

A PRELIMINARY STUDY ON THE SOCIAL AND EMOTIONAL EXPERIENCES OF PARENTS OF CHILDREN WITH CLEFT LIP AND PALATE

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ABSTRACT

There are very few studies that describe the emotional and social experiences of parents of children with cleft lip and/or palate who are undergoing treatment. To understand these circumstances, 34 parents of children with cleft lip and/or palate were surveyed to find out about the parents' social and emotional experiences of having children with this physical disorder. The research was carried out using structured questionnaires that parents completed during a support group meeting. The questionnaires included questions on the reactions of people toward the child, parents' emotional reactions, social support, coping strategies and resources used. Results of the study indicated that parents do need some assistance during the early stages of treatment. Furthermore, pediatricians play a very important role in the follow-up of treatment, empowerment of parents, and dissemination of information on the child's condition. Contrary to much speculation, the parents reported that they are generally not stigmatized, and took a proactive approach towards finding out information about the disorder, and also about caring for their children. The study concluded by indicating that future studies would need to have larger samples, span a wider age groups, focus on the children's first 12 months, and also their experiences when they begin to attend school.

Key words: cleft lip and palate, parents, children, social experiences, coping.

INTRODUCTION

When children are born with physical deformities, their parents generally have negative feelings and emotions. Medical staff often comment that, in the case of cleft lip and palate, the parents often also worry that the disorder may be caused by something that they have done, and also eventually suffer a stigma from their extended families and communities. However, much of this information consists of comments that medical staff heard about on the wards, and there has not been much systematically collected information on these experiences. Thus, the purpose of this study is to systematically document the experiences

of parents of children of cleft lip and palate. It is hoped that the information obtained would provide health care providers with more information on the social experiences and coping strategies of this group of parents, and thus the information could be used to assist parents, who are having difficulty coping, cope in a better manner.

The literature review initially describes the medical condition called cleft lip and palate, and provides some description of what related studies have observed on how parents adjust and cope with their children's medical condition. The review also examines some findings that examine the mental health problems experienced by children with cleft lip and/or palate.

Children with cleft lip and palate have faces which are partially developed and stopped in the midline facial area. This usually happens during the first trimester (Felix-Schollaart, Hoeksma, Van de Velde, Puyenbroek, & Prah-Andersen, 1992). The cleft lip may be unilateral or bilateral and may involve the bones of the upper jaw and/or upper gum ridge and also the lips (Speltz, Endriga, Fisher, & Mason, 1997). The clefts can occur in the hard or soft palate or both (Speltz *et al.*, 1997).

Many studies indicate that parents of children born with medical deformities experience a degree of psychological distress. This assumption has been documented in several studies that show that a child's illness seems to, very quickly, affect and change their parents' psychological well-being (Azarnoff, 1984; Miles, Carter, Spincher, & Hassanein, 1984; Rothstein, 1980).

Whilst not many studies have been conducted on the emotional effects of parents of children of cleft lip and palate, several studies have been carried out on parents of children with other medical conditions. In a study of Korean mothers' psychosocial adjustment to their children's cancer, Han (2003) observed that maternal psychosocial adjustment was affected by their stress, coping with the illness, social support and time since diagnosis. In terms of stress, the more stress the mothers experienced, the poorer their psychosocial adjustment. Mothers of children with cancer were better adjusted when there were more positive coping strategies to the illness, and also social support. In addition, it was noted that mothers tend to be more distressed and poorly adjusted when they were first told about their children's cancer.

Children's medical conditions tend to affect parents' adjustment. Beaumont (2005) found that mothers, of children with clefts, who were unprepared for the birth of a child with undiagnosed cleft experienced more grief, whereas mothers who had a child and whose baby had been diagnosed with a cleft, whilst the fetus was still in the womb, tended to be more positive and were not so shocked at the birth.

Whilst parents feel distressed upon finding out their children's medical conditions, this distress decreases over time. Wong and Chan (2005) found that Chinese parents would first express initial shock and disbelief upon learning their children's illness. However, the parents would quickly accept the situation as fated, and eventually the distress would decrease. To help themselves cope, parents would seek information and emotional support.

Parents who worry about their child's condition may experience interpersonal problems. During the ordeal, studies indicate that parents of children with a medical condition try to cope, but often have problems with social support. Lai and Salili (1997) carried out a study on 90 Chinese mothers with Hepatitis-B-carrying children aged from 3 to 7 years old. The study observed that these parents adopted coping strategies that involved depending more on themselves, facing the reality of the situation and solving their own

problems. However, these parents reported that they were not satisfied with the social support provided by friends. In addition to this, they also reported not having a clear sense of purpose in life when compared with parents who did not have ill children.

The studies on parents of children with medical problems suggest parents of children with cleft lip and palate would probably experience some similar adjustment problems. Some of these would probably be attributed to the shock of finding out about the diagnosis, and subsequently attempting to cope in a variety of negative ways.

Given that there are not many studies on the experiences of parents of children with cleft lip and/or palate, we could refer to studies that examine experiences of parents with children suffering from a medical condition. During the ordeal of coping with a child's medical condition, parents go through a variety of social experiences. Some of these may be helpful, others may not be and may in fact contribute to additional stress. Jackson, Antonucci and Gibson (1991) documented a number of social interactions where parents derive their coping strategies from. These include support from family, assistance from multidisciplinary team in the clinic, and contact with other parents who are in a similar situation. These social interactions eventually affect the parents' ability to focus on the positive aspects of the situation, their self-efficacy, and commitment to and love for the child.

Some studies indicate that not having enough information on the child's medical condition leads to an increase in the parents' distress. Sadler (2005) interviewed nurses who worked with parents with cleft lip children and found that after the diagnosis, parents were left confused, tense, isolated and vulnerable. Mothers had limited information and support on how to breastfeed the cleft-lip babies. The interviews also indicated that parents' responses may differ. Whilst some parents were surprised and overwhelmed and had difficulty coping, other parents still tried to gather information and wanted to talk about their child's problems.

Given the physical deformities that children with cleft lip and palate have, it can be assumed that these children may experience social and mental health problems. Several studies have indicated that children with cleft lip are more socially withdrawn and inhibited especially in the classroom (Richman, 1983, Richman & Harper, 1979; Richman & Millard, 1997). In addition to this, there are indications that these children tend to have lower self-concept when compared with their developing peers who do not have cleft lip or palate (Broder, Smith, & Strauss, 1994; Broder & Strauss, 1989; Kapp-Simon, 1986).

The assumption that children of cleft lip and palate have more mental health problems, when compared with their peers does not seem to be consistent across all studies. In a study that consisted of 86 adolescents, aged between 16 and 20 years old, Persson, Aniansson, Becker and Svensson (2002) found that those born with cleft lip and palate had normal or higher self-concept, when compared with a control group. These results are consistent with other studies that have found similar findings (Kapp-Simon, Simon, & Kristovich, 1992; Leonard, Brust, Abrahams, & Sielaff, 1991; Richman, 1983; Richman, Holmes, & Eliason, 1985).

The review indicates that whilst parents of children with cleft lip and palate do appear to have some emotional difficulties, there are some inconsistencies in the findings about whether children with cleft lips and/or palate do have more mental health problems. Perhaps, the way these children cope may have something to do with the manner in which their parents cope. Given these findings, the main purpose of this study is to understand the

experiences of parents when they have a child with cleft lip or palate. The research question is quite simple, involving a detailed examination of the reactions, coping strategies, resources and social support that these parents experienced and used. Results obtained may help to shed some light on the various positive coping strategies that these parents have used to cope.

METHODOLOGY

Research Design

The design used in this study was a single group cluster sample, and data was obtained using survey methodology.

Subjects

The subjects of this study consisted of 34 parents of children with cleft lip and/or palate. The parents had children whose ages ranged from between 3 months and 180 months (i.e., 15 years old) with mean age of 47.8 months (i.e., 3 years 9 months). Racially, the sample consisted of 26 (76.5%) Malays, 6 (17.6%) Chinese, 1 (2.9%) Indian and 1 (2.9%) non-Malay Bumiputera. In terms of religion, there were 27 (79.4%) Muslims, 5 (14.7%) Buddhists, 1 (2.9%) Hindu and 1 (2.9%) Christian. In terms of the children's diagnosis, the diagnosis included 5 (14.7%) cleft lip only, 5 (14.7%) cleft palate only, 22 (64.7%) with both cleft lip and palate, and others 2 (5.9%).

Measurement Instrument

The aims of the study generally focus on finding out about the social and emotional experiences of parents of children with a cleft lip and/or palate. The measurement instrument consisted of 60 questions that were grouped into six sections (see Appendix). The sections are as follows:

- Part A: Demographic Information
- Part B: How do people generally react to your child?
- Part C: How did you feel when you found out that your child had cleft palate or lip?
- Part D: How did you cope with your child's condition?
- Part E: What resources did you turn to for help?
- Part F: General Open-Ended Questions

Apart from the questions in Part F, all the questions have answers which are of a multiple-choice response format. As there are no scales that specifically examine the

experiences of parents of children with cleft lip and/or palate, all the questions have been designed by the researchers.

Procedures

The parents whose children suffered from cleft lip and/or palate were all members of the Cleft Lip and Palate Association of Malaysia (CLAPAM). The subjects were approached during the CLAPAM annual general meeting. It took most subjects about 10 minutes to complete the questionnaires which most returned at the end of the meeting.

RESULTS

The research question of this study involved a detailed examination of the emotional reactions, coping strategies, resources and social support that parents of children with cleft lip and/or palate experience used. To answer the research questions, a series of statistical analyses are conducted. The main statistical analysis utilized was frequency counts and percentages.

Parents were asked which specialists they sought help from, other than the plastic surgeon. The results indicated that many parents sought assistance from pediatricians (50%). No assistance was sought from psychologists and psychiatrists. Other specialists who were sometimes consulted included were occupational therapists (8.8%), speech therapists (26.5%), neurosurgeons (5.9%), and other unspecified specialists (23.5%) (see Table 1).

Table 1. Help from Other Medical Specialists Other Than the Plastic Surgeon

Medical Specialists	Yes (%)	No (%)
Occupational Therapists	3 (8.8)	31 (91.2)
Speech Therapists	9 (26.5)	25 (73.5)
Neurosurgeons	2 (5.9)	32 (92.4)
Pediatricians	17 (50.0)	17 (50.0)
Psychologists	0 (0.0)	34 (100.0)
Psychiatrists	0 (0.0)	34 (100.0)
Others	8 (23.5)	26 (76.5)

Parents were also asked how people reacted to their children who had a cleft lip and/or palate. Most parents reported that people were generally very supportive (88.2%) and reacted with sympathy (85.3%). Most people were not nasty, did not say nasty things, did not blame or socially exclude the parents. Very few parents reported that other people kept away (2.9%) and gave them nasty looks (2.9%) (see Table 2)

Table 2. Reactions of Other people

Reactions	Yes (%)	No (%)
Sympathy	29 (85.3)	5 (14.7)
Supportive	30 (88.2)	4 (11.8)
Being nasty and blame	0 (0.0)	34 (100.0)
Socially excluded	0 (0.0)	34 (100.0)
Keep away	1 (2.9)	33 (97.1)
Say nasty things	0 (0.0)	34 (100.0)
Give nasty looks	1 (2.9)	32 (94.1)

Parents were asked how they reacted when they discovered that their child had a cleft lip and/or palate. Most parents reported being worried (88.2%) and feeling confused (76.5%). Some reacted with denial (20.6%), cried (44.1%), blamed themselves (26.5%), thought that they had done something wrong (50.0%), thought God was punishing them (20.6%), felt ashamed (20.6%) and were worried that their spouses would leave them (11.8%). However, none of the parents reported wanting to give their child away or feeling suicidal (see Table 3).

Table 3. Reactions of the Parents

Reactions	Yes (%)	No (%)
Confused	26 (76.5)	8 (23.5)
Denial	7 (20.6)	27 (79.4)
Cry	15 (44.1)	19 (55.9)
Give the child away	0 (0.0)	34 (100.0)
Blame self	9 (26.5)	25 (73.5)
Thought they had done wrong things	17 (50.0)	17 (50.0)
Thought God was punishing them	7 (20.6)	27 (79.4)
Suicidal	0 (0.0)	34 (100.0)
Worry	30 (88.2)	4 (11.8)
Ashamed	7 (20.6)	26 (76.5)
Worried spouse would leave	4 (11.8)	30 (88.2)

Parents were asked how they coped when they discovered that their child had cleft lip and/or palate. Most parents reported that they sought help from other people (88.2%), tried to get information on their child's condition (88.2%), joined groups (82.4%), thought positively (82.4%), reached out to society (61.8%), attended talks (79.4%) and reached out to God (73.5%). In doing so, many parents reported that they found meaning and purpose in life when helping their children (76.5%), and developed as a person (82.4%). Very few parents reported keeping themselves away from society (8.8%) (see Table 4).

Table 4. Facing the Condition

Conditions	Frequent (%)	Neutral (%)	Less (%)
Sought help	30 (88.2)	2 (5.9)	1 (2.9)
Get information	30 (88.2)	3 (8.8)	0 (0.0)
Found meaning and purpose	26 (76.5)	5 (14.7)	1 (2.9)
Develop as a person	28 (82.4)	3 (8.8)	1 (2.9)
Keep away	3 (8.8)	1 (2.9)	29 (85.3)
Join groups	28 (82.4)	3 (8.8)	1 (2.9)
Think positively	28 (82.4)	2 (5.9)	0 (0.0)
Reach out to society	21 (61.8)	6 (17.6)	5 (14.7)
Attended talk	27 (79.4)	5 (14.7)	0 (0.0)
Reach out to God	25 (73.5)	4 (11.8)	1 (2.9)

Parents were asked whom or where they turn to for help. Obtaining assistance from doctors were the most preferred choice (97.1%), whilst utilizing traditional medicine was the least popular choice (8.8%). Other sources of information included books (61.8%), medical books (64.7%), pamphlets (85.3%), websites (64.7%), support groups (94.1%), attending talks (82.4%) and seeking religious healers (23.5%) (see Table 5).

Table 5. Sources of Help

Sources	Yes (%)	No (%)
Doctor	33 (97.1)	1 (2.9)
Books	21 (61.8)	13 (38.2)
Medical books	22 (64.7)	12 (35.3)
Pamphlets	29 (85.3)	5 (14.7)
Websites	22 (64.7)	12 (35.3)
Groups	32 (94.1)	2 (5.9)
Talks	28 (82.4)	6 (17.6)
Traditional medicine	3 (8.8)	31 (91.2)
Religious healer	8 (23.5)	25 (73.5)

DISCUSSION AND CONCLUSION

This study was designed to understand the experiences of parents when they have a child with cleft lip or palate. In addition to this, the study also surveyed the reactions, coping strategies and social support of the parents.

Several findings were obtained from the study. These can be summarized in the following manner. Half the parents (50%) reported that they sought the assistance from pediatricians more often, as compared to other health professionals. This would be normal, given that once the child's wounds have healed, a pediatrician is normally the physician most often seen when a child gets ill. The results also indicated that parents did not approach psychologists or psychiatrists (0%) for assistance with their child's behaviors or emotions.

Whilst there has been an assumption that children with cleft lip or palate may be stigmatized (Broder & Strauss, 1989; Kelton, 2000), the results of this study indicate otherwise. Most parents reported that people whom they interacted with were generally very supportive (88.2%) and reacted with sympathy (85.3%) towards them and their child.

Parents were also asked how they reacted when they discovered that their child had a cleft lip and/or palate. Most parents reported being worried (88.2%) and feeling confused (85.3%). These results were identical to those of Sadler (2005) whose subjects also experienced a lot of emotional distress. During this phase, parents in the present study reported that they often sought help from other people (88.2%), tried to get information on their child's condition (88.2%), joined support groups (82.4%), and tried to think positively about the future (82.4%). Most indicated that they preferred obtaining assistance from doctors (97.1%). These results of this study are similar to those of Jackson *et al.* (1991) and Wong and Chan (2005) whose parents also actively sought information and emotional support from a variety of sources.

Given the results of the study, several suggestions can be made. Firstly, most parents report that a pediatrician is often sought for assistance in managing the child. Thus, it would make sense to empower pediatricians with more knowledge and skills on the physical and psychological issues that surround children with cleft lip and palate. This could be done via continuing medical education workshops, seminars and written information. When it comes to written information, brochures and books could be circulated to the parents via the pediatricians. In this case, the pediatricians would be in an even stronger position to assist these children and their families.

The results also indicate that parents of children with cleft lip and palate do not feel stigmatized. Thus, the focus on dealing with these parents should be proactive, rather than sympathetic. To play a more proactive role, more informative workshops on practical child rearing issues such as feeding, speech development and disciplining could be organized to further enhance the role that parents have in raising the children. Some of these workshops could be open to parents with children with other conditions, thus sending the message that many of the behavioral and emotional issues are universal to all children, rather than strictly within a single group of physical disorders.

When parents first encounter their child's disorder, they feel confused and worried. It is important to note that services need to be made available to the parents at this early and emotionally vulnerable stage. Information such as the nature of the condition, future child development and related problems need to be highlighted both verbally and also in writing.

During this period it is also important to take into consideration the parents' emotional state. Thus, pediatricians, plastic surgeons and nurses working with the parents could be trained to handle emotional issues. At this point, it is also useful to harness the support of parents who are already members of a support group to assist with consoling distressed parents. When the parents have difficulty overcoming their grief, professional counselors could be included to provide grief counseling for parents, and help them to plan and implement the next stage of their child's treatment.

This study was set up as a pilot study to begin to understand the needs of parents of children with cleft lip and palate. Thus, there are several strengths and limitations that may have affected the results. Where limitations are concerned, the first thing to acknowledge is the relatively small sample size and limited age range. The second limitation concerns the sampling of this study. All parents surveyed come from a support group for parents of children with cleft lip and palate. Parents within support groups may tend to be more proactive in their child's development, and may take steps to empower themselves. Given this situation, one wonders whether the responses for stigmatization and other social experiences would have been different if the parents were not part of a support group. Thus, future studies may seek to include parents who are not part of support groups. However, despite these limitations, a strength of this study would be that it is contributing towards the understanding of the experiences of parents of children with a physical disorder where there has been very little published.

The results of this study highlight a period of confusion and worry when parents first discover their child's disorder. Thus, future studies may want to focus more on studying the experiences and needs of parents much closer to the time when the child's cleft lip and palate has been diagnosed, and the child is undergoing surgery. This would normally occur within the first 12 months of the child's life. As this study has only focused on the parents' perspective, future studies may also want to obtain the child's perspective on how he/she is treated when at kindergarten or school. This is an important area to focus on, given that all children with cleft palate have speech development problems.

This pilot study of the social and emotional experiences of parents of children with cleft lip and/or palate indicated that parents do need some assistance during the early stages of treatment. Furthermore, it was concluded that pediatricians play a very important role in follow-up of treatment, and would be the ideal person to support and empower parents to care for their children. In addition to this, parents reported that they are generally not stigmatized, and that a more proactive approach which involves the provision of information, and also the teaching of skills to care for their children, would be needed. Finally, as this is only a pilot study, future studies would need to have larger samples, span wider age groups, focus on the child's first 12 months, and also the experiences of the children when they begin to attend school.

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APPENDIX**Children's Cleft Lip and Palate Parent Experiences Survey**

Instruction: Finding out that your child has a cleft lip or palate would have had an impact on you. This study seeks to find out about the social and emotional experiences of parents of children with cleft lip, cleft palate or both. In the long run, understanding how parents feel and what they are going through would help us plan for better services for children and their parents.

Part A: Demographic Information

- A1. I am the child's 1. Father 2. Mother 3. Relative
4. Non-biological parent
- A2. Child's Age: _____ year _____ months
- A3. Child's Gender
1. Male 2. Female
- A4. Race
1. Malay 2. Chinese 3. Indian 4. Bumiputera
5. Other
- A5. Religion
1. Muslim 4. Hindu
2. Christian 5. No religion
3. Buddhist 6. Other (please specify : _____)
- A6. Residence
1. City 2. Rural area 3. Semi rural area
- A7. How long has it been since your child had his/her last surgery? ____ years
- A8. How many surgeries has your child undergone? _____
- A9. Does your child have a 1. Cleft Lip 2. Cleft Palatte
3. Cleft Lip and Palatte
- A10. Does your child have any mental problems (e.g., mental retardation, Down's Syndrome) 1. Yes 2. No

A11. Other than a plastic surgeon, does your child seek the assistance of any other health professionals?

1. Yes 2. No

If Yes, which of the following health professionals does your child regularly have to see?

- | | | | |
|-------|------------------------|--------|-------|
| A11a. | Occupational Therapist | 1. Yes | 2. No |
| A11b. | Speech Therapist | 1. Yes | 2. No |
| A11c. | Neurosurgeon | 1. Yes | 2. No |
| A11d. | Pediatrician | 1. Yes | 2. No |
| A11e. | Psychologist | 1. Yes | 2. No |
| A11f. | Psychiatrist | 1. Yes | 2. No |
| A11g. | Others, please specify | 1. Yes | 2. No |
-

Part B:

How do people generally react to your child?

- | | | | |
|-----|--|--------|-------|
| B1. | Sympathy and consideration | 1. Yes | 2. No |
| B2. | Supportive and helpful | 1. Yes | 2. No |
| B3. | Relatives said nasty things about you and blamed you | 1. Yes | 2. No |
| B4. | Your family was excluded from social and family events | 1. Yes | 2. No |
| B5. | Kept away | 1. Yes | 2. No |
| B6. | Say mean and nasty things | 1. Yes | 2. No |
| B7. | Stare hard and give nasty looks | 1. Yes | 2. No |

Part C

How did you feel when you found out that your child had cleft palate or lip?

- | | | | |
|------|---|--------|-------|
| C1. | Puzzled and confused | 1. Yes | 2. No |
| C2. | Denied that this was happening to you | 1. Yes | 2. No |
| C3. | Cried a lot | 1. Yes | 2. No |
| C4. | Felt like giving away the child | 1. Yes | 2. No |
| C5. | Blamed yourself | 1. Yes | 2. No |
| C6. | Asked what you had done wrong to deserve this | 1. Yes | 2. No |
| C7. | Thought God was punishing you | 1. Yes | 2. No |
| C8. | Felt suicidal | 1. Yes | 2. No |
| C9. | Worried about how the child would grow up | 1. Yes | 2. No |
| C10. | Ashamed of showing the child to other people | 1. Yes | 2. No |
| C11. | Worried that your spouse would not want you | 1. Yes | 2. No |

Part D

How did you cope with your child's condition?

		<i>Almost always</i>			<i>Never</i>	
D 1.	Tried to do something to help my child.	1	2	3	4	5
D 2.	Looked for as much information about my child's problem.	1	2	3	4	5
D 3.	Found meaning and purpose in life when helping my child.	1	2	3	4	5
D 4.	Grew and developed as a person through helping my child.	1	2	3	4	5
D 5.	Kept away from relatives and friends.	1	2	3	4	5
D 6.	Joined a support group (e.g. CLAPAM)	1	2	3	4	5
D 7.	Tried to think positively about the situation	1	2	3	4	5
D 8.	Reached out to relatives and friends for support and help.	1	2	3	4	5
D 9.	Talked a lot to the doctor.	1	2	3	4	5
D 10.	Asked God for help.	1	2	3	4	5

Part E

What resources did you turn to for help?

E1.	Doctor	1. Yes	2. No
E2.	Self-Help Books	1. Yes	2. No
E3.	Medical Textbooks	1. Yes	2. No
E4.	Pamphlets	1. Yes	2. No
E5.	Internet Web-pages	1. Yes	2. No
E6.	Support group (i.e., CLAPAM)	1. Yes	2. No
E7.	Seminars and talks	1. Yes	2. No
E8.	Traditional medicine	1. Yes	2. No
E9.	Religious healers	1. Yes	2. No

Part F

F1. Please describe how was it like caring for a child who has to go through surgery:

F2. What worried your child the most about the way he/she looked?

F3. What sorts of things did your child's friends say about his/her looks?

F4. What sorts of things have relatives said about your child's looks?

F5. What sorts of things have the teachers said about your child's looks?

If you would like us to send you a copy of the results of this study, please write down your name and address below:

Postcode _____

Thank you for taking part in this survey!