

Attitudes and Concerns of Parents of Cleft Palate Children about Speech Problems and Therapy

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Abstract

Aim: The purpose of the study was to investigate: 1-The attitudes and concerns of patients with cleft palate (CP) and their parents toward speech problems and therapy 2-The impact of speech problems on the patient's life.

Subjects and Methods: This study was conducted in the cleft palate unit of Montréal Children's Hospital, Canada. A questionnaire was used to collect the data on CP patients and their parents' attitudes and concerns about speech problems and therapy.

Results: Subjects of this study were divided into two groups; patients who have not had speech problem (group 1 = 26 subjects, 70%) and patients who have had speech problems (group 2 = 11 subjects, 30%). The majority (91%) of the parents in group 2 noticed the speech problem of their child when they were ≤ 3 years. In half of these patients, the speech therapy started when they were 3 years old. The majority of speech therapy was long-term and conducted by a speech-language pathologist with some parental involvement. More than half of group 2 thought that the school

teacher reacted in a positive way to their speech problem and most had not been teased due to their speech problem. About 63% thought their speech problem had a minor effect on their school results. The low teasing rate was reflected by the high confidence level of this group, 82% denied that they have less confidence level because of their speech problem.

Conclusions: Our results suggested the parent's had positive perception about the role of day care and school in improving the speech. Unlike most of previous reports, patients with only CP showed low risk of developing problems with confidence level, teasing, and peer relationships. In addition they showed normal school achievement.

Introduction

Management of a child with a cleft lip (CL) or palate (CP) necessitates a team approach since the problems that such a child incurs are abundant; they require the skills of a plastic surgeon, speech-language pathologist, pediatric dentist, orthodontist, otolaryngologist, pediatrician, geneticist, and audiologist.¹ The development of normal speech is among the most important goals. It is well recognized that patients with non-operated CP have severely disordered speech.² Speech-language pathologists assessing and treating persons with CP have a crucial role in speech development, remediation, and providing the interdisciplinary team with information that facilitate appropriate and timely decisions regarding the need for physical management of velopharyngeal problems. The role of the speech-language pathologists is to assess speech in relation to oral structures and to identify structural limitations.³

It has been reported that approximately 3% to 25% of children with CLP will develop completely normal speech after primary surgery, whereas others require many 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 acceptability⁴. Bureau *et al* in 2001 reported that a significant improvement in speech is noticeable after a closure of oronasal fistula and concluded that early oronasal fistula closure might prevent permanent speech distortion of the CP patient at an early age.⁴

Counseling of parents and children 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 for them

to foster speech and language at home. School-age patients are frequently included in the counseling provided by speech-language pathologists. Walesky-Rainbow and Morris concluded in their study that CP patients must be given more information about treatment plans, be aware of expected outcomes to promote acceptance of their disabilities, and to stimulate continuation of speech therapy, as necessary.⁵

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.³ 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 On the other hand, it has been found that speech difficulties are associated with teasing.⁹ However, concerns regarding speech are thought to be less significant than appearance in contributing to low self-

esteem among cleft affected 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 a cleft subtype. This relationship indicated that children with CP only were found to have more general disabilities. This resulted in more extensive cognitive-learning difficulties. Millard and Richman found that children with CP appear to have the highest risk because of reported problems in both adjustment and learning.¹² Children with CP have significant speech difficulties and learning problems.³ They should receive careful monitoring, not just for cleft related conditions but also for possible learning and adjustment problems as well.¹² It has been reported that there is good agreement between parents and their children on issues regarding cleft¹³ and some studies reported few inconsistencies between parents and patients concerns.¹⁴ However, Turner et al (1997) reported lack of agreement between parents and their children in issues regarding cleft.⁹ The purpose of the study was to investigate the attitudes and concerns of patients with CP and their parents toward speech problems and therapy and the impact of speech problems on the patient's life.

Subjects and Methods

Subjects

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 CP 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 diagnosed genetic syndrome other than CP.
3. Minimum age was nine years.

Surveying Procedures

A questionnaire was designed to investigate the following variables:

Speech problem and therapy:

- Presence of speech problem: yes or no.
- Onset of speech problem: 1 years old , 3 years old or > 4 years old.
- Onset of speech therapy if any: >3 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 more parent participation.
- Did school and day care improved speech: yes or no.
- Did surgery and orthodontic treatment improved speech: yes or no.

Impact of the speech status in the educational, social and emotional feeling of the patients:

- Reaction of school teacher to the speech problem: positive way (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 improved after surgery: yes or no.
- Did speech improved after orthodontic treatment: yes or no.
- Did speech improved after day care: yes or no.
- Did speech improved after school: yes or no.

Some of the questions were obtained from previous studies.^{9, 14}

Pretest was conducted including interviews with subjects to ensure that the questioner was comprehensible and valid. Appropriate modifications were made before these questionnaires were distributed.

The questionnaire was 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). Age range of patients was from 9 to 23 years of age with mean age was 15.1 years (standard deviation = 3). The sample consisted of 24 females (65%) and 13 male (35%). The mean age and gender distribution of the respondents are similar to the overall sample. The results revealed that the agreement between parents and patients was high enough with

very minor differences thus, it was decided to consider the parent's questionnaires for easier interpretation and presentation but we will still show the differences between parents and patients responses (Fig. 1, 3 and 4). It should be stressed that our results are parent-reported, and not necessarily objective. Reports from parents were not compared to the child's case records and professional speech evaluations. Subjects of this study were divided into two groups; patients who have not had speech problem, their speech might be different however, they still 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 when they were 3 years or less. In more than half of these patients (7 patients), the speech therapy started when they were 3 years old and in 27% (3 patients) therapy started when they were between 3 and 6 years old. Only one patient (9%) started speech therapy when he was between 6 and 9 years old.

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 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 reaction was little. Only one patient thought that there was no reaction at all. Only one patient thought that having a speech problem had a major effect on the

school results. Finally, 63% (7 patients) thought their speech problem had a minor effect on their school results, and 18% (2 patients) denied any effect.

It is encouraging that 82% (9 patients) of group 2 had not been teased in association 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 1: Responses of group 2 to some variables:

Onset of speech problem	1 year old	3 years old	> 4 years old
	64%	27%	9%
Onset of speech therapy	>3 year old	3-6 years old	6-9 years old
	27%	46%	27%
Type of speech therapy	Only evaluation	Long with little parent participation	Short with more parent participation
	9%	55%	27%
Reaction of school teacher to the speech problem	Positive way	Little	No reaction
	55%	36%	9%
Effect of speech problem on school results	Very much affected	Very little	Not affected
	9%	63%	18 %
Teasing rate associated with speech	Always	Sometimes	Never
	9%	9%	82%
Less confident due to speech	Always	Sometimes	Never
	0%	18%	82%

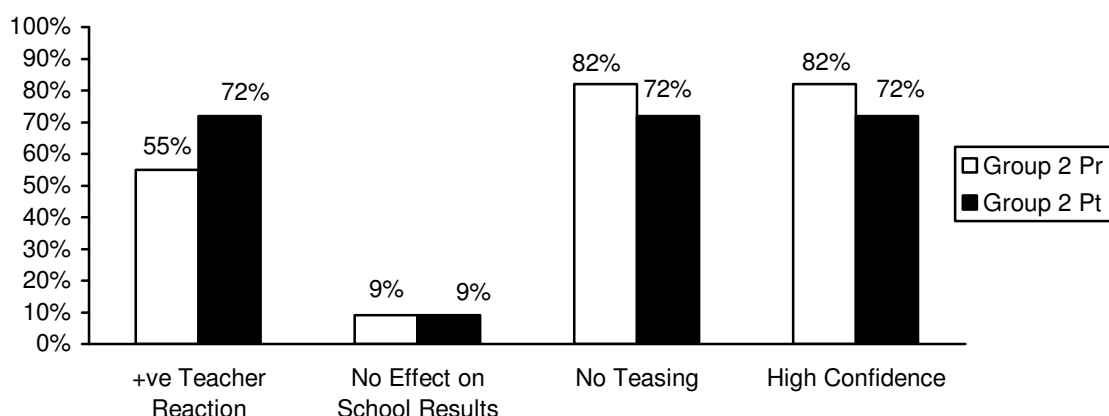


Fig 1: The high agreement between parents (Pr) and patients (Pt) in group 2 regarding speech issues

Differences between the Two Groups in Some Variables:

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 and only 61 % of group 1 (16 patents) though this way, this difference was statistically significant ($\chi.^2= 5.64$, $df=1$, $p=.018$). 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 ($\chi.^2= 1.21$, $df=2$, $p=.55$). All of group 2 whose children 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 ($\chi.^2= 18.00$, $df=2$, $p=.00$) and ($\chi.^2= 17.113$, $df=2$, $p=.00$) 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 ($\chi.^2= 11.6$, $df=2$, $p=.003$).

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 ($\chi.^2= 4.8$, $df=2$, $p=.091$).

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 ($\chi.^2= 4.677$, $df=1$, $p=.031$).

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 ($p > .05$).

Table 2: Statistical differences between the two groups in parents' responses 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

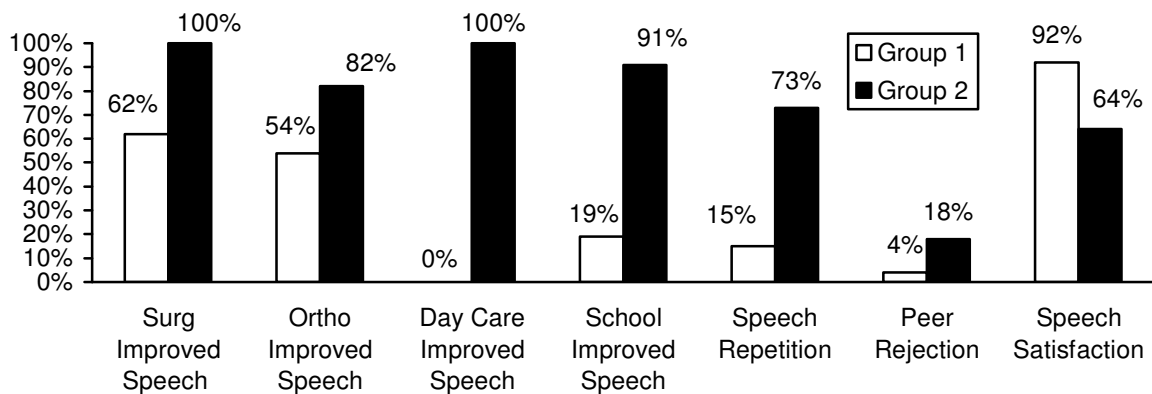


Fig 2: The statistical differences between parent' responses of the two groups to certain variables.

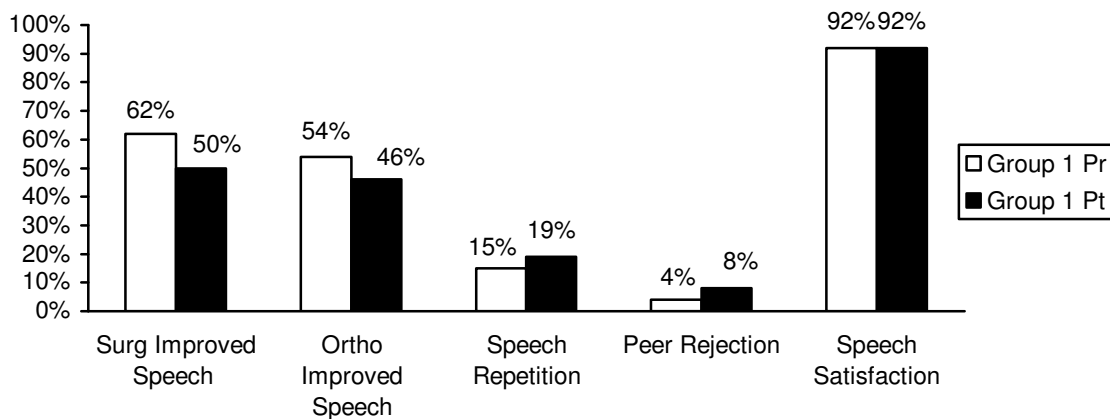


Fig 3: The high agreement between parents (Pr) and patients (Pt) in group 1 regarding certain variables.

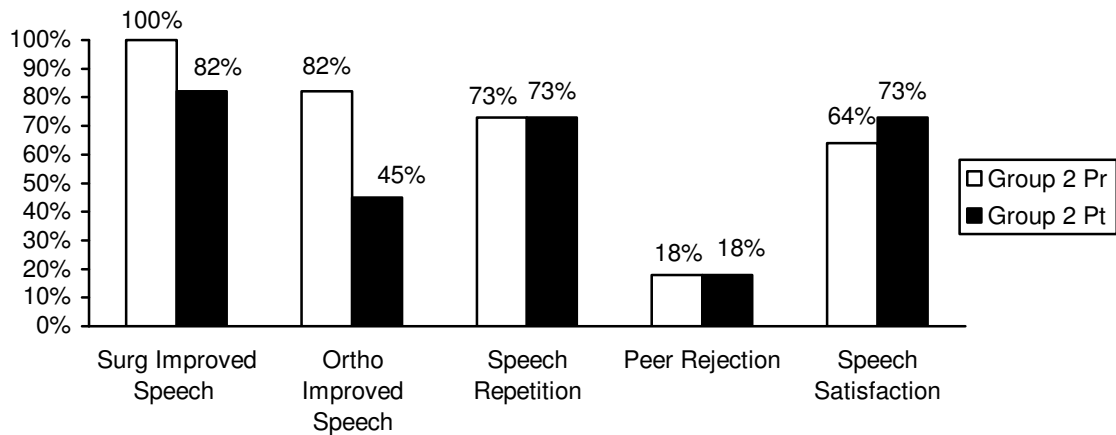


Fig 4: The high agreement between parents (Pr) and patients (Pt) in group 2 regarding certain variables.

Discussion

Few reports have studied the speech problem of patients with only CP specifically and its impact to 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 our results, 30% of our sample have had speech problems in the past which required speech therapy. This finding agrees the previous reports by Strauss et al. (1988) and Persson et al. (2002).^{13, 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're included in the speech therapy.^{7, 8} Only 27% of our sample have 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.

Our results 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) which showed 46% of their sample had learning disabilities.¹⁷ 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 surgery improved their speech. On the other hand, only 61% of group 1 thought 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 have 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

Our results 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 want¹⁴, or some of them engaged 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 are 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.

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