of the mothers were involved in any social support group or non-governmental organizations related to their child's disability. This is certainly due to logistic reason, where all the organizations are usually in the towns. This social support group or organization is very important to the mothers, particularly in developing countries, where medical, educational and social services are not provided by legislation.

There are several limitations in this study. The husbands' occupation and involvement in the caring of the disabled children are significant factors that may influence the mothers' coping skills, however, they were not taken into account in this study. The wide variability of the mothers' characteristics and the different levels of disabilities among the children may also affect the accuracy of the results. An important

aspect to be considered, is the association between the mothers' level of anxiety and depression with their coping skills. These factors influence the coping skills of the mothers and should be looked into in future studies.

### Conclusion

The mothers in this study were using a mixture of coping strategies, namely task-oriented, emotional oriented, avoidance, distraction and social diversion. However, the mothers were more inclined to use task-oriented and emotional-oriented coping styles as the mean T-score for these were more than average. Divorced mothers and those with lower level of education tend to use more of emotional-oriented coping strategies while mothers with disabled children aged five years old or less are inclined to use avoidance coping styles. It is important for health workers, in particular the primary care doctors, community health nurses and social workers to understand the coping styles of these mothers. Health workers play a significant role in helping families with disabled children to work through their difficult moments in adjusting to the stressful situation. They should educate the mothers on how to develop effective coping skills, acceptance of the disabled child, reorganizing themselves to meet the child's needs based on realistic understanding of the illness and developing effective social support networks.

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