

Assessment of Change in SOC of Parents Participating in the Treatment of Their Children Having Cleft Lip & Palate Anomalies

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ABSTRACT

BACKGROUND

Cleft lip and palate (CLCP) is one of the most common birth defects. The birth of a child with a facial cleft is a tragic incident for the family that the child is born in. Not only is the family devastated by the apparent facial deformity, but also worried about several other issues such as care of the child, the treatment options, and the social impact that the cleft will have for the child and for the family. The purpose of the study was to assess the sense of coherence in parents participating in the treatment of their children with CLCP.

METHODS

50 parents of children with CLCP were evaluated and a questionnaire study was carried out at time intervals of T0, T1 and T2.

RESULTS

Most of the parameters were found to be statistically significant ($P < 0.05$). Overall subjective results were found to be non-significant from T0 - T1. In our study, we found that undergoing orthodontic treatment had positive effects on the parents of patients with CLCP. It was observed that it altered the psychological, financial, emotional and social wellbeing of the parents.

CONCLUSIONS

It was concluded that orthodontic treatment should be aimed at both physical and psychological rehabilitation of cleft patients.

KEY WORDS

Sense of Coherence, Cleft Lip and Palate

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BACKGROUND

Cleft lip and palate (CLCP) is one of the most common birth defects, causing significant costs in terms of rehabilitation, emotional difficulties, and economy.¹ The condition is considered to be multifactorial and polygenic in nature.² It is documented that the birth prevalence of children with CLCP significantly differs between geographical boundaries. It was estimated that a total of 0.033% of all Indian population suffers from CLCP. The estimated prevalence rate/100,000 was 33.27 for males, 31.01 for females, and 32.18 combined for both genders. The total unmet cleft treatment need was estimated at 79,430 or 18.76% of the total Indian cleft population with CLCP.³

Parents and relatives of physically disabled children or patients with chronic illnesses undergo tremendous amount of stress, which negatively affects the family per se. These potential stress factors are followed by other related stress factors.⁴ Various adversities suffered by families include diseases and disability. The mothers to such children with birth defects face many difficulties including economic and social distress, and the child requiring sudden healthcare.⁵ Also, due to the facial appearance and difficulty in communicating, teasing has become part of the child's life which makes them socially recluse and they are comfortable only in interacting with their family members.⁶

A questionnaire was developed by Antonovsky et al. (1987)⁷ to quantify the sense of coherence (SOC). SOC is defined as a global orientation to express the degree to which the subject has a pervasive, enduring though dynamic feeling of confidence about the following-

1. The subject's internal and external environments' giving a stimulus in the course of living are structured, predictable, and explicable (comprehensibility);
2. The available resources will fulfil the needs produced by these stimuli (manageability);
3. The needs in question are worthy of investment and engagement (meaningfulness).

The Orientation to Life Questionnaire, has 29 items, 11 to measure comprehensibility, 10 for manageability, and 8 to evaluate meaningfulness. The response lies between 1 to 7 points, where the ends indicate extreme feelings about questions. These are inquiries about how the subject experiences their life (e.g. 'while talking to someone, do you feel they are not comprehending?' is scored with 1 being never felt this way to 7 being always feel this way). Total score ranges between 29 and 203, for the original scale of 29 questions (SOC-29). SOC-13 offers a smaller questionnaire with 13 items and a score ranging between 13 and 91. It was originally intended by Antonovsky to evaluate results based on a single total score and not component scores.⁸

Parents of children with CLCP are actively involved in the treatment of their child, and they themselves may require support during the treatment. Their psychological status may be affected by this. The hopes of a normal ordinary life with a healthy child in the family, becomes more or less un-realistic for these parents. With the current understanding, the genetic predisposition for CLCP isn't clear, leading the parents to ask questions like 'Why is my child like this?' or 'Why me?'.⁹

SOC gives an idea about the subject's orientation to life, their way of experiencing life as comprehensible, manageable & meaningful. To parents with a differently abled children, this also provide a positive experience such as an increased sense of purpose, priorities, spirituality, tolerance and understanding, personal growth and strength, and personal/social network growth. IT is important to pay register and understand the feelings of such parents.¹⁰

Nonetheless, there is a paucity of studies based in India, which focuses on positive developments in parents to CLCP affected children. Certainly, this has been rarely clarified that what kind of life-events are linked to positive developments and what causes parents to have a high SOC even after experiencing adversity? This will lead to suggestions and generation of concrete support for parents and families of children with CLCP or disabilities. Furthermore, clarifying the relationship between positive changes and SOC will provide hints to support health for all people.

The purpose of this study was to clarify how much and what kind of positive change parents of children with CLCP experience during orthodontic treatment and to search the factors relevant to positive change and SOC before, during and after orthodontic treatment of the child.

METHODS

The questionnaire study was conducted in the Department of Orthodontics and Dentofacial Orthopaedics. Ethical clearance was obtained from the Institutional Ethics Committee D.M.I.M.S. (D.U.). We targeted 50 parents with children having cleft lip and palate undergoing orthodontic treatment. All cases enrolled in the smile train cleft care program were selected for the study which was the basis for selection of the sample size. Questionnaire to evaluate SOC of Parents undergoing orthodontic treatment was prepared in English, Hindi & Marathi Language. The questionnaire was validated by School of Health Professionals of Datta Meghe Institute of Medical Sciences.

The questionnaire consisted of six parts. First part consisted of demographic details, the second part consisted of positive and negative changes experienced by the parents of children with CLCP. The third part was assessment of parents SOC using short version of SOC -13 (Antonovsky, 1987)¹¹ & SOC total score ranged from 13-91. Negatively worded items were reverse scored, so a high score indicated a strong SOC. The fourth part was family impact questions. The fifth part was regarding support from hospital staff during treatment. The sixth part was subjective questionnaire for the parents.

Data was collected through questionnaires which was distributed to parents of children having cleft lip and palate undergoing orthodontic treatment. The questionnaires were collected after 30 minutes and were checked for completeness. Same questionnaire was distributed to same sample at various time intervals-

- T0- At the time of reporting.
- T1- After 2 months of treatment.
- T2- After 6 months of treatment.

Each question except for the subjective questionnaire for parents was rated on a 5-point scale from 1 (totally disagree) to 5 (totally agree).

Statistical Analysis

All the descriptive and inferential collected data was subjected to statistical analysis which was done using statistical Wilcoxon Signed Rank test and software used in the analysis was SPSS 22.0 version and GraphPad Prism 6.0 version and $p < 0.05$ was considered as level of significance.

Rank Test statistically significant changes on Family impact were observed between T0-T1 ($z = 4.36$, $p = 0.0001$) as well as between T0-T2 ($z = 6.11$, $p = 0.0001$) (Table 3, Graph no 3)

RESULTS

Que. No.		T0	T1	T2	Z-Value Wilcoxon Signed Rank Test	
					T0-T1	T0-T2
A	Psychological Strength	1.86 ± 0.60	2.54 ± 0.57	2.88 ± 0.32	5.20	5.90
B	Self-confidence to overcome life's challenges	1.94 ± 0.68	2.58 ± 0.57	2.74 ± 0.44	5.16	5.60
C	New purposes or joy of life	1.98 ± 0.71	2.84 ± 0.37	2.84 ± 0.37	5.59	5.59
D	The desire to be useful to people and society	2.00 ± 0.72	2.64 ± 0.48	2.84 ± 0.37	4.70	5.15
E	Started to think as though everything is getting by	1.84 ± 0.68	2.34 ± 0.65	2.68 ± 0.45	4.34	5.27
F	Feelings about how every day pass by	1.98 ± 0.71	2.40 ± 0.60	2.74 ± 0.44	4.18	4.91
G	Your ties with your family	2.44 ± 0.78	2.92 ± 0.27	2.94 ± 0.23	3.52	3.62
H	Your ties with your friends	2.46 ± 0.76	2.92 ± 0.27	2.96 ± 0.19	3.75	3.72
I	New reliable friends and acquaintances	2.46 ± 0.76	2.90 ± 0.41	2.96 ± 0.19	3.78	3.98
J	Pay attention to your health	2.38 ± 0.63	2.90 ± 0.41	2.96 ± 0.19	4.73	5.03
Total		21.36 ± 5.26	27 ± 2.89	28.80 ± 1.03	6.18	4.78

Table 1. Positive and Negative Changes Experienced by Mother / Father of Children with CLCP

The mean of total score for Positive and negative changes experienced by mother/father of children with CLCP at the time of reporting to the department (T0) was 21.36 ± 5.26 , after 2 months of treatment (T1) was 27 ± 2.89 & after 6 months of treatment (T3) was 28.80 ± 1.03 . By using Wilcoxon Signed Rank Test statistically significant Positive changes experienced by mother/ father of children with CLCP were observed between T0-T1 ($z = 6.18$, $p = 0.0001$) as well as between T0-T2 ($z = 4.78$, $p = 0.0001$) (Table 1 Graph no 1)

The mean of total score for Mother's/Father's subjective experience in the child rearing process at the time of reporting to the department (T0) was 45.46 ± 5.21 , after 2 months of treatment (T1) was 48.90 ± 4.76 & after 6 months of treatment (T3) was 55.96 ± 2.16 . By using Wilcoxon Signed Rank Test statistically significant improvement in Mother's/Father's subjective experience in the child rearing process was observed between T0-T1 ($z = 4.28$, $p = 0.0001$) as well as between T0-T2 ($z = 6.16$, $p = 0.0001$) (Table 2, Graph no 2)

The mean of total score for Family impact questions at the time of reporting to the department (T0) was 13 ± 3.77 , after 2 months of treatment (T1) was 10.36 ± 2.68 & after 6 months of treatment (T3) was 6.84 ± 1.86 . By using Wilcoxon Signed

Que. No.		T0	T1	T2	Z-Value Wilcoxon Signed Rank Test	
					T0-T1	T0-T2
A	My spouse understands my feelings well	3.76 ± 0.62	4.18 ± 0.48	4.92 ± 0.27	3.66	6.62
B	Parents-in-law understand my feelings well	3.70 ± 0.73	4.06 ± 0.48	4.88 ± 0.32	2.98	5.97
C	My parents understand my feelings well	3.58 ± 0.73	3.96 ± 0.80	4.74 ± 0.44	3.08	6.35
D	I feel like I am raising and treating my child by myself	3.90 ± 0.58	4.14 ± 0.45	4.76 ± 0.435	2.65	5.59
E	My spouse actively participates in treatment and care of my child with CLCP	3.94 ± 0.65	4.08 ± 0.89	4.60 ± 0.57	1.08	4.65
F	There are unforgettably severe of stigmatic words regarding CLCP from surrounding people	3.34 ± 0.87	2.70 ± 0.88	1.94 ± 0.54	3.84	5.51
G	There are people who are familiar with information about cleft lip/cleft palate near me	2.96 ± 0.78	3.04 ± 0.96	4.26 ± 0.80	0.61	5.93
H	For me, there are people close by with whom I can share feelings about CLCP	3.36 ± 0.74	4 ± 0.49	4.70 ± 0.46	4.05	5.88
I	I think I will explain CLCP properly to my child	3.60 ± 0.72	4.10 ± 0.61	4.78 ± 0.41	3.61	5.68
J	I think I can manage our life very well	3.52 ± 0.67	4.06 ± 0.51	4.88 ± 0.32	3.98	6.24
K	I anticipate that my child's personal life in future will be meaningful	3.60 ± 0.60	4.06 ± 0.54	4.86 ± 0.35	4.12	6.04
L	I feel that I don't know exactly what's about to happen in future	3.10 ± 0.84	3.44 ± 0.73	4.58 ± 0.49	2.16	5.82
M	I feel that raising my child with CLCP has changes the routine things in my daily life	3.10 ± 0.83	3.08 ± 1.08	2.06 ± 0.42	0.19	5.01
Total		45.46 ± 5.21	48.90 ± 4.76	55.96 ± 2.16	4.28	6.16

Table 2. Mother's / Father's Subjective Experience in the Child Rearing Process

Que. No.		T0	T1	T2	Z-Value Wilcoxon Signed Rank Test	
					T0-T1	T0-T2
A	Because of this I am unable to give enough time to my family	2.86 ± 0.94	2.16 ± 0.68	1.24 ± 0.51	4.48	6.15
B	Because of this I am unable to give enough time to my spouse	2.80 ± 0.96	2.14 ± 0.67	1.40 ± 0.60	4.0	5.85
C	Because of this I am unable to give enough time to my other kids	2.68 ± 1.05	2.04 ± 0.66	1.36 ± 0.56	3.69	5.49
D	My social life is disturbed	2.38 ± 0.72	2.08 ± 0.48	1.56 ± 0.54	2.49	5.06
E	It is having negative impact on our family income and budget	2.28 ± 0.78	1.94 ± 0.46	1.33 ± 0.54	2.63	4.01
Total		13 ± 3.77	10.36 ± 2.68	6.84 ± 1.86	4.36	6.11

Table 3. Family Impact Questions

The mean of total score for Receipt of support from hospital staff during treatment at the time of reporting to the department (T0) was 23.02 ± 2.15 , after 2 months of treatment (T1) was 24.38 ± 1.22 & after 6 months of treatment (T3) was 24.86 ± 0.45 . By using Wilcoxon Signed Rank Test statistically significant improvement in the perception of parents regarding Receipt of support from hospital staff during

treatment was observed between T0-T1 ($z = 4.50, p = 0.0001$) as well as between T0-T2 ($z = 4.80, p = 0.0001$) (Table 4, Graph no 4)

The mean of total score for Subjective Questionnaire at the time of reporting to the department (T0) was 2.24 ± 1.50 , after 2 months of treatment (T1) was 2.08 ± 1.00 & after 6 months of treatment (T3) was 1.62 ± 0.49 . By using Wilcoxon Signed Rank Test statistically no significant difference in Subjective Questionnaire were observed between T0-T1 ($z = 1.08, p = 0.27$) and statistically significant difference between T0-T2 ($z = 2.46, p = 0.018, S$) (Table 5, Graph no 5).

Que. No.		T0	T1	T2	Z-Value	
					Wilcoxon Signed Rank Test	
					T0-T1	T0-T2
A	Doctor listened to my feelings and story carefully	4.54 ± 0.50	4.78 ± 0.41	4.94 ± 0.23	3.64 p= 0.001,S	4.47 p= 0.0001,S
B	Doctor responded with a polite attitude	4.60 ± 0.49	4.92 ± 0.27	5 ± 0	4.00 p= 0.001,S	4.47 p= 0.0001,S
C	Doctor explained about CLCP to grandparents	4.52 ± 0.50	4.82 ± 0.38	4.96 ± 0.19	3.87 p= 0.001,S	4.69 p= 0.0001,S
D	Doctor provided information about treatment of CLCP	4.64 ± 0.48	4.94 ± 0.23	4.96 ± 0.19	3.87 p= 0.001,S	4.00 p= 0.0001,S
E	Regarding disability of the child, I was told by Doctor that 'you should not be blamed'	4.72 ± 0.45	4.92 ± 0.27	5 ± 0	3.16 p= 0.002,S	3.74 p= 0.0001,S
Total		23.02 ± 2.15	24.38 ± 1.22	24.86 ± 0.45	4.50 p= 0.0001,S	4.80 p= 0.0001,S

Table 4. Receipt of Support from Hospital Staff during Treatment

Que. No.	Subjective criteria	T0	T1	T2	Z-Value	
					Wilcoxon Signed Rank Test	
					T0-T1	T0-T2
A	Are you aware of the problem/disease	0.28 ± 0.45	0.82 ± 0.38	1 ± 0	5.19 p= 0.0001,S	6.00 p= 0.0001,S
B	Do you over protect your child and treat them differently than other siblings	0.12 ± 0.32	0.20 ± 0.40	0 ± 0	1.63 p= 0.10,NS	2.44 p= 0.014,S
C	Other siblings tease the child	0.10 ± 0.30	0.04 ± 0.19	0 ± 0	1.73 p= 0.08,NS	2.14 p= 0.025,S
D	Are you teased by school friends	0.30 ± 0.46	0.08 ± 0.27	0 ± 0	3.31 p= 0.001,S	3.87 p= 0.025,S
E	Are you not comfortable in introducing your child to new people	0.84 ± 0.37	0.72 ± 0.45	0.58 ± 0.49	1.601 p= 0.10,NS	2.71 p= 0.007,S
F	Do you feel is cleft hampering the child's communication with others	0.36 ± 0.48	0.12 ± 0.32	0 ± 0	3.00 p= 0.003,S	4.24 p= 0.0001,S
G	Do you experience problem in your married life because of having a child with cleft	0.24 ± 0.43	0.10 ± 0.30	0.04 ± 0.19	2.64 p= 0.008,S	2.67 p= 0.008,S
Total		2.24 ± 1.50	2.08 ± 1.00	1.62 ± 0.49	1.08 p= 0.27,NS	2.46 p= 0.018,S

Table 5. Subjective Questionnaire

DISCUSSION

Cleft lip and palate (CLCP) are some of the most common birth defects. The birth of a child with a facial cleft is a tragic incident for the family that the child is born in. Not only is the family devastated by the apparent facial deformity, but also worried about several other issues such as care of the child, the treatment options, and the social impact that the cleft will have for the child and for the family.

Children with CLCP have to undergo treatment procedures right from infancy to adolescence. Treatment care given by orthodontists not only corrects the deformity but also

improves the aesthetics and function of the child, which in turn mends the psychological state of parents and children.

When parents start seeing the changes they get really motivated and the response that is given in return for the treatment is very satisfactory and positive. Therefore, outcome of orthodontic treatment changes their outlook and perception regarding the deformity of their children. Also improves the mental status of the family.

In the positive and negative changes experienced by the parents of children with CLCP we got significant results for most of the parameters (Table 1). Parents being positive in such stressful situation helps the child and the entire family to accept such child with deformity.

The questions about psychological strength of parents, self-confidence to overcome life's changes, new purposes or joy in life were considered by Omiya et al (2017)⁵ and the results were in accordance to our study.

Antonovosky (1987)¹¹ got results similar to our study that were significant in the questions "started to think as if everything is getting by/ feelings about how every day pass by/new reliable friends and acquaintances for me there are people close by with whom I share feelings about CLCP."

We considered the question "your ties with your family" in the same category and got significant results. Kumada (2009)¹² and Kimura (2016)¹³ got moderately significant results for the same.

In the mothers/ fathers subjective experience in the child rearing process we got significant results for most of the questions (Table 2). Child rearing becomes extremely difficult for the parents having children with CLCP so at such times co-operation of the family members becomes important as the treatment procedure for such conditions involves multiple visits and long treatment time.

The question like "my spouse/ my parents understand my feelings well, I feel like I am raising and treating my child by myself and there are unforgettably severe of stigmatic words regarding CLCP from surrounding people" we got significant results which were similar to the study done by Omiya et al (2017)⁵. The question about stigmatic words was also considered by Omiya et al (2016)¹⁴ and results were in accordance to our study.

Our results were also comparable with the results of Antonovsky (1987),¹⁰ da Silva et al (2011)¹⁵ and Omiya et al (2012)¹⁶ studies for the question "I anticipate that my child's personal life in future will be meaningful".

In family impact questions we got significant results for most of the questions (Table 3). Parents or caregivers of the children suffering from CLCP are devoid of social and personal time also they are unable to give time to the other members of their family and spouse as much of their time is spent in caring for their children.

In the questions defining impact on the family we considered the question "because of this I am unable to give enough time to my family/ spouse/ other kids" for which we got significant results and they were similar to a study done by Bergh et al (2012).¹⁷

One of the most important factors for the treatment of such patients suffering from CLCP is the motivation of the parents, caregivers and family members. This motivation is provided by none other than the treating doctor, their subordinates and hospital staff.

In the category of receipt of support from hospital staff during treatment (Table 4) we considered the question “regarding disability of the child I was properly explained about the treatment and its effects by doctor that” and got significant results are results were in accordance to a study done by Omiya et al (2012).¹⁶

Also “doctor explained CLCP to grandparents/ provided information about treatment of CLCP” we got significant results that were in accordance with the study done by Omiya et al (2017)⁵ and Bergh et al (2012).¹⁷

In the subjective questionnaire we asked yes/no type of questions in which we got insignificant results from T0-T1 (Table 5). In this set we considered the question “Are you aware of the problem/disease” and we received a positive answer which was also similar to a study done by Omiya et al (2012).¹⁵

In the same category we got significant results for “ other siblings tease the child/ are you teased by school friends”, the results were in accordance to study done by Hunt O et al (2005),¹⁸ Bernstein NR et al (1981),¹⁹ Heller A (1981),²⁰ Noar JH (1992).²¹

CONCLUSIONS

In our study we found that undergoing orthodontic treatment had positive effects on the parents of patients with CLCP. It was observed that it altered the psychological, financial, emotional and social well-being of the parents. An orthodontic treatment should be aimed at both physical and psychological rehabilitation of cleft patients. Time to time psychological counselling of the patient and their relatives is necessary for the positive treatment outcome and well-being of the patients and their families.

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