ATTITUDES AND CONCERNS OF PARENTS OF CLEFT PALATE CHILDREN ABOUT SPEECH PROBLEMS AND THERAPY IN THEIR CHILDREN

*RA'ED AL-SADHAN, BDS, MS, Diplom Amer Board of Oral & Maxillofacial Radiol
**IBRAHIM AL-MOTLAQ, BDS, DScD
***JON KAPALA, BS, DMD, MScD, FACD

ABSTRACT

The purpose of the study was to investigate: 1 - The attitudes and concerns of cleft palate (CP) patients and their parents toward speech problems and therapy, and 2 - The impact of speech problems on the CP patients' life. The study was conducted in the cleft palate unit of Montréal Children's Hospital, Canada. A questionnaire was used to collect the required data. The CP patients were divided into two groups; those without speech problem [group 1 = 26 (70%) patients] and others who had speech problems [group 2 = 11 (30%) patients]. The majority (91%) of parents of group 2 CP patients noticed the speech problem in their children when they were ≤3 years old. In more than half of these patients, the speech therapy started when they were 3 years old. The speech therapy was mostly long-term and conducted by a speech-language pathologist with some parental involvement. More than half of group 2 parents thought that the school teachers reacted in a positive way to their child's speech problem, and most had not been teased due to their speech problem. The low teasing rate was reflected by the high confidence level of this group; as 82% denied that they have less confidence level because of their speech problem. About two-third (64%) of the group 2 parents thought that their child's speech problems had a minor effect on their school results. Our results suggest that the parents of the CP children with speech problems had positive perception about the role of day care / school in improving the speech of their child. CP patients with speech problems showed low risk of developing problems such as confidence level, teasing by others, peer relationships and school performance.

INTRODUCTION

Management of a child with a cleft lip (CL) or palate (CP) necessitates a team effort as these children have multiple problems. They require the skills of a plastic surgeon, speech-language pathologist, pediatric dentist, orthodontist, otolaryngologist, pediatrician, geneticist, and an audiologist.[1] The development of normal speech is among the most important goals in these children. It is well recognized that patients with non-operated CP have severely disordered speech.[2] Speech-language pathologists assessing and treating CP individuals have a crucial role in speech development, remediation, and providing the interdisciplinary team with information to facilitate appropriate and timely decisions regarding physical management of velopharyngeal problems. The speech-language pathologists assess speech in relation to oral structures and to identify structural limitations.[3]

It has been reported that approximately 3% to 25% of CLP children will develop completely normal speech

* Assistant Professor, Department of Maxillofacial Surgery and Diagnostic Sciences, College of Dentistry, King Saud University, Riyadh, Saudi Arabia

** Consultant Pediatric Dentist, Security Forces Hospital Program, Riyadh, Saudi Arabia

*** Assistant Professor, Department of Pediatric Dentistry, Goldman School of Dental Medicine, Boston University, USA

Correspondence: Dr. Ra'ed Al-Sadhan, College of Dentistry, King Saud University, PO Box 60169, Riyadh 11545, Saudi Arabia. Telephone: +966-506479246, Facsimile: +966 1 4677422

after primary surgery, whereas others require multiple interventions throughout childhood and adolescence.[2] The problems that can occur in "CP speech" include abnormal articulation, resonance, nasal emission, laryngeal voice quality, intelligibility and acceptability[4]. Bureau *et al* (2001) reported a significant improvement in speech after closure of oronasal fistula, and concluded that early oronasal fistula closure might prevent permanent speech distortion in CP patient at an early age.[4]

Counseling of CP children and their parents is part of the clinical assessment process of the speech-language pathologist. Its purpose includes allaying parental concerns about the appropriate development of verbal communication and providing ways to foster speech and language at home. School-age patients are frequently included in the counseling provided by speech-language pathologists. Walesky-Rainbow & Morris (1978)[5] suggested that CP patients must be provided with more information about treatment plans and expected outcomes, to promote acceptance of their disabilities and stimulate continuation of speech therapy as necessary.

Speech program goals may include counseling of parents about early language development. It also includes a home speech and language stimulation program directed by the speech-language pathologist or direct therapy for the child when indicated.[6] Speech therapy can possibly begin as early as 2 years of age. Speech therapy focuses on preventing development of compensatory articulation behaviors and production of sounds appropriate for the child's chronological age.[3]

It has been proposed that attempts to foster social and communication development must not be limited to direct clinical and educational activities. It must pervade the child's natural partnerships.[7] CP patients accompanied by their mothers during speech intervention had significantly better language skills compared with patients treated with a speech-language pathologist only.[7] Pamplona et al (2001) reported that mothers made excellent improvements in their communication style and mode of interaction with their children when they were included as active participants and had the opportunity to learn and to use the facilitative strategies. They also recommended that both parents should be encouraged to participate actively during the speech intervention sessions and, most importantly, to use the strategies naturally during everyday activities.[8] It may also be mentioned here that speech difficulties have been reported to be associated with teasing.[9]

Concerns regarding speech development are thought to be less significant than appearance in contributing to low self-esteem among CP individuals, and it has been shown that age has an important effect on the rating of importance of appearance and/or speech concerns.[10,11] Interestingly, language and learning problems constituted a relationship to cleft types. The children with CP only were found to have more general disabilities and extensive cognitive-learning difficulties[12]. Millard and Richman found that CP children appear to have the highest risk of learning and adjustment problems because of reported problems in both adjustment and learning.[12] As CP children have significant speech difficulties and learning problems[3], they should receive careful monitoring not only for cleft related conditions but also for possible learning and adjustment problems.[12]

It has been reported that there is a good agreement between parents and their children on issues regarding cleft[13] and some studies also reported few inconsistencies between parents and patients concerns.[14] However, Turner et al (1997)[9] reported a lack of agreement between parents and their children on issues regarding the cleft palate. The purpose of the present study was to investigate the attitudes and concerns of CP patients and their parents toward speech problems and therapy, and the impact of speech problems on some aspects of the CP patient's life.

SUBJECTS AND METHODS

Patient Selection

This study was conducted in the cleft palate unit of Montréal Children's Hospital, Canada. Patient selection criteria included the following:

1. Patients with a diagnosis of CP only. The focus only on the CP patients may contribute to a better understanding of the possible effect of speech problems in everyday life without the confounding variables related to appearance.

2. Patients were excluded if they had a genetic syndrome other than the CP.

3. Minimum age was nine years.

Surveying Procedures:

A questionnaire was designed to obtain information about the following variables:

Speech problem and therapy:

- Presence of speech problem (yes or no).
- Age of onset of speech problem: one year old, three years old or > four years old.
- Age of onset of speech therapy if any: ≤ three year old, 3-6 year old or 6-9 year old.
- Type of speech therapy: only evaluation, more than 10 sessions with little parent participation or not more than 10 sessions with parents' participation.
- Did school and day care improve speech: yes or no.
- Did surgery and orthodontic treatment improve speech: yes or no.

Impact of the speech status in the educational, social and emotional feelings of the patient:

- Reaction of school teacher to the speech problem: positive (supportive and participated in improving child's speech), little reaction, or no reaction.
- Effect of speech problem on school results: very much affected, very little effect, or not affected.
- Teasing rate associated with speech: always, sometimes or never.
- Are you less confident due to speech (making new friends, speaking to people and in public): always, sometimes or never.
- Repetition and shortness of speech: yes or no.
- Have you felt rejected by peers due to speech: yes or no.
- Are you satisfied with the current speech: yes or no.

Role of surgery, orthodontic treatment, day care and school in improving speech:

- Did speech improve after surgery: yes or no.
- Did speech improve after orthodontic treatment: yes or no.
- Did speech improve after day care: yes or no.
- Did speech improve after school: yes or no.

Some of the questions were obtained from previous studies.[9,14] The questionnaire was pretested and appropriate modifications were made before the questionnaires were distributed. The questionnaires were distributed by mail to each subject along with a consent form to be signed by parents (and patients if applicable). Patients and the parents received the same questionnaires except for three questions. Patients were not asked about the onset of the speech problem and the role of the school or day care in improving speech. It was stressed that questionnaires should be absolutely not discussed between child and parent. A total of 110 questionnaires were sent to all the active patients with complete contact address to respond and mail them back to Montréal Children's Hospital.

RESULTS

Thirty seven families returned their questionnaires with both the parents and the patients answering the questions (30% response rate). Patients' age ranged from 9-23 years with a mean of 15.1 (SD 3.0) years. The sample consisted of 24 females (65%) and 13 male (35%). The results revealed that the response agreement between parents and patients was high enough with very minor differences. Therefore, it was decided to consider the parent's questionnaires for easier interpretation and presentation. However, the insignificant differences between parents' and patients' responses are presented in Figs. 1, 3 and 4. It is important to emphasize that the results are parent-reported, and therefore not necessarily objective. Reports from parents were not compared to the child's case records and professional speech evaluations.

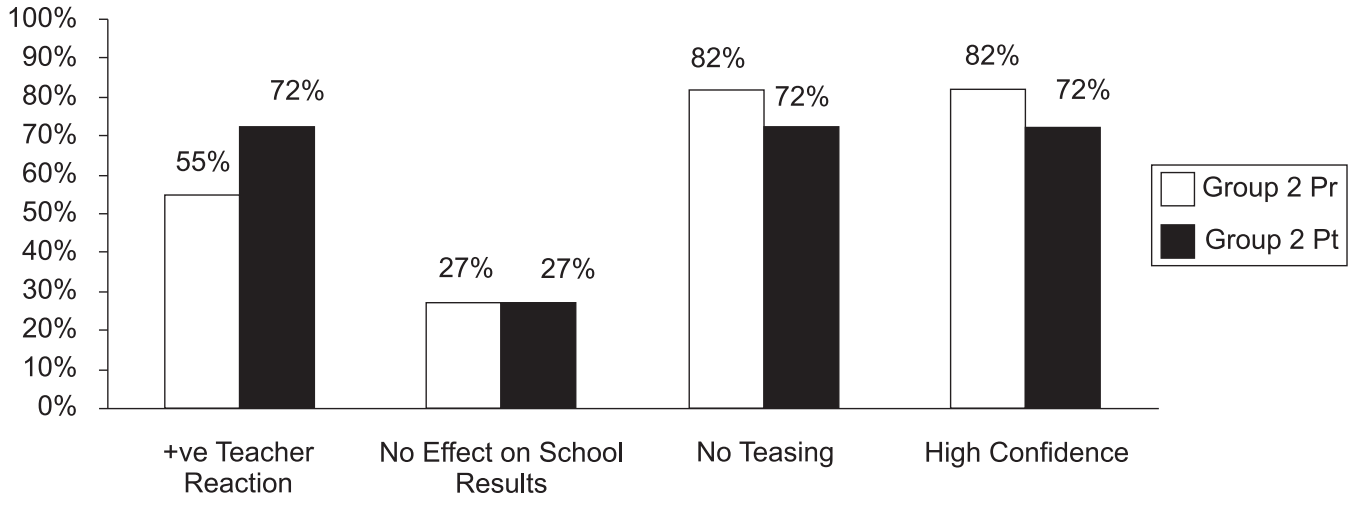

Fig 1: The high agreement between parents (Pr) and patients (Pt) in group 2 regarding speech issues

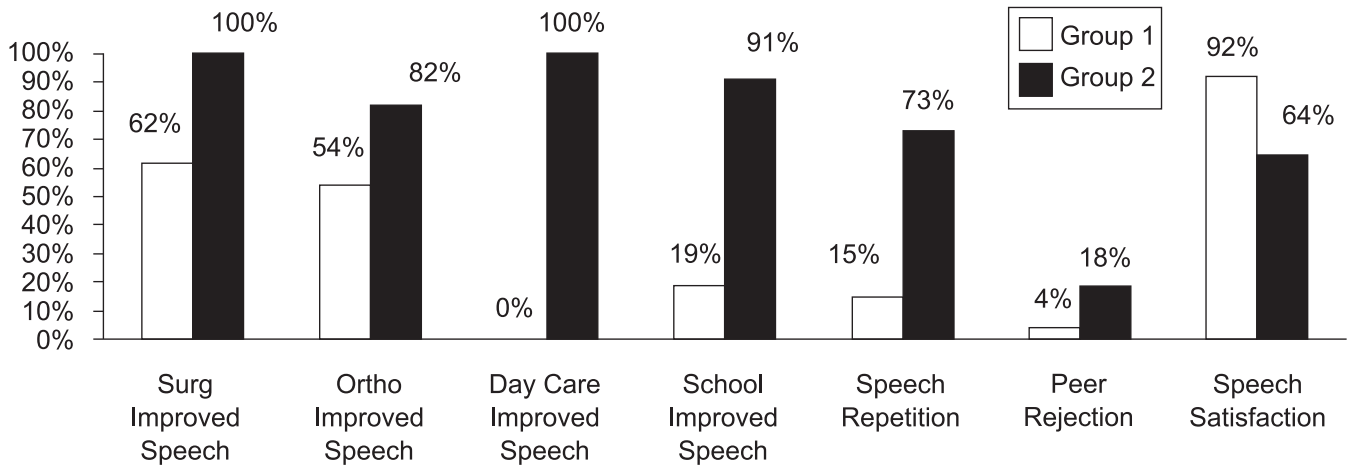

Fig 2. The statistical differences between parents' responses of the two groups to certain variables.

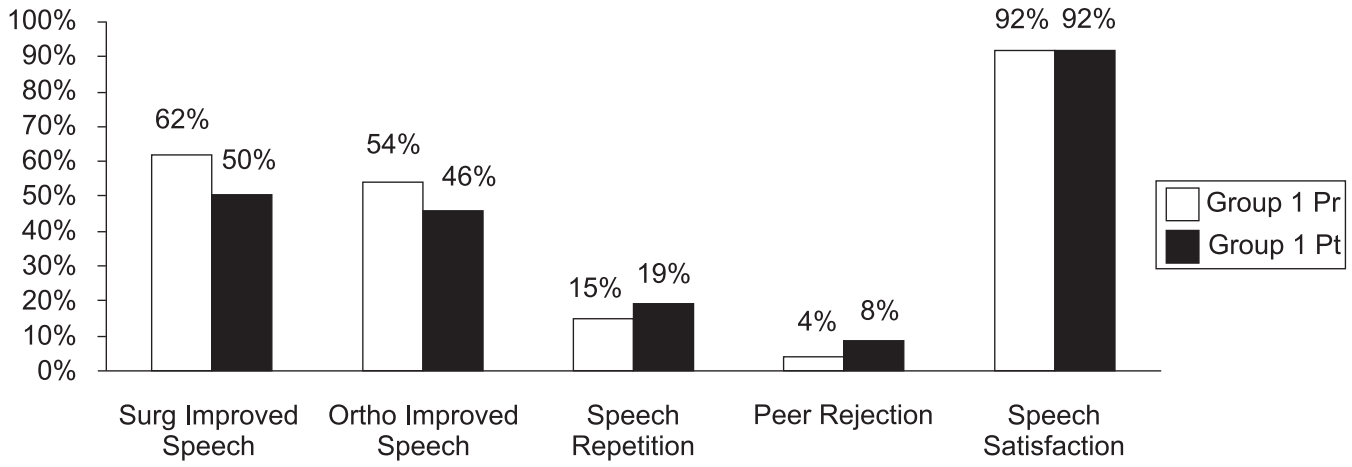

Fig 3: The high agreement between parents (Pr) and patients (Pt) in group 1 regarding certain variables.

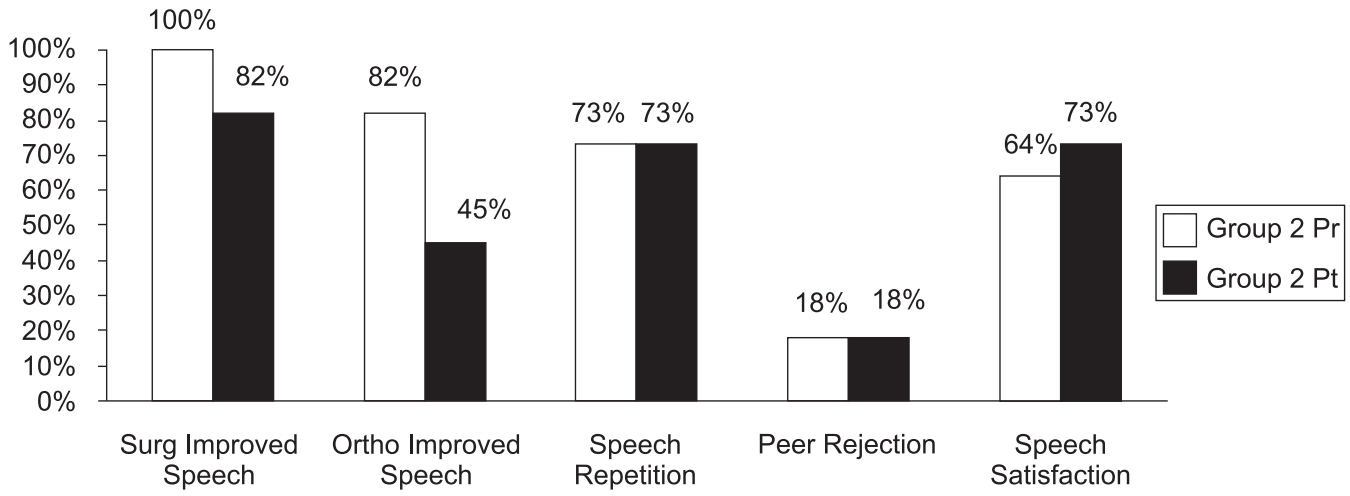

Fig 4: The high agreement between parents (Pr) and patients (Pt) in group 2 regarding certain variables.

The study sample was divided into two groups; patients who did not consider themselves to have a speech problem (group 1 = 26 subjects, 70%) and patients who considered themselves to have a speech problem (group 2 = 11 subjects, 30%). The majority (91%, 10 patients) of the parents of patients with a history of speech problem (group 2) noticed the speech problem of their child at the age of three years or less. In more than half of these patients (7 patients), the speech therapy started when they were three years old and in three patients the therapy started when they were between 3 and 6 years old. Only one patient started speech therapy between the age 6 to 9 years.

The majority of speech therapy (55%, 6 patients) was long-term conducted by a speech-language pathologist (more than 10 sessions) with some parental involvement. Three patients (27%) had been under short-term therapy by a speech-language pathologist (not more than 10 sessions). Only one patient had been under evaluation by the speech-language pathologist without active treatment.

More than half of the group 2 (55%, 6 patients) thought that the school teacher reacted in a positive way to their speech problem and 36% (4 patients) thought that the teacher showed little reaction. Only

Onset of speech problem	1 year old 64%	3 years old 27%	> 4 years old 9%
Onset of speech therapy	≤3 year old 64%	3-6 years old 27%	6-9 years old 9%
Type of speech therapy	Only evaluation 9%	Long with little parent participation 55%	Short with more parent participation 27%
Reaction of school teacher to the speech problem	Positive way 55%	Little 36%	No reaction 9%
Effect of speech problem on school results	Very much affected 9%	Very little 64%	Not affected 27 %
Teasing rate associated with speech	Always 9%	Sometimes 9%	Never 82%
Less confident due to speech	Always 0%	Sometimes 18%	Never 82%

TABLE 1: RESPONSES OF GROUP 2 TO SOME VARIABLES

	Group 1	Group 2	p-value	Stat. difference
Speech improved after surgery	62%	100%	.018	Significant
Speech improved after orthodontic treatment	54%	82%	.547	Not significant
Speech improved after day care	0%	100%	.000	Significant
Speech improved after school	19%	91%	.000	Significant
Repetition and shortness of speech	15%	73%	.003	Significant
Felt rejected by peers due to speech	4%	18%	.100	Not significant
Satisfied with the current speech	92%	64%	.031	Significant

TABLE 2: STATISTICAL DIFFERENCES BETWEEN THE TWO GROUPS IN PARENTS' RESPONSES TO SOME VARIABLES.

one patient thought that there was no reaction at all. Finally, only in one patient it was thought that having a speech problem had a major effect on the school results and 64% (7 patients) thought that their speech problem had a minor effect on their school results, and 27% (3 patients) denied any effect.

It is encouraging that 82% (9 patients) of group 2 had not been teased due to their speech problem and only 18% (2 patients) had been teased always or sometimes. The low teasing rate was reflected by the high confidence level of this group, 82% (9 patients) denied that they have less confidence level because of their speech problem. The agreement between the parents and patients responding to these variables was high and the differences between them were not statistically significant ($p>.05$).

Table 2 and Figure 2 illustrate differences between the two groups in some variables. Only 19% of the total sample (7 patients) required a secondary surgery after the initial surgery. All of group 2 subjects thought that the surgery improved their speech while 61% of group 1 (16 patients) thought this way, this difference was statistically significant ($X.^2= 5.64$, df=1, p=.018). Orthodontic treatment had been done for 65% of the patients in the total sample (24 patients), 80% of group 2 (9 patients) thought that it improved their speech and 53% of group 1 (14 patients) thought so. This difference was not statistically significant ($X.^2= 1.21$, df=2, p=.55). All of group 2 whose children who had been in the day care thought that speech improved in their children. In addition, 91% (10 patients) thought that school improved the speech of their children. However, none of the parents in group 1 shared the same opinion for the day care effect and only 19% (5 patients) did for the school. These differences were statistically significant ($X.^2= 18.00$, df=2, p=.00 and $X.^2= 17.113$, df=2, p=.00 respectively).

The vast majority of group 2 (73%, 8 patients) have some speech difficulties reflected by repetition or shortness of what they say to be understandable. In contrast, only 15% (4 patients) of group 1 have the same problem. This difference was statistically significant ($X.^2= 11.6$, df=2, p=.003). Only 18% of group 2 (2 patients) thought that they had been rejected by peers because of their speech problem and only one patient (4%) in group 1 thought the same way. This difference was not statistically significant ($X.^2= 4.8$, df=2, p=.091). The satisfaction level with current speech between the two groups was different as 64% of group 2 (7 patients) were satisfied and 92% of group 1 (24 patients) were satisfied. This difference was statistically significant ($X.^2= 4.677$, df=1, p=.031). The agreement between the parents and patients responding to these variables (in both group 1 and group 2) was high. The differences between them were not statistically significant ($p>.05$).

DISCUSSION

Few studies have reported the speech problem of patients with only CP specifically and its impact on their life. However, many reports have focused on patients with cleft lip and palate (CLP) including patients with CP in same studies. These reports may have reduced the significance of the results since the ratings for appearance and speech among patients with CP were grouped together with those rankings from patients with CLP.[9]

According to the results of the present study, 30% of the sample had speech problems in the past which required speech therapy. This finding agrees the previous reports by Strauss et al. (1988)[13] and Persson et al. (2002).[15] On the other hand, some other reports have shown that 80% of their sample had required speech therapy.[2,16]

Active participation of the mothers results in excellent improvement in the communicative style and mode of interaction with their children when they are included in the speech therapy.[7,8] Only 27% of our sample has had active participation by their parents. The reason for the imbalance is the cleft unit has recently implemented this modified type of speech therapy after most of our sample already had finished their therapy.

The results of the present study showed the important role that the school might play in improving the speech of patients with CP. That observation can be explained in different ways; first, most of the parents felt that entering day care and school improved their children's speech. Second, most of parents felt that school teachers reacted in a positive way to improve their child's speech. Third, only 9% of our sample felt having speech problems affected their school results. These results do not agree with the findings of Broder et al (1998)[17] which showed 46% of their sample had learning disabilities. In addition a higher rate of reading and learning disabilities were found among children with CP than among patients with CLP.[12,18] Reviewing the school reports of our sample may be helpful to confirm these finding.

Only 19% of the total sample (7 patients) required secondary surgery which is within the normal range (11%-25%).[19,20] As reported earlier by Noar (2001)[14], our results showed high satisfaction with the surgery and all of Group 2 felt that surgery improved their speech. On the other hand, only 61% of group 1 thought that speech had been improved by surgery, their lower perception of improvement may be related to a lack of need for such surgery which was most likely performed to address other indications different from the speech problem specifically. This could also explain group 1 lower perception of improvement by orthodontic treatment and day care. Similarly group 1 lower perception of speech difficulties, rejection and satisfaction with speech can be explained the lack of a definitive speech problem.

Only 18% of Group 2 has been teased and the same number felt less confident because of their speech problem. These results are much lower than other reports which indicated 60%-75% of their sample had been teased and 50%-73% felt less confident due to their cleft problem.[9,14] Another report revealed that the group with CP was rated as showing significantly higher levels of depression, anxiety, and increased problems on self perception than the group with CLP.[12]

Although most of Group 2 have current speech difficulties (repetition and shortness of speech), they have adjusted themselves to defeat this problem and act like normal individuals in interpersonal relationships and being accepted by peers. These findings contradict other findings that indicate children with CP appear to have the highest risk of psychological problems because of reported problems in both adjustment and self-perception.[12] Another report suggested that individuals with cleft expressed self-concern and self-doubt regarding interpersonal relationships.[21] The adjustment and the self-confidence of our samples are reflected by their high satisfaction with their speech at the moment of conducting these questionnaires and by agreement on the high satisfaction with speech that have been reported earlier.[9,12-14,17]

Although the survey questions with yes or no answers will provide fewer differences in agreement between parents and their children than graded scale questions, the fact that there was a high overall agreement suggests that those responses were realistic appraisals of treatment outcome and speech.[13] The possibility exists that adolescents with cleft and their parents are able to agree when focusing in treatment status. Care of adolescent with cleft usually calls for the adolescent patients and their parents to work together, to be mutually supportive, and to share treatment decisions.

The results of the present study should be carefully interpreted for the following reasons; first, one should not draw close parallels between our study and studies carried out in the United States and the United Kingdom since the attitude toward psychological medicine and body image may differ between populations.[14] Second, parents and patients may have given socially

desirable responses anticipating what investigators want [14], or some of them engaged in denial. [13] Third, our sample size is small which may have hidden some realities and made differences between various responses not statistically significant. Unfortunately generalizations of the findings of this study are limited. Inclusion of more participants in such a study might make the results more representative. Alternatively, replication studies in the same hospital or in other centers with larger sample size would be helpful. The low response rate in this study may be explained in different ways. First, patients have not been under the care of cleft team since a long time. Second, some of the patients were married and separated from their parents.

CONCLUSIONS

1 Parents and patients in this study shared the same positive concerns and attitudes to treatment outcome and speech.

2 The parent's had positive perception about the role of day care and school in improving the speech of CP children.

3 Patients with CP reported low risk of developing problems with confidence level, teasing, and peer relationships. In addition they reported normal school achievement.

REFERENCES

1 Austin PW. Speech, language, and hearing management of the child with cleft palate. Med Health R I 2001;84:401-2.

2 Sell D, Grunwell P, Mildinhall S, Murphy T, Cornish TA, Bearn D, et al. Cleft lip and palate care in the United Kingdom—the Clinical Standards Advisory Group (CSAG) Study. Part 3: speech outcomes. Cleft Palate Craniofac J 2001;38:30-7.

3 Kuehn DP, Moller KT. Speech and Language Issues in the Cleft Palate Population: The State of the Art. Cleft Palate Craniofac J. 2000;37(4):348-48.

4 Bureau S, Penko M, McFadden L. Speech outcome after closure of oronasal fistulas with bone grafts. J Oral Maxillofac Surg 2001;59:1408-13; discussion 13-4.

5 Walesky-Rainbow PA, Morris HL. An assessment of informative-counseling procedures for cleft palate children. Cleft Palate J 1978;15:20-9.

6 Schaefer L, Sullivan MD. The speech-language pathologist's role on the craniofacial team. Ear Nose Throat J 1986;65:30-42.

7 Pamplona MC, Ysunza A. Active participation of mothers during speech therapy improved language development of children with cleft palate. Scand J Plast Reconstr Surg Hand Surg 2000;34:231-6.

8 Pamplona MC, Ysunza A, Jimenez-Murat Y. Mothers of children with cleft palate undergoing speech intervention change communicative interaction. Int J Pediatr Otorhinolaryngol 2001;59:173-9.

9 Turner SR, Thomas PW, Dowell T, Rumsey N, Sandy JR. Psychological outcomes amongst cleft patients and their families. Br J Plast Surg 1997;50:1-9.

10 Richman LC. Self-reported social, speech, and facial concerns and personality adjustment of adolescents with cleft lip and palate. Cleft Palate J 1983;20:108-12.

11 Richman LC. Facial and speech relationships to behavior of children with clefts across three age levels. Cleft Palate Craniofac J 1997;34:390-5.

12 Millard T, Richman LC. Different cleft conditions, facial appearance, and speech: relationship to psychological variables. Cleft Palate Craniofac J 2001;38:68-75.

13 Strauss RP, Broder H, Helms RW. Perceptions of appearance and speech by adolescent patients with cleft lip and palate and by their parents. Cleft Palate J 1988;25:335-42.

14 Noar JH. Questionnaire survey of attitudes and concerns of patients with cleft lip and palate and their parents. Cleft Palate Craniofac J 1991;28:279-84.

15 Persson C, Elander A, Lohmander-Agerskov A, Soderpalm E. Speech outcomes in isolated cleft palate: impact of cleft extent and additional malformations. Cleft Palate Craniofac J 2002;39:397-408.

16 Peterson-Falzone SJ. Speech outcomes in adolescents with cleft lip and palate. Cleft Palate Craniofac J 1995;32:125-8.

17 Broder HL, Richman LC, Matheson PB. Learning disability, school achievement, and grade retention among children with cleft: a two-center study. Cleft Palate Craniofac J 1998;35:127-31.

18 Richman LC, Eliason MJ, Lindgren SD. Reading disability in children with clefts. Cleft Palate J 1988;25:21-5.

19 Morris HL, Bardach J, Ardinger H, Jones D, Kelly KM, Olin WH, et al. Multidisciplinary treatment results for patients with isolated cleft palate. Plast Reconstr Surg 1993;92:842-51.

20 Muzaffar AR, Byrd HS, Rohrich RJ, Johns DF, LeBlanc D, Beran SJ, et al. Incidence of cleft palate fistula: an institutional experience with two-stage palatal repair. Plast Reconstr Surg 2001;108:1515-8.

21 Harper DC, Richman LC. Personality profiles of physically impaired adolescents. J Clin Psychol 1978;34:636-42.