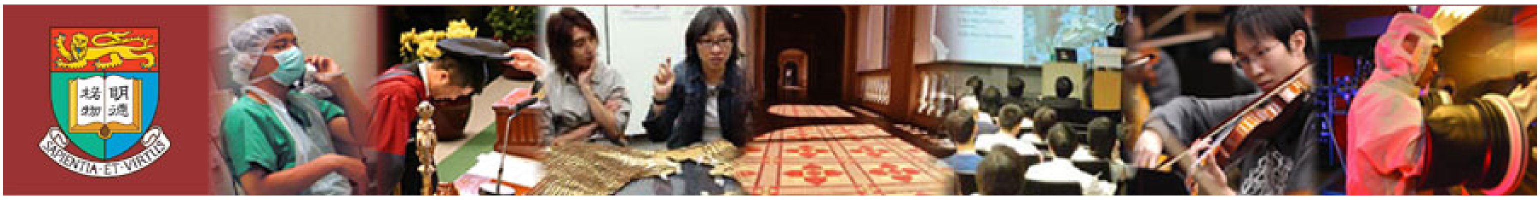

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Parents' Attitudes about Their Children's Cleft Lip and Palate in Hong Kong

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Parents’ Attitudes about Their Children’s Cleft Lip and Palate in Hong Kong

Chu Wing Yan, Annie

Abstract

This study investigates the concerns, attitudes and stress of Hong Kong parents of children with cleft lip and/or palate (CLP). Twenty-three parents participated and were asked to fill in two questionnaires. The results showed that parents generally had similar concerns to other parents in Hong Kong, including health, social development and performance in school. They tended to possess positive attitudes towards CLP. However, they would not want their children to have CLP if they could choose. More than half of the parents were experiencing high parenting stress. The results gave insight regarding the need for expanded speech therapy services in public hospitals and inclusion of counseling services in the multidisciplinary craniofacial team.

Parents' Attitudes about Their Children's Cleft Lip and Palate in Hong Kong

Chu Wing Yan, Annie

The closest companions for children with cleft lip and/or palate (CLP) are their parents. Parents play a crucial role in determining the kind and frequency of surgery or therapy for their children, particularly when the children are young. The parents are service recipients. Their opinions are very important in reviewing and upgrading the current services provided. It is therefore essential to investigate parents' concerns, attitudes and stress about their children's CLP conditions and services that their children have received (American Cleft-Palate Craniofacial Association, ACPA, 2007).

As a coin has two sides, attitudes also have both positive and negative sides. Clifford (1983) opened a discussion to explore the normalcy of attitudes of individuals with CLP. However, many researchers have mainly focused on understanding the negative psychosocial outcomes of children's CLP for their parents. In the United Kingdom, Noar (1991) sent questionnaires to 30 parents of children with CLP and found that parents felt their children were emotionally and socially influenced because of their conditions. In Ireland, Hunt, Burden, Hepper, Stevenson and Johnston (2007) used checklists and semi-structured interviews to study the psychosocial functioning of parents. One hundred and twenty-nine parents of children with CLP and 96 parents of children without CLP were recruited. The results were compared and the researchers found five main concerns for parents with CLP children, including behavioral problems, less satisfaction with speech, unhappiness with appearance, increased anxiety level in general and being unhappier in general. There is a current shift in the trend of research in the craniofacial literature in revealing the positive side of the issue. In the United Kingdom, Baker, Owens, Stern and Willmot (2009) recruited 103 parents of children with CLP. Coping strategies, social support, adjustment and psychological distress were measured using validated psychological questionnaires. The study concluded that parents reported higher levels of positive adjustment than negative outcomes by the experience of their children's CLP. The positive adjustment obtained included increased optimism and personal strength, enhanced capabilities to regulate affection, and greater sense of belonging and religiousness. In the United States, Eiserman (2001) conducted a pilot study of 11 parents of children with CLP. Each participant completed an 11-page questionnaire and participated in an unstructured interview. Increased appreciation of diversity, community involvement and spiritual beliefs were some of the positive outcomes located.

Other than exploring parents' psychosocial attitudes as a result of their children's CLP, parents' point of views on the services they have been receiving are also essential to review so as to improve the current services. A multidisciplinary craniofacial team, usually including pediatrician, otolaryngologist, surgeon, dentist, speech therapist, audiologist and psychologist, is responsible for giving suggestions on therapies that should be received to parents of children with CLP (ACPA, 2007). Parents believed that professionals seldom discussed the positive outcomes with them (Eiserman, 2001). Strauss, Sharp, Lorch and Kachalia (1995) found that parents wanted more compassion from professionals and greater opportunity to discuss their concerns than they had received. Strauss (2001) suggested three steps that clinicians could take in order to change the social and family perceptions of CLP. Instead of focusing on the negative issues, clinicians could create positivity around birth and diagnosis, ask questions about their children's positive qualities and appreciate parents' resilience towards issues raised by their children's CLP.

Few researchers have investigated the concerns and attitudes of Hong Kong parents of children with CLP regarding their children's conditions. Chan, McPherson and Whitehill (2006) recruited 39 parents, 27 teachers and 37 employers to investigate difference in attitudes towards CLP. With the use of validated questionnaires, the study showed that with increased degree of contact with CLP individuals, more favorable attitude would be established. Cheng (1990) described the cultural differences in the perspectives of Asian Americans towards CLP. The article stated many folk beliefs and superstitions about CLP in China, such as pregnant women should not eat rabbit meat. It also revealed that a lot of parents did not understand the role of speech therapists and the function of speech therapy for children with CLP. However, there have been no previous studies investigating the stress experienced by the parents and their comments on the service received.

It was hypothesized that Hong Kong parents of children with CLP would have concerns on their children’s development in general. For example, they would concern about their children’s academic performance, which was a common worry of local parents (Ho, Chiu & Chan, 1989; The Boys’ and Girls’ Clubs Association of Hong Kong, BGCA, 1984). It was expected that parents would have positive attitudes towards CLP as revealed in studies in other countries (Eiserman, 2001; Strauss, 2001). Although bearing a child with CLP was an exhausting experience, parents were expected to cope with the situations and they would think positively from the experience. However, in addition, high parenting stress was expected to be endured by the parents. Speltz, Armsden and Clarren (1990) found that higher levels of stress were reported for mothers of children with CLP than that without CLP.

To summarize, the purpose of this study focused on developing a comprehensive psychological profile of Hong Kong parents of children with CLP. Their concerns, attitudes, stress and opinions about services received regarding their children’s CLP were investigated. This could provide valuable information for designing and improving current services for children with CLP. Besides, this study represented the contribution of Hong Kong sector as it was one part of a collaborative project with other partners, including the United States and

Ireland. The results of the study could be compared with information obtained from other countries in the future. This could allow the comparison of any cross-cultural similarities and differences so that region-specific recommendations could be made.

Method

Participants

The three inclusion criteria for this study were parents whose children were born with CLP, whose children with CLP were aged between two to 12, and who were Cantonese-speaking Hong Kong residents. Parents were recruited from three sources. The first was the Cleft Lip and Palate Centre, The University of Hong Kong/Prince Philip Dental Hospital. The second was the Hong Kong Association for Cleft Lip and Palate (HKACP), a local support group which organized a wide range of community activities and sharing groups for parents of children with CLP. The third was the Hong Kong Speech and Swallowing Therapy Centre, a local private clinic which served a number of children with CLP.

Forty-four parents accepted the invitation for the study. However, only 24 parents participated in the end. Demographic information collected from the participants is shown in Table 1.

Materials

Two self-report questionnaires were used in the study. The first questionnaire (see Appendix) was developed by the collaboration work of the three partners. For the initial part of the questionnaire, parents were asked to fill in the personal information about their children, such as age, gender and type of cleft. Twenty-three questions were included in total, ten open-ended questions and nine closed-ended questions. The questions aimed to investigate parents' three major concerns about their children and comment on the services

TABLE 1 Summary of Demographics

	Parent	*Child*
Gender		
Female	19 (79.2%)	12 (50.0%)
Male	5 (20.8%)	12 (50.0%)
Age (whole sample), mean (SD)	—	7.09 (3.17)
Age groups, mean (SD)		
0 to 6 years	—	4.38 (1.60)
7 to 12 years	—	9.80 (1.54)
Total number of children		
1	9 (37.5%)	—
2	9 (37.5%)	—
3	6 (25.0%)	—
Cleft condition		
Cleft lip only	—	4 (16.7%)
Cleft palate only	—	5 (20.8%)
Cleft lip and palate	—	15 (62.5%)

received. The four remaining questions contained a five-point rating scale. Two were questions regarding the child's speech intelligibility to them and other people. The points were labeled as *completely unintelligible*, *mostly unintelligible*, *somewhat intelligible*, *mostly intelligible* and *completely intelligible*. One question asked parents to rate the levels of concern about their children in six areas, such as physical appearance and social development (*no concerns* – 1, *concerned* – 3, *extremely concerned* – 5). An additional question consisted of 15 statements studying their level of agreement towards statements related to CLP. The points were labeled as *strongly disagree, disagree, neutral, agree* and *strongly agree*. Six items covered positive attitudes, supported by the current trend of research (Eiserman, 2001; Strauss, 2001). Six items were negative and the remaining three items studied parents' beliefs about speech and speech therapy. The initial version of the questionnaire was written in English so that partners in other countries could use the same questionnaire and the results obtained could be compared cross-culturally. The questionnaire was then translated into standard Chinese. A backward translation was done by another Chinese origin/bilingual (Chinese, English) Year Four undergraduate in Speech and Hearing Sciences. The two English versions were compared to ensure every item of the questionnaire was translated appropriately. Five amendments were made in the Chinese version so that the desired nuances of meaning were maintained.

The second questionnaire was the Chinese version of the Parenting Stress Index (PSI; Abidin, 1995). The PSI is a screening and diagnostic assessment designed to tap the sources of difficulties and the level of parenting stress experienced by parents. This questionnaire was chosen because it explored the origin of parenting stress with respect to child domain and parent domain. The child domain examined parents' perceptions of stress resulting from the child. Its subscales included child's distractibility, reinforcement to parents, moodiness, acceptability, adaptability and demandingness. The parent domain reflected the perceived social and psychological cost of parenting. Its subscales consisted of sense of competence, feelings of attachment, restrictions of roles, depression, relationship with spouse, social isolation and parent health. The child domain and parent domain contained 101 items on a five-point Likert scale including 1 = *strongly disagree,* 2 = *disagree,* 3 = *neutral,* 4 = *agree* and 5 = *strongly agree*. The score range for each response was 1 to 5. No cut-off point for the Chinese version was reported. The scoring system developed by Abidin (1995) was used to interpret parents' responses. If the score of a subscale was equal or greater than the percentile score of 85, which was named as normative high score, parent were experiencing high parenting stress that might be caused by that particular subscale. If the total stress score was at or above 260, a referral to professional consultation with psychologist definitely should be offered. The PSI also includes an optional 19-item life stress subscale to find out whether parents were in stressful situational circumstances that were often beyond their control, such as the death of a relative and loss of a job. Additionally, a defensive responding score could be obtained by summation of the score of 15 specific items. If the score was 24 or less, the participant might give the answers in a defensive manner and caution might be needed in interpreting the remaining scores. The PSI has been used in a variety of overseas and local studies. Although the PSI has been validated in Chinese populations (Pearson & Chan, 1993), it had not been used previously with parents with CLP children in Hong Kong. The Cronbach's alpha coefficient found in this study was 0.844, indicating that this scale had a reasonably good internal consistency.

Procedure

All the participants were asked to sign a consent form before they filled in the questionnaires. Parents were allowed to fill in the questionnaires in the form of semi-structured interview or filling out the questionnaires themselves. They returned their questionnaires by post, email or fax. They were given a small gift as a reward for their participation.

Data analysis

For open-ended questions, the data were coded and content was analyzed to reveal themes. For closed-ended items and questions requiring ratings, the data were analyzed using descriptive statistics.

Results

Parents' concerns

Parents were asked to list out three major concerns about their children at present in an open question. The responses were categorized into themes and the sums in each theme are summarized in Table 2. Only two major concerns were counted from four parents as they either wrote answers with similar themes or they only wrote two concerns, whereas only one major concern was counted from three parents. The four major concerns of parents were children's health, social development, performance in school and speech development.

TABLE 2 Parental Concerns towards Different Themes

Theme	*Sum of responses*
Health	13
Social development	11
Performance in school	9
Speech	9
Appearance	6
Craniofacial surgery	5
Growth development	3
Personality	3
Others (Relationship with parents, friendship, financial problem)	3

The percentages of the level of parental concern towards different issues in the rating scale are summarized in Table 3. For social development and getting needed services, the distribution was more centered on *concerned* to *very concerned* level. About two-thirds of parents rated the level as *concerned* or above. For the child's physical appearance, the percentage was distributed across *slightly concerned* to *very concerned* level. For the child's performance in school, the distribution was more concentrated at the *slightly concerned* to *concerned* level. For speech, the distribution was spread across the ratings. Nearly 60 percent of parents rated the level as *concerned* or above for these three issues. For financial problems, the distribution shifted to *no concern* or *slightly concerned* level, with only 40 percent of parents rated the level as *concerned* or above.

For the child's speech intelligibility to the parents and unfamiliar people, the results of the rating scale are outlined in Table 4. About 80 percent of the parents rated their children's speech intelligibility was *mostly intelligible* to them, with a slightly lower percentage for speech intelligibility to others.

Parents' attitudes

Table 5 shows the means and percentage distribution of the parents' level of agreement towards different statements related to CLP. For the statements focusing on negative attitudes (statements 1, 3 to 7), a large proportion of the parents rated from *strongly disagree* to *neutral*. The parents showed strongest disagreement with statement 6, in which they believed that parents should not be blamed for their children's CLP. About the additional comments for statements 4 to 6, one mother believed that she would feel discriminated if people said that parents were blamed for their children's CLP or they were punished by God or fate. Two mothers expressed that having children with CLP might be an obstacle or a gift rather than a punishment.

For the statements investigating positive outcomes (statements 2, 8 to 12), nearly all parents rated from *neutral* to *strongly agree* for statements 2 and 9 to 12. In the open question, one mother commented that she became more tolerant of her son's facial difference. She sincerely believed he was a beautiful angel. One father said he learnt to become considerate after joining the HKACP in doing voluntary work. Parents showed strongest agreement for statement 8 that they would not want their children to have CLP if they could choose.

For the statements studying beliefs about speech therapy (statements 13 to 15), the distribution was relatively dispersed for statements 13 and 15. Sixty percent of the parents rated *neutral* to *strongly agree,* indicating that they did not understand the importance of speech therapy when the palate was not surgically closed and at the time immediately after palatal surgery. For statement 14, about 60 percent of the parents rated *strongly agree* to *agree*, revealing that they knew the child's speech could be encouraged even before the completion of repair surgery.

Parenting stress

Table 6 illustrates the means for the various subscales of the PSI. In the child domain, the participants indicated high parenting stress in their perceptions of the child's demandingness, when compared the mean with the normative high score of 22. In the parent domain, high parenting stress was noted in the subscales of sense of competence and feelings of attachment, when compared the means with the normative high scores of 35 and 16 respectively. One father had a score of 22 for the defensive responding score, indicating that he might have responded in a defensive manner.

Table 7 reports the comparison of means in different domains of the PSI with the normative high scores. The means of the parent domain and total stress found were larger than the normative high scores. More than half of the participants had total stress score higher than the normative high score.

Parents' comments on services received

Parents were asked to indicate all sources of information obtained about CLP when the child was born. The sums of each source are illustrated in Table 8. Hospital personnel

TABLE 3 Percentage Distribution of the Level of Parental Concern on Different Issues

Issue	*No concern*	*Slightly concerned*	*Concerned*	*Very concerned*	*Extremely concerned*
Social development	16.7	12.5	33.3	25.0	12.5
Getting needed services	20.8	12.5	29.2	29.2	8.3
Physical appearance	12.5	29.2	29.2	25.0	4.2
Performance in school	12.5	29.2	33.3	16.7	8.3
Speech	20.8	20.8	16.7	29.2	12.5
Financial problems	33.3	25.0	8.3	8.3	25.0

TABLE 4 Percentage of Parents' Perception on their Children's Speech Intelligibility

Speech intelligibility	*Completely unintelligible*	*Mostly unintelligible*	*Somewhat intelligible*	*Mostly intelligible*	*Completely intelligible*
to parents	8.3	0.0	8.3	33.3	50.0
to unfamiliar people	0.0	4.2	20.8	33.3	41.7

TABLE 5 Means and Percentage Distribution of the Level of Agreement towards Statements Related to CLP

Statement	*Mean (SD)*	*Strongly disagree*	*Disagree*	*Neutral*	*Agree*	*Strongly agree*
1. Beautiful children seldom have cleft lips and/or palates.	2.17 (1.09)	37.5	20.8	29.2	12.5	0.0
2. Typical parents can have children with clefts.	4.25 (1.07)	4.2	0.0	20.8	16.7	58.3
3. A child born with a cleft is often the parent's fault.	2.21 (1.25)	37.5	25.0	25.0	4.2	8.3
4. Children with clefts are punished by God or fate.	1.62 (0.97)	66.7	8.3	20.8	4.2	0.0
5. Parents of children with clefts are being punished by God or fate.	1.58 (1.02)	70.8	8.3	12.5	8.3	0.0
6. Parents are blamed for their children's cleft by others.	1.42 (0.97)	79.2	8.3	8.3	0.0	4.2
7. Mothers of children who have clefts have done something against traditional or old beliefs while pregnant that caused the cleft.	1.79 (1.02)	58.3	8.3	29.2	4.2	0.0
8. If I could choose, I would not want my child to have cleft lip and/or palate.	4.62 (0.77)	0.0	0.0	16.7	4.2	79.2

(Continued) *Statement*	*Mean (SD)*	*Strongly disagree*	*Disagree*	*Neutral*	*Agree*	*Strongly agree*
9. Since the birth of my child, I have become more tolerant of differences in others.	4.04 (0.86)	0.0	0.0	33.3	29.2	37.5
10. I have always been tolerant of differences in others.	4.12 (0.74)	0.0	0.0	20.8	45.8	33.3
11. Since the birth of my child, I have become more involved with groups or activities in the community, church, at online websites, etc.	3.25 (0.61)	0.0	4.2	70.8	20.8	4.2
12. My child can achieve anything he or she wants to achieve; my child will not be held back by the cleft.	4.17 (0.82)	0.0	0.0	25.0	33.3	41.7
13. Speech therapy is not effective until after the palate is surgically closed.	2.71 (1.27)	20.8	20.8	37.5	8.3	12.5
14. The child's speech should be discouraged until after the palate is repaired so that the child will not learn errors.	2.29 (1.20)	33.3	25.0	25.0	12.5	4.2
15. You have to wait several months after palatal surgery to start or resume speech treatment.	2.75 (1.33)	25.0	12.5	37.5	12.5	12.5

TABLE 6 Participants' Scores on the PSI

Subscale	*Mean (SD)*
1. Child domain	
a. Distractibility	24.58 (5.37)
b. Reinforcement to parents	11.62 (4.23)
c. Moodiness	11.50 (3.26)
d. Acceptability	15.04 (4.53)
e. Adaptability	26.00 (8.15)
f. Demandingness	23.3 (6.02)
2. Parent domain	
a. Sense of competence	35.92 (6.01)
b. Feelings of attachment	17.83 (3.81)
c. Restrictions of roles	20.46 (4.95)
d. Depression	24.00 (6.12)
e. Relationship with spouse	20.33 (5.25)
f. Social isolation	15.54 (3.73)
g. Parent health	15.54 (3.50)
3. Life stress	7.29 (5.95)

TABLE 7 Comparisons of Means in Different Domains of the PSI with the Norm

	Child domain	*Parent domain*	*Total stress*
Normative high score	116	148	258
Mean (SD)	112.00 (23.65)	149.62 (24.53)	263.21 (42.08)
Number of participants who scored at or above the normative high score	11 (45.8%)	12 (50.0%)	13 (54.2%)

TABLE 8 Sources of Information on CLP when the Child was Born

Source of information	*Sum of responses*
Hospital personnel, including nursing staff, speech therapist and social worker	20
Internet	8
General practitioner	7
Friends and/or Family	6
Surgeon	5
Books	3
HKACP	3

attained the highest scores, indicating that it was the most important source of information to the parents. Seven parents expressed that they still lack some information at present, mostly about the information on surgery. Some of parents also voiced their opinions on the need for improvement of current services. Three participants expressed that more detailed information system should be provided to parents by the hospital personnel. A detailed outline of the surgeries needed at each age, including information such as fee required and outcomes of the surgeries, was also suggested. One parent commented that more communication should be established between the hospital personnel and HKACP. When there was newborn of a child with CLP, the hospital personnel could give the information about HKACP to the parent immediately so that they could gain information and support. One parent wanted to know any financial support available for family with CLP children. One parent would like to know about the possible preventive measures of having a child with CLP.

The participants were also asked to choose the best support system when bringing up their children, as shown in Table 9. However, seven participants chose more than one system.

Therefore, the sums were calculated with and without the inclusion of their responses respectively. Family was chosen as the best support system among the choices. Cleft palate team was ranked as the second.

TABLE 9 Best Support System

Support system	*Sum of responses (n = 17)*	*Sum of responses (n = 24)*
Family	9	15
Medical Team/ Cleft Palate Team	3	9
Support Group	3	8
Religion	2	4
Friends	0	5

The parents were also asked to indicate what kind of rehabilitation services their children are currently receiving and had received in the past, which is shown in Table 10. Sixty percent of the children had received or were currently receiving speech therapy. One mother mentioned that her child should receive speech therapy but she was waiting for the service. For other medical specialists that parents had been seen besides surgeon, only one mother said that she had met the geneticist.

TABLE 10 Rehabilitation Services Received

Rehabilitation service	*Sum of responses*
Speech therapy - at present	10
- in the past	5
Dental surgery - at present	3
- in the past	8
Occupational therapy - at present	3
Physiotherapy - at present	1

Discussion

Parents' concerns

The present study revealed the four major parental concerns at present, including the child's health, social development, performance in school and speech development. For social development and performance in school, over 60 percent of the parents rated the level as concerned or above. The participants had great concern on their children's academic performance as other parents in Hong Kong (Ho et al., 1989; Stevenson & Lee, 1996).

Speech development of the child was rated as the fourth major concern among the parents. This could be explained because more than 60 percent (15 children) were currently receiving or have been received speech therapy in the past. Although the parents were quite concerned with their children's speech, they generally rated it as mostly intelligible to them and other people. As there was no objective measure of speech intelligibility in this study, it is possible that the parents might have overestimated their children's speech intelligibility. Also, the children may have had speech problems which did not interfere with intelligibility in a great extent, such as hypernasality or mild articulation errors (Fletcher, 1978).

For the child's appearance, contradictory findings were observed. Only six parents listed appearance a major concern. In addition, parents generally disagreed with the statement that beautiful children seldom have CLP. However, about sixty percent (13 parents) rated the level as concerned or above in the rating scale. As there were only five parents having children with CPO, the reason for this phenomenon was probably not due to the difference in the type of cleft. One hypothesis was the indirect approach that Chinese people adopt for self-disclosure (Bond, 1991). Chinese tend to reveal less about themselves so they might not be willing to disclose their concerns on the children's appearance. Another hypothesis was that the parents used an avoidance coping strategy. This persevering approach derives from

Confucius, with self-control strategies such as stopping thought and self-instruction in patience (Bond, 1991). They might persuade themselves that they should not solely focus on the appearance of their children.

For the issue of getting needed services, about two-thirds (15 parents) rated the level as concerned or above. One mother also commented that her child was waiting for speech therapy. For financial problems, the distribution shifted to no concern to slightly concerned level. Despite this, one mother wanted to know of any financial support available for families with CLP children. These implied that improvement should be made on the allocation of limited fiscal and health resources. Currently, there was a long waiting queue for speech therapy services in public hospitals. One and a half year waiting time for non-urgent cases, such as articulation disorders, was indicated in the report from a local hospital (The Hong Kong Association of Speech Therapists, n.d.). However, the parents might not be able to afford private speech therapy services. Therefore, the Hospital Authority should evaluate and consider the possibility in increasing the number of speech therapists working in public hospitals.

Parents' attitudes

The parents generally disagreed with the negative statements. Although an earlier study described many folk beliefs and superstitions about CLP in the Chinese population (Cheng, 1990), the parents disagreed with the statement that mothers had done something against traditional beliefs during pregnancy. This might imply that current views of Chinese towards CLP have changed. Maybe parents would find out the medical evidence for the underlying causes instead of believing old beliefs blindly. For the four statements investigating whether the parents should be blamed for their child's cleft or whether CLP was a punishment to the children and the parents, parents also disagreed with them. Some parents also voiced their opinions in disagreeing with the statements. Again, the results were dissimilar to those found in a previous study (Chan et al., 2006), in which the parents viewed CLP might be a punishment from God. This suggested that parental attitudes on this issue might have changed in these years.

On the other hand, the parents mostly agreed with the statements investigating positive outcomes found by recent research. They appeared to have become more tolerant of differences in others, more involved in the support groups or activities in the community and more appreciated the possibilities of things that their children could achieve. These findings were consistent with recent studies (Eiserman, 2001; Strauss, 2001) and revealed that the parents of CLP children thought in a more positive way than other people believed. For the most controversial statement, the parents largely agreed that they would not want their child to have CLP if they could choose. None of them rated disagree or strongly disagree. These results were different from those of Eiserman (2001) conducted in the United States, in which about half of the parents would not choose to remove their children's CLP if they had a choice. This might indicate a difference in the attitudes between Americans and Hong Kong Chinese. The Hong Kong parents might be overprotective so that they did not want their children to suffer if they could choose (Cheung, Loh & Ho, 2007).

For the statements focusing on speech therapy, it was discovered that a large proportion of the parents did not know the appropriate time to start speech therapy, despite that about 60 percent of participants (14 parents) had children who are receiving or had received speech therapy. They did not know the importance of speech therapy even when the palate was not surgically closed and at the time immediately after the palatal surgery. This might suggest that the parents did not know much about the benefits and importance of speech therapy throughout the whole period of the child's development. The functions of speech therapy may need to be explained clearly with sharing of successful cases (Cheng, 1990). Therefore, speech therapists should give accurate suggestions and provide more informative counseling to the parents if necessary in order to clarify any misconceptions.

Parenting stress

With reference to the total stress in the PSI, the mean was higher than the normative high score, which was consistent with the previous findings in the United States (Speltz, et al. 1990). More than half (13 parents) had total stress higher than 260, indicating a referral to professional consultation should be offered definitely. The findings showed the importance of affective counseling for parents in the clinical management of CLP children. However, psychologists, social workers and geneticists are rarely members of the multidisciplinary team in Hong Kong. Availability of social support was scarce. Only one mother noted she had seen a geneticist and none of them indicated that they had received any services from psychologists or social workers. Referral must be made so as to receive any psychological and genetic consultations. Therefore, the inclusion of counselors to the cleft palate team should be considered regarding the high level of stress endured by parents.

In the child domain, the findings suggested that parents underwent high parenting stress when they perceived their children as demanding. This was similar to the results from a study investigating the mental health of parents in Hong Kong (Kwok & Wong, 2000). Demandingness referred to the direct pressure the children placed on the parents. When the parents were coping with the children’s stressors, pressure resulted from facing defiance and demands for attention and service. Particularly in Hong Kong, the academic achievement of young children was highly concerned by parents as it affected the chance of admission to their preferred primary or secondary schools. It was a common belief in Hong Kong that success in school would bring better future and prospects (Ho et al., 1989). Parents have to make a tremendously large amount of effort to provide better education to their children, such as tutoring their children themselves (BGCA, 1984) or hiring private tutors (Bray & Kwok, 2003). As the parents' third concern was the child's performance in school, they might feel demands concerning the child's academic development.

In the parent domain, the mean was higher than the normative high score. By looking at the subscales, the parents encountered high parenting stress as they had doubts about their sense of competence and attachment from the child. Speltz et al. (1990) also found significantly elevated score for mothers of children with CLP in the competence subscale. They might not have enough knowledge in bearing children with physical defects. More areas of concern were resulted from CLP, such as child's appearance and craniofacial surgeries needed. Additionally, the parents' motivation to their parental roles was lower than other parents in Hong Kong. This might be contributed by not feeling a sense of emotional bonding from the child or inability to understand the child's feelings and needs.

In terms of service implications, training classes and support programmes may be offered to the parents so that they could gather suggestions on the child management. The suggestion to bridge the communication between the hospital personnel and the HKACP could also be adopted. The multidisciplinary team was responsible for giving assistance to form and encourage parent-run support groups (ACPA, 2007). Given that professional counseling service was scarce and costly, the hospital personnel could advice the parents to join the HKACP whenever they found parents who were in need of social support.

Parents' comments on the services received

The effects of parental stress could be moderated by the existence of social support. The best support system indicated by the parents was family. This personal social network could give them emotional and material support in facing the obstacles (Cochran & Brassard, 1979).

Hospital personnel were chosen by over 80 percent of the participants (20 parents) as their major source of information about CLP. Therefore, the hospital personnel act as frontline service providers to transmit accurate message to the parents, especially about the detailed schedule of the craniofacial surgeries required.

Certain parameters of this study may be viewed as limitations. First, the sample size was restricted. The findings might not be able to be generalized to all Hong Kong parents of children with CLP. Second, there was some concern about the representativeness of the sample. Parents who received services from public hospitals and other local private clinics were not studied. Future researches might invite parents from these sources so as to increase the sample size and make the sample become more representative. Third, the parenting stress of Hong Kong parents of children without CLP was not investigated. In Chicago, Krueckeberg and Kapp-Simon (1993) found that there was no difference in the parenting stress between parents with and without CLP children. Future investigations might give more indications of parenting stress solely contributed by CLP in Hong Kong. Finally, there was a lack of an established local norm with regard to the cut-off scores of the Chinese version of the PSI. Caution should be taken in drawing the conclusions about the prevalence of parenting stress of Hong Kong parents. Nonetheless, the information collected could help understand the relationship between parenting stress and child behavior problems. This can also be used for future comparisons. Further researches would be needed to establish the standard high stress scores among Chinese.

To conclude, the current study revealed the areas of concern, beliefs about CLP and sources of stress experienced by Hong Kong parents of children with CLP. The results revealed the importance of several improvements in the current medical and social services provided.

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Appendix

Parental Questionnaire

FOR RESEARCHER USE ONLY:

Date: ___________________________________

Participant Number: _______________________ Name: _____________________________

Background Information

Gender of Child: ________ Where was the child born (city/country)? _________________

Race/Ethnicity: __________________ (What culture or ethnicity do you most identify with?)

What is your nationality? __________

DOB: __________________________ Age: __________________________

Type of Cleft: CL CL&P CP SubMuc UniL BiL

Surgeries: ____

Language(s) spoken at home: ____

Interviewee: Mom_____ Dad_____

Occupation: Mom __________________________ Dad ____________________________

Private Health Insurance _______________ Public Health/ Medical Card ____________

What were three major concerns when your child was born? (In order of concern)

1. _________________________________
2. _________________________________
3. _________________________________

What are three major concerns at this point? (In order of concern)

1. _________________________________
2. _________________________________
3. _________________________________

Where did you obtain information about cleft lip and palate when your child was born?

Check all that apply.

___ Hospital personnel (e.g., nursing staff, speech and language therapist, social worker)

___ General Practitioner (GP)

___ Surgeon

___ Internet

___ Friends and/or Family

___ Books

___ TV/Radio/Newspaper

___ Other: ____

What do you believe are potential causes of cleft abnormalities?

____

Were you aware of what cleft lip and palate was prior to the birth of your child? YES NO

If YES, did you make any special preparations for the birth? ______________________

Presently, do you feel there is any information you are lacking? YES NO

If YES, what information do you need?

____

How many children do you have? _____________

If more than one, do any of your other children have a cleft lip and/or palate? ________

What services are you currently receiving for your child?

Occupational therapy Speech Therapy Physiotherapy Other: ___________

What services have you received in the past? _______________________________________

What type of medical specialists have you seen besides the surgeon?

Geneticist Neurologist Other: _____________________________

How well do you understand your child's speech?

Completely unintelligible	Mostly unintelligible	Somewhat intelligible	Mostly intelligible	Completely intelligible
1	2	3	4	5

How do you think others who aren't familiar with your child would rate his/her speech?

Completely unintelligible	Mostly unintelligible	Somewhat intelligible	Mostly intelligible	Completely intelligible
1	2	3	4	5

In your opinion what has been your best support system (check one only)?

___ Family

___ Friends

___ Medical Team/Cleft Palate Team

___ Religion (e.g., church groups, priest)

___ Support group (professional or non-professional support groups for parents who have children with cleft lip and/or palate)

___ Other: ____

For those at 5 years old or younger, "What form of care is your child receiving now?"

___ Preschool ______________________________________ (name)

___ A home-based daycare

___ Babysitter/ Family member

For those at 6 years old or older, "What is your child's school setting?"

___ Public School

___ Private School

Why did you choose that particular form of schooling? ______________________

Parents level of education:

Mom	Dad
___ Primary School	___ Primary School
___ Secondary School	___ Secondary School
___ Diploma	___ Diploma
___ Degree	___ Degree
___ Postgraduate	___ Postgraduate

Please rate your present level of concern on the following issues concerning your child:

	No concerns		Concerned		Extremely concerned
Physical appearance	1	2	3	4	5
Social development	1	2	3	4	5
Performance in school	1	2	3	4	5
Speech	1	2	3	4	5
Financial problems	1	2	3	4	5
Getting needed services	1	2	3	4	5

Please rate the following statements based on your level of agreement with those statements:

	Strongly disagree		Neutral		Strongly agree
Beautiful children seldom have cleft lips and/or palates.	1	2	3	4	5
Typical parents can have children with clefts.	1	2	3	4	5
A child born with a cleft is often the parent's fault.	1	2	3	4	5

(Continued)

	Strongly disagree		Neutral	Strongly agree	
Children with clefts are punished by God or fate.	1	2	3	4	5
Parents of children with clefts are being punished by God or fate.	1	2	3	4	5
Parents are blamed for their child's cleft by others.	1	2	3	4	5
Mothers of children who have clefts have done something against traditional or old beliefs while pregnant that caused the cleft.	1	2	3	4	5
If I could choose, I would not want my child to have cleft lip and/or palate. [a]	1	2	3	4	5
Since the birth of my child, I have become more tolerant of differences in others. [a]	1	2	3	4	5
I have always been tolerant of differences in others.	1	2	3	4	5
Since the birth of my child, I have become more involved with groups or activities in the community, church, at online websites, etc. [a,b]	1	2	3	4	5

(Continued)

	Strongly disagree		Neutral		Strongly agree
My child can achieve anything he or she wants to achieve; my child will not be held back by the cleft. [a,b]	1	2	3	4	5
Speech therapy is not effective until after the palate is surgically closed.	1	2	3	4	5
The child's speech should be discouraged until after the palate is repaired so that the child will not learn errors.	1	2	3	4	5
You have to wait several months after palatal surgery to start or resume speech treatment.	1	2	3	4	5

Do you have any additional comments you would like to add about the experiences you have had: ____

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