

DEVELOPMENT AND STANDARDIZATION OF A
QUESTIONNAIRE FOR EARLY IDENTIFICATION OF
PSYCHOSOCIAL ISSUES IN CHILDREN WITH CLEFT
LIP AND PALATE

PROJECT REPORT

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LIST OF ABBREVIATIONS

CLP Cleft Lip/Palate

TD Typically Developing

PCA Principal Component Analysis

Chapter 1

INTRODUCTION & REVIEW OF LITERATURE

Cleft lip and palate (CLP) is a congenital malformation of the face and oral cavity that occurs during pregnancy (Kummer, 2008). CLP requires multiple surgical and other intervention procedures to deal with issues such as facial abnormalities, difficulty feeding, speech impairments, abnormal resonance and hearing difficulties (Baker et al., 2008; Kummer, 2008; Kapp-Simon, 2004). The approximate incidence of CLP is 1.4 per 1,000 live births in India (Times of India report, 2010). Due to complex nature of CLP, it is important to understand not only the medical implications of the disease and treatment, but the psychosocial implications as well (Cheung, Pheng & Ho, 2006).

The term “psychosocial” refers to an individual’s psychological development and interaction with a social environment. Thus, psychosocial comprises of two term, first psychological refers to the individuals inner world their feelings, thoughts, desires, beliefs and values and how they perceive themselves and others. It includes concepts such as perception, cognition, emotion, motivation, personality, behaviour and interpersonal relationships. Few psychological problems in children are disturbances in feeling (depression and anxiety), bodily function (psychosomatic disorders), behavioural problems (conduct disturbance, passive aggressive behaviour), in performance (learning) etc. The concept of psychological aspects of clefting often refers to studies of intelligence, self image, personality and the psychopathology of cleft patients (McWilliams, 1982). “Social” refers to the relationships and

environment of an individual. It includes the material world and the social and cultural context in which people live, ranging from the intricate network of their relationships, over manifold cultural expressions to the community and the state. It includes social interaction, social acceptance, group influence etc. The inner world (psycho) and the outer world (social) influence each other. Thus, psychosocial issues of children with CLP are an important issue to be investigated.

1.1 Role of Early Childhood in Later Personality Development

The personality pattern, the foundation of which is laid in babyhood, begins to take form in early childhood. Individuality, which is apparent at birth, becomes increasingly more so in babyhood. Individuality is greatly influenced by early social experiences outside the home. When these experiences are unfavourable, children are likely to become unsocial in their relationships with people and to compensate in unsocial ways, such as spending their playtime watching television and imagining themselves as martyrs who are picked on by others. Because parents, siblings, and other relatives constitute the social world of young children, how they feel about them and how they treat them are important factors in shaping self-concepts – the core of the personality pattern. Glasner (1961) commented that self- concept of a child is “formed within the womb of family relationships”.

As early childhood progresses, young children have more and more contacts with peers either in the neighbourhood or in preschool. The attitudes of their peers and the way they behaviour then begin to have an effect on their self-concepts, an effect which may reinforce the effect of family members or may contradict and counteract some of the family influences. By the time early childhood is over and

children are ready to enter school, the patterns of their personalities can be readily distinguished.

Research has shown that during the early preschool years (ages 3–5), children with CLP tend to have a self-concept that is similar to their peers without a cleft. However, as they grow older and their social interactions increase, children with clefts tend to report more dissatisfaction with peer relationships and higher levels of social anxiety. Experts conclude that this is probably due to the associated stigma of visible deformities and possible speech impediments. Children with cleft tend to report feelings of anger, sadness, fear, and alienation from their peers, but these children were similar to their peers in regard to "how well they liked themselves (Spriestersbach, 1961; Tisza et al., 1958; Ruess, 1965)." It is also reported that elevated stress levels in mothers correlated with reduced social skills in their children (Kinnis, 1954). Strong parent support networks may help to prevent the development of negative self-concept in children with CLP. In the later preschool and early elementary years, the development of social skills is no longer only impacted by parental attitudes but is beginning to be shaped by their peers. A CLP may affect the behaviour of preschoolers. A child who is entering school should learn the proper (age-appropriate) terms related to the cleft.

As children reach adolescence, the period of time between age 13 and 19, the dynamics of the parent-child relationship change as peer groups are now the focus of attention. An adolescent with cleft lip/palate will deal with the typical challenges faced by most of their peers including issues related to self esteem and social acceptance. Adolescents however, view appearance as the most important

characteristic above intelligence and humour. This being the case, adolescents are susceptible to additional problems because they cannot hide their facial differences from their peers. Adolescent boys typically deal with issues relating to withdrawal, attention, thought and internalizing problems and may possibly develop anxiousness, depression and aggressive behaviours. Adolescent girls are more likely to develop problems relating to self concept and appearance. Individuals with CLP often deal with threats to their quality of life for multiple reasons including: unsuccessful social relationships, deviance in social appearance and multiple surgeries (Reinherz et al., 1989).

It is thus evident that favourable early childhood environment is extremely important in shaping the future personality of any child, also children with CLP have difficult early childhood which hinder in their personality formation.

1.2 Factors Influencing Psychosocial development of CLP Children

Various physiological and socio-cultural factors contribute in the development of psychosocial issues among individuals with any form of facial anomaly in general.

The high value placed by our society upon physical attractiveness, especially facial attractiveness, makes CLP potent to psychosocial issues. Research has shown that attractive children are seen by others as brighter, having more positive social behaviour and receive more positive treatment than their less attractive counterparts (Turner et al., 1997).

Parental influence is another factor which shapes the psychosocial perception and social experience of individual with CLP. For example, parents may have encountered negative reactions from others as a result of their child's condition

and may feel overprotective and hesitant to encourage social interactions (Richman & Harper, 1978; Brantley & Clifford, 1979). The attitudes, expectations and degree of support shown by parents can influence the child's perception of his/her cleft impairment (Lansdown & Hunter, 1991; Bull & Rumsey, 1988). Parents of children with clefts may be more tolerant of misbehaviour in their child and are more likely to spoil their child by being overprotective (Turner et al., 1997; Harper & Richman, 1978).

Peer interaction is another factor in maintaining psychosocial limitations of person with CLP. Many children with CLP may have a less attractive facial appearance or speech than their peers. A high incidence of teasing over facial appearance is reported among those with CLP leading to social withdrawal and increased number of behavioural problems in such children (Hunt et al., 2005; Clifford, 1978). Medical and functional limitations may impede involvement of children and adolescent with CLP in sports or other types of activities, thereby reducing opportunities for developing peer relationships (Snyder et al., 2005).

1.3 Psychosocial Issues in Different Areas

Hunt et al. (2005a) conducted a systematic review to determine whether the presence of CLP places an individual at an increased risk of having psychosocial problems. Results of the study revealed that although the majority of individuals with CLP do not experience major psychosocial problems, specific problems may arise including behavioural problems, dissatisfaction with facial appearance, depression and anxiety, poor social and personal self concept, decreased social functioning and

problem in attachment, development and learning. Brand et al. (2008) conducted a case-control study to investigate the psychosocial functioning in children and adolescents with CLP and found that children with CLP were six times more likely to report difficulties in participating within the general social environment and in proactive behaviour, although no differences were noted during interaction with family, friends or peers, or with respect to emotional problems, conduct problems or hyperactivity. Children with clefts also tend to report feelings of anger, sadness, fear, and alienation from their peers. Adolescent boys and girls with CLP also showed increased risk for clinical levels of deficits in scholastic competence (Snyder et al., 2005). Similarly, Snyder and Pope (2009) indicated that children with CLP showed elevations into the clinical range with regards to social problems, school capability and activities when compared to other craniofacial diagnosis groups and these difficulties increased with age, although there was little evidence of true psychological disorder in any age group.

There are abundant studies indicating the psychosocial issues of adolescents and adults with CLP but there are very limited studies focussing the psychosocial aspect of primary school age children with CLP. In one of the study Kapp- Simon (1986) reported that primary school- age children with CLP were found more “at risk” category for poor self concept than normal controls. Kapp-Simon (1986) further found such children as passive, isolated unhappy and dissatisfied. This is consistent with the findings of Broder and Strauss (1989). Their study also illustrated the negative impact and stigmatizing consequence of facial defects on the self concept of children with CLP as early as 7 years. As adaptive behaviour and school achievement are influenced by self concept, early primary school age children with clefts appear to be

at risk. Murray et al. (2010) carried out research on children with CLP from infancy and followed them till 7 years of age. Based on parents and teachers report they concluded that children with CLP have more social problems, they are anxious, withdrawn-depressed and are poor in social relationships. Hunt et al. (2007) evaluated parents report regarding psychological functioning of their children with CLP and found that majority of parents believe that their child with CLP are at psychosocial disadvantage. They had described their children as having less self esteem, having greater anxiety and being unhappier in general compared with reports of parents with children without cleft lip/palate. A number of previous studies have assessed parental opinion of children with CLP in terms of psychosocial functioning. However, these studies have mainly focused on single issues such as behavioral problems (Schneiderman & Auer, 1984; Tobiasen & Hiebert, 1984; Heller et al., 1985; Richman, 1978, 1997) or satisfaction with facial appearance (Thomas et al., 1997; Broder et al., 1992; Noar, 1991). It is difficult to generalize about the overall psychosocial functioning of children with CLP by studying a single psychological construct and therefore a need arise for a detail evaluation of psychosocial construct of children with CLP. To summarize, it is found that sooner or later children and adults with CLP develop psychosocial issues which may even take the form of disorder if not taken care of.

Upon analysis it is also found that most of the studies are conducted in late childhood, adolescence and adulthood. There is also lack of evidence supporting the presence of psychosocial issues in early childhood. However, identification of psychosocial issues in early childhood is of keen importance as early childhood is a tender age when the temperamental attributes begin forming. Unhealthy psychosocial

situations may interfere in optimum development of the child and may lead to psychological problems in later life. Thus, early childhood is the age in which preventive measure can be taken and healthy personality development can be promoted.

Therefore, this study was targeted to develop a questionnaire for early identification of psychosocial issues in children with CLP. Review reveal that major problem among children and adult with CLP is pertaining to anxiety, depression, limited social interaction, poor body image, low self esteem, lack of assertiveness and excessive behavioural problem in children. Therefore, questionnaire was planned to evaluate six major areas in children with CLP i.e. anxiety, depression, social interaction, self esteem, assertiveness and behaviour problems. But the major barrier in analysis of psychosocial issues of children with CLP in early childhood is their limited and hypernasal speech. Also children in their early years may have difficulty in identifying and labelling their feelings and emotions. Therefore, this study was planned to include questions highlighting the real life situations which reflect the presence of psychosocial problems of children with CLP and therefore is easily observable and identifiable by parents.

Also, there is a lack of questionnaire exclusively for children with CLP. Most of the previous studies have adopted usual tests for assessment of CLP children and adult. Also, more number of tests has to be used to screen different problem. Thus, this study fulfils dual role of identifying the psychosocial issues in early children and by developing a standard test for children CLP covering the entire major psychosocial problem under one heading.

Chapter 2

METHODOLOGY

2.1 Aim: The aim of the present study is to develop a questionnaire for early identification of psychosocial issues of children with CLP.

2.2 Objectives

- To assess psychosocial issues of children with CLP falling in the age range of 3-8 years on domains like assertiveness, social interaction, behaviour problems, self esteem, depression and anxiety.
- To develop a questionnaire for children with CLP covering major psychosocial issues.

2.3 Sample: The study was proposed on children falling in the age range of 3-8 years.

Based upon purposive sampling technique 35 parents of children with CLP falling in the age range of 3-8 years were chosen from U-SOFA of AIISH and remaining 35 parents of typically developing (TD) children were chosen from nearby schools of AIISH. A Socio-Demographic and Clinical Data Sheet was specially designed to collect the socio-demographic details of children (appendix 1). Table 1 elaborates the socio-demographic details of children chosen for the study.

2.3.1 Inclusion Criteria for experimental group

- Parents of children with CLP falling in the age range of 3-8 years.
- Parents with minimum primary education.
- Parents who are cooperative for the interview.
- Parents who give informed consent for the study.

2.3.2 Exclusion Criteria for Experimental Group

- Parents of children who are not falling in the age range of 3-8 years.
- Parents of children using prosthetic device.
- Parents of children with co-morbid conditions like seizures, mental retardation or any other neurological, physical or major psychiatric illness.
- Parents who are illiterate.
- Parents who are uncooperative and do not give informed consent for the study.

2.3.3 Inclusion Criteria for Matched Control group

- Parents of typically developing children falling in the age range of 3-8 years.
- Parents with minimum primary education.
- Parents and children who are cooperative for the interview.
- Parents who give informed consent for the study.

2.3.4 Exclusion Criteria for Matched Control group

- Parents of children who are not falling in the age range of 3-8 years.
- Parents of children with psychological, social, behavioural or academic problems.
- Parents of children with conditions like seizures, mental retardation or any other neurological, physical or major psychiatric illness.
- Parents who are illiterate.
- Parents who are uncooperative and do not give informed consent for the study.

Table 1: Sample Characteristics

S. No	Variables	TD Children (N=35)	CLP Children (N=35)	
1.	Age	3-3.11 Years	7	2
		4-4.11 Years	9	9
		5-5.11 Years	6	5
		6-6.11 Years	7	4
		7-7.11 Years	3	6
		8-8.11 Years	3	9
2.	Sex	Male	16	16
		Female	19	19
3.	Education	Preschool	10	2
		LKG	8	9
		UKG	6	1
		1 st	5	3
		2 nd	4	4
		3 rd	2	11
4.	Religion	Hindu	35	28
		Muslim	-	5
		Christian	-	1
		Others	-	1
5.	Socio-Economic Status	Middle	35	25
		Higher	-	1
		Lower	-	9
6.	Family Type	Nuclear	21	21
		Joint	14	14
7.	Residence	Urban	35	10
		Rural	-	23
		Semi-Urban	-	2

2.4 Research Design: An age stratified two groups comparative research design based on informant report is used for the particular study. Experimental group comprise of parents of children with CLP falling in the age range of 3-8 years. Matched control group consist of parents of children with TD falling in the age range of 3-8 years.

2.5 Procedure

(a) **Phase I: Identification For Items For Inclusion In The Questionnaire:** An informal interview of 41 parents of children with CLP was carried out. The responses were recorded down and common problems in all the 41 cases was identified and later sorted out in 6 major areas i.e. Assertiveness, Social Interaction, Self Esteem, Behavioural Problems, Depression and Anxiety.

(b) **Phase II: Construction of Questionnaire:** The information collected from the parents and some pre-existing questionnaires related to the study were studied thoroughly and hints were taken to frame questions for present the questionnaire. The list of the pre-existing questionnaire referred for the study are as follows:

1. Childhood Behaviour Checklist (Achenbach,1991)
2. Brief Self-Esteem Inventory (Williams, 2000)
3. Social Skills Questionnaire (Spence, 1995)
4. Mohite Home Environment Inventory (Mohite, 2004)
5. Conformity Behaviour (Rai, 1994)
6. Children Self Concept Scale (Ahluwalia, 1999)

7. Interpersonal Judgment Scale (Rai & Mehta, 2008)
8. Comprehensive Anxiety Test (Bharadwaj & Bhargava, 1998)
9. The Scale of Emotional Competencies (Sharma & Bharadwaj, 2007)
10. Social Skills Problem Behaviour Checklist (Mathur & Aurora, 2005)
11. Scales Measuring Self Perception (Agarwal, 1991)
12. SHAH Security-Insecurity Scale (Shah, 2010)
13. AGNIHOTRI'S Self-Confidence Inventory (ASCI: Gupta, 2011)
14. Perceived Loneliness Scale (Jha, 1997)

The questions were framed in such a manner that it depicted the real life situations of the child and displayed a clear picture of the child's problems. Initially 60 items were framed and each question was written in three possible way, these questions were then evaluated by co-investigators and were asked to choose the best alternative of the three options. Based upon the opinions of the co-investigators 60 items were finally chosen for the study. Also, to evaluate the severity of the problem a 5 point rating scale was initially used to collect the information.

Once the entire questionnaire was completed it was evaluated by 3 clinical psychologists with 2 year M.Phil in Medical and Social Psychology (1. Nawab Akhtar Khan, Lecturer in Clinical Psychology, JSS Medical College, Mysore, 2. U. Pratibha, Clinical Psychologist, AIISH, 3. Dr. G. Jayarama, Reader in Clinical Psychology, AIISH). The wordings, content and grammar of the questions was corrected as per the suggestions made by the experts. Also, upon their suggestion 31 additional items were included in the

questionnaire and the rating was reduced from 5 to 4 point rating scale. The numbers of items were increased so that after factor analysis the strength of items in each area is maintained and therefore give a clear understanding of the problem inherent.

Once the questionnaire was approved by the experts it was translated into Kannada with the help of Yashodhar Kumar (co-investigator) and Dr. P. Purshottam (Research Assistant, Dept. of Clinical Psychology, AIISH), in order to maintain the objectivity of the data collected by both English and Kannada speaking parents. The Kannada items were again reversely translated into English by Madhuchandra M.K (Assistant professor in Psychology, Padmashree Group of Institutions, Bangalore) to check the validity of the translation. Lastly the original English questionnaire and the translated English questionnaire were matched to avoid any discrepancy in the data collected. The 91 item English and Kannada questionnaire prepared for data collection is attached in appendix (appendix III, IV).

(c) **Phase III: Data Collection Phase:** Once the questionnaire was completed data collection was started. Different nearby schools (DMS, Tom & Jerry, Gangotri Mahavidyalaya & Mahabodhi School) were targeted to collect data from TD children. Approval from school Principal/Authority was taken and later teachers were requested to call parents of children falling in our age group. Information from 33 parents of children falling in the age range of 3-8 years was collected after their consent to participate in the study. Some parents

of children were approached on their parents meeting day and were interviewed in the school itself.

Simultaneously, letters were send to old cases from U-SOFA and were given a due date for evaluation. New cases were also targeted at the same time. Overall, 35 parents of children with CLP were evaluated for the study.

(d) **Phase IV: Statistical Analysis:** Once the data was completed, statistical procedures were carried out to evaluate the significance of the questionnaire. SPSS-16 was utilized to compute the data.

Factor Analysis (Principal Component Analysis) was used for item analysis. Multiple analysis of variance was used to compare the scores of typically developing children and CLP children. Confidence of Interval was used to decipher the lower limit and upper limit of the scores obtained by typically developing children and CLP children. Cronbach's α , Split Half Correlation and Spearman Brown Prophecy method was used to assess the reliability of the entire questionnaire, for individual subtest Cronbach's α was used for evaluating the reliability.

Chapter 3

RESULTS AND DISCUSSION

The results of the present study are described below.

Table 2 highlights the statistical analysis of the socio-demographic variables collected through Socio-Demographic and Clinical Data Sheet. Mean and SD for the both the groups was calculated using descriptive statistics option of SPSS-16. Finally both the groups were compared using χ^2 . The results reveal that there was no statistical difference between experimental and control group and were matched together in all the areas expect in socio-economic status and the place of residence. The probable reason behind this difference could be the free surgical and therapeutic intervention provided by the institute which fetches more clients from lower socio-economic strata and rural background.

Table 2: Statistical Significance of Socio-Demographic Details

Variables	TD Children (N=35)		CLP Children (N=35)		χ^2
	Mean	SD	Mean	SD	
Age	5.03	1.57	5.86	1.717	6.76 (NS)
Gender	1.55	.506	1.54	.505	.000 (NS)
Education	2.52	1.59	3.60	2.22	12.77 (NS)
Religion	1.00	.000	1.40	.847	7.35 (NS)
Family Type	1.36	.489	1.40	.497	.095 (NS)
Socio-economic Status	2.00	.000	1.77	.490	11.05*
Residence	1.00	.000	2.37	.910	37.27**

*p<0.05; **p<0.01

Table 3: Clinical Profile of Children with CLP

	CHARACTERISTICS	NO. OF PATIENTS
DIAGNOSIS	Cleft Palate	19
	Cleft Lip and palate	14
	Submucous Cleft Palate	2
HYPERNASALITY	Present	35
	Absent	--
SURGICAL INTERVENTION	Repaired	30
	Unrepaired	5
INTELLECTUAL FUNCTIONING	Average	35
	Borderline Intellectual functioning	--
	Mental Retardation	--

Table 3 further highlights the characteristics of CLP children chosen for the study. The results highlights that there were more children with cleft palate with hypernasal speech and most of the children had undergone surgical intervention and were falling in average intellectual functioning range.

As mentioned above Principal Component Analysis (PCA) was carried out to screen important items for the final questionnaire. Initially, PCA was conducted only for CLP group but the extraction results showed high communality for all the items and therefore, PCA was conducted on all the subjects (including CLP and TD children). In general, communalities after extraction should probably be above 0.5 (Field, 2005). Therefore, items having communality value (deciphered through Principal Component Analysis) higher than 0.5 were chosen for the final

questionnaire. Subtests in which all the items were having high communality value, in those subtests communality value above 0.6 was chosen as the criteria, this was done to prevent major discrepancy in the number of items in each subtest. It was tried that all the subtests have more or less same number of items.

Further few tables (4, 5, 6, 7, 8 & 9) highlight the item analysis scores for 6 subtest chosen for the questionnaire to be developed. Items mentioned in bold & italic are those items which were finally excluded from final questionnaire.

Table 4, reveals items pertaining to anxiety along with their communality ascertained through PCA. Item number 5, 12 & 14 (in bold & italic) were excluded from the final questionnaire.

Table 5, reveals items pertaining to depression along with their communality ascertained through PCA. Item number 3, 4, 7, 9 & 10 (in bold & italic) were excluded from the final questionnaire.

Table 6 highlights the PCA scores (communality) of subtest social interaction. Finally, item no. 5, 6, 10, 12 & 13 (in bold & italic) were excluded from the study.

Table 7 further highlight the communalities of subtest assertiveness. Item no. 3, 7 & 11 were excluded from the final questionnaire (in bold & italic).

Table 8 include items of subtest self esteem. Along with their communality, items excluded from the final questionnaire were item no. 1, 4, 7 & 10.

Finally, Table 9 reveals the items of subtest behavioural problem along with their communalities, items excluded are item no. 11 & 12.

Table 4: Principal Component Analysis of Subtest Anxiety

S. No	Anxiety (Total Items : 15)	PCA communality
1.	If any stranger comes to our home and tries to interact with my child, he / she feel tense.	.770
2.	My child's performance in games gets poor in presence of others.	.699
3.	Even in a funny situation or conversation, my child does not laugh or smile openly in presence of strangers.	.665
4.	My child avoids eye contact while speaking.	.701
5.	<i>My child shows this habit of unnecessarily shaking legs/wiggling hands while speaking.</i>	.562
6.	My child covers his/her mouth with hands while speaking.	.763
7.	In a social gathering/function, my child feels uncomfortable and insists that we get back home quickly.	.667
8.	My child feels conscious that people are looking him.	.699
9.	Instead of answering to a phone call, my child hands over the phone to others.	.764
10.	My child has a fear of being made fun off by others.	.784
11.	My child is hesitant to go anywhere alone (even in play situation) and insist us to accompany him/her.	.666
12.	<i>My child has nightmares of getting apart from us.</i>	.548
13.	While talking to strangers my child's voice gets too low.	.663
14.	<i>My child is scared to sleep alone.</i>	.431
15.	If others are laughing among themselves, my child feels that they are laughing on him/her.	.769

Table 5: Principal Component Analysis of Subtest Depression

S. No	Depression (Total Items : 15)	PCA communality
1.	My child appears lethargic while playing with other children.	.873
2.	It takes longer time for my child to fall asleep.	.753
3.	<i>My child often complains of headache, body ache and other bodily problems.</i>	.693
4.	<i>I have found my child weeping alone.</i>	.629
5.	If anybody scolds my child, he/she is unable to forget it easily.	.734
6.	My child appears sad for most of the time.	.858
7.	<i>My child tells that no one seems to understand him / her.</i>	.691
8.	My child recalls his/her past painful experiences.	.783
9.	<i>My child shows lack of interest in interacting with others even if the topic is related to him/her.</i>	.665
10.	<i>Since few days, my child appears not to be enjoying his favourite games & activities.</i>	.638
11.	From past few days my child is sleeping more than usual.	.838
12.	From past few days my child is not copying class work from board.	.810
13.	From past few days we are observing that our child gets quickly irritated.	.705
14.	My child show lack of enthusiasm even when we bring some new toy/doll for him/her.	.857
15.	From past few days my child does not seem to enjoy his/her favourite food items.	.777

Table 6: Principal Component Analysis of Subtest Social Interaction

S. No	Social Interaction (Total Items : 15)	PCA communality
1.	My child does not take initiative during play with other children.	.730
2.	When unfamiliar guests come home, my child restricts him/her self in a room.	.682
3.	My child hesitates to play with children of opposite gender.	.699
4.	My child is unable to make friends easily.	.626
5.	<i>My child is unable to express his/her feelings to others.</i>	<i>.472</i>
6.	<i>My child avoids going to any picnic / school tour/ summer camp etc.</i>	<i>.523</i>
7.	Unlike other children, my child does not play and mingle with others in parties and social gathering.	.668
8.	My child spends more time with toys/ watching T.V than playing with other children.	.652
9.	My child finds it hard to adjust readily to new situations.	.621
10.	<i>If neighbours try to speak to my child, he remains silent and does not respond back.</i>	<i>.564</i>
11.	My child avoids going by public transport like bus, train etc.	.714
12.	<i>My child is reluctant to stay away from home with close relatives for overnight.</i>	<i>.579</i>
13.	<i>While interacting with children's, if others come and join the group, then my child walks away from the group.</i>	<i>.547</i>
14.	My child avoids participating in any co-curricular activity like singing, dancing etc.	.607
15.	My child cries excessively/show lack of interest while going to school.	.605

Table 7: Principal Component Analysis of Subtest Assertiveness

S. No	Assertiveness (Total Items : 15)	PCA communality
1.	My child hesitates to ask for pencil / pen from other students in the class, even if he/she has nothing to write with	.706
2.	My child is hesitant to take permission from teacher to go to toilet.	.697
3.	<i>While purchasing anything my child is unable to ask directly from the shopkeeper and requires our help.</i>	.474
4.	Teacher has to ask question repeatedly to get answer from my child.	.752
5.	Even though my child is knowledgeable, he / she is unable to put forward his/her views clearly.	.742
6.	My child will not ask for any notes or discuss about his/her studies with peers on resuming school after a leave.	.639
7.	<i>Even if my child needs anything urgently, he/she won't ask it in front of others.</i>	.494
8.	My child avoids being the class monitor/ main player of the game.	.749
9.	My child is unable to respond back even if someone hits him / her or snatches anything from him / her.	.672
10.	If others are making fun of my child, he/she will cry, but will not complain about it to the teachers/ parents.	.845
11.	<i>If anyone tells my child that he/she is wrong, he/she accepts it without questioning.</i>	.498
12.	My child is hesitant to ask for water from students in class/ waiter in restaurant.	.644
13.	While going anywhere (school) by rickshaw/bus/auto, my child is unable to ask for space from others.	.731
14.	My child is unable to make his/her choice for clothes/toys/food products etc.	.764
15.	While purchasing anything (chocolate, chips) if the shopkeeper gives less item, my child is unable to ask it back.	.746

Table 8: Principal Component Analysis of Subtest Self Esteem

S. No	Self Esteem (Total Items : 15)	PCA communality
1.	<i>My child always wants reassurance for all his/her work.</i>	.583
2.	My child feels inferior to his/her sibling.	.618
3.	My child spends more time in front of the mirror.	.727
4.	<i>When exposed to any new toy or activity, my child quickly gives up his/her efforts to learn it.</i>	.516
5.	I find my child playing with children younger to him/her.	.631
6.	My child feels that he/she is not liked by teachers and peers.	.632
7.	<i>My child feels that others do not consider him/her as good looking.</i>	.538
8.	My child feels that we (parents) don't love him/her.	.672
9.	My child feels he/she is neglected at home and outside.	.767
10.	<i>My child feels that he/she will not be able to win any game.</i>	.472
11.	My child is hesitant to learn anything new.	.710
12.	My child keeps checking whether he/she has done things right.	.622
13.	My child avoids showing his/her toys to other children.	.600
14.	My child feels that he/she will never get good marks.	.780
15.	My child prefers to sit at the back in classroom.	.765
16.	My child avoids seeing mirror.	.720

Table 9: Principal Component Analysis of Subtest Behavioural Problem

S. No	Behavioural Problem (Total Items : 15)	PCA communality
1.	My child often hits or beats others while playing	.808
2.	My child will cry excessively or show temper tantrums when his demands are not fulfilled immediately	.673
3.	My child has the tendency of grabbing things from others	.652
4.	I find my child hurting himself/ herself.	.784
5.	My child can't stand still for long.	.730
6.	My child bed wets during his/her night sleep.	.669
7.	My child destroys his/her own things.	.741
8.	Teachers complain that my child is disobedient at school.	.827
9.	I have seen my child telling lies.	.674
10.	Thumb sucking and nail biting is observed in my child.	.734
11.	<i>My child blames others for his/her mistakes.</i>	.559
12.	<i>If anyone tries to correct my child about his misdeeds he runs away from home.</i>	.595
13.	My child cannot stay on any task for longer.	.737
14.	It is difficult for my child to wait for his turn in queue.	.705
15.	My child does not obey the commands of elders.	.729

Table 10: Summary of Items Chosen for Final Questionnaire

Sub Tests	No. Of Items	Rating Point	Minimum Scores (No of items * 0)	Maximum Scores (No of items * 3)
Anxiety	12	0-3	0	36
Depression	10	0-3	0	30
Social Interaction	10	0-3	0	30
Assertiveness	12	0-3	0	36
Self Esteem	12	0-3	0	36
Behavioural Problem	13	0-3	0	39
Minimum Score				0
Maximum Score				207

To summarize, after item analysis 69 items were chosen out of 91 items prepared initially for the study. Table 10 reveal the final number of items in each subtest and the maximum marks that can procured by the child.

Once all the final items (total 69) were selected for each subtest, then between group analyses was carried out using multiple analyses of variance to study the group difference i.e. difference between experimental and control group for all the subtests. The results reveal the combined mean and SD for both the groups and the F value indicating that each subtest score of experimental group was significantly different from control group which signifies that each item is significant in differentiating CLP and TD children (Table 11). In another way it can be interpreted that each item is valid in identifying what it is intended to elicit.

Table 11: Multiple Analysis Variance of Experimental and Control Group on Various Subtests

Dependent Variable	Mean	SD	Mean Square	F Value
Anxiety	6.22	6.608	2631.309	60.258***
Depression	5.82	3.661	2306.118	172.083***
Social Interaction	4.18	4.655	1186.118	54.736***
Assertiveness	6.51	5.951	2886.015	81.485***
Self Esteem	5.16	4.846	1811.779	77.160***
Behavioural Problem	12.09	7.722	9936.529	166.626***

*** p<.001

The results also reveal that in comparison to TD children, CLP children have significant psychosocial issues. They have difficulty in social interactions with peers and adults; they lack assertiveness, suffer from low confidence and are restless while talking to relatives, teachers and neighbors. Some children are excessively shy and internalize their problems while other externalizes it through behavioural problems, which is apparent through the scores of TD and CLP children.

Further, reliability of the questionnaire was assessed. Table 12 reveal the reliability scores. Inter item correlation was assessed using Cronbach's α , split half measure and spearman brown prophecy. All the scores reveal high inter-item correlation which suggests the test developed is reliable and yield consistent results.

Table 12: Reliability Score of the Final Questionnaire

Test Statistics	Inter-item correlation scores
Cronbach's α	.872
Split-Half (odd-even) Correlation	.720
Spearman-Brown Prophecy	.837

Table 13 reveal the reliability scores for all the subtests. Cronbach's α was utilized to analyze the reliability scores. Test scores suggest that except for subtest depression each subtest has high inter item correlation indicating that the item chosen for the final questionnaire elicit reliable results. Correlation for subtest depression falls in middle range.

Table 13: Reliability Score of Subtests

Sub Tests	Cronbach's α
Anxiety	.773
Depression	.405
Social Interaction	.694
Assertiveness	.655
Self esteem	.647
Behavioural Problems	.733

Table 14 further reveals the confidence of interval score. Interval estimation is used in a sample data to calculate an interval of possible (or probable) values of an unknown population parameter. A confidence interval is a type of interval estimate of a population parameter and is used to indicate the reliability of an

estimate. To elaborate it, if this study is conducted on another sample of the same population, it will yield result between these two intervals of mean. In this study 95% of confidence of interval was estimated i.e. 95% of times the test will yield true value only in 5% of cases there can be errors. This table is useful when we want to interpret scores according to the areas of assessment, it does not give a cut off score for the entire test however, it gives the lower bound and upper bound scores for all the subscales. It is thus effective in elaborating the specific area in which the child has more problems and in which area the child has fewer problems and thereby appropriate measures of intervention can be chosen for the specific area which is hampered.

Table 14: Comparison of TD and CLP Children through Confidence Interval for Mean

SUBTESTS	GROUP							
	TD Children				CLP Children			
	Mean	95% Confidence Interval For Mean		SD	Mean	95% Confidence Interval For Mean		SD
		Lower Bound	Upper Bound			Lower Bound	Upper Bound	
Anxiety	8.16	4.91	11.41	9.15	25.87	18.76	32.98	20.69
Depression	14.44	10.77	18.17	10.52	24.09	19.99	28.19	11.93
Social Interaction	8.48	4.46	12.50	11.33	19.04	13.12	24.97	17.25
Assertiveness	11.86	8.27	15.46	10.14	27.22	21.15	33.29	17.66
Self Esteem	10.28	7.17	13.39	8.76	20.69	14.75	26.62	17.27
Behavioural Problem	26.65	19.89	33.40	19.05	35.09	28.26	41.92	19.87

The table reveal the score for both the groups and for all the subtests of the questionnaire. The scores appear to be valid in nature because the confidence of interval scores for CLP children for all the subtest is falling outside the range of TD children. For e.g. in subtest anxiety the mean score is 8, and in normal course any child can obtain the score between 4 to 11, whereas the score for CLP child falls between 18-22. Thus, any child with CLP obtaining a score of 18 and above in anxiety subtest can be interpreted as having significant anxiety problem. Similarly, in subtest depression scores cut off point is 19, scores below the score of 19 can be considered as normal whereas above it reveals major psychosocial issues.

Similarly, in subtest social interaction, scores below 12 is considered as normal phenomena whereas scores above it can be categorized as problematic. In subtest assertiveness, a CLP child should score above 21 to be categorized as problematic. In self esteem scale score above 20 is indicative of major psychosocial area. Lastly, in subtest behavioural problem it is found that both TD children and CLP have high mean score indicating that behavioural problem is apparent in both the groups however in CLP children the problem is more reflected. It is also found that the upper bound (33) of TD children is exceeding the lower bound (28) of CLP children. In this case the scores can be interpreted using the mean score which 26 for TD children and 35 for CLP children.

The aim of the present study is thus fulfilled. A questionnaire has been developed to rule out psychological problems of children with CLP. The questionnaire is valid and reliable in yielding results. It is also found that in early childhood itself children with CLP are facing many psychological barriers in

comparison to TD children. Their childhood is occupied with their persistent problem for which they have no escape. Therefore, if steps are not taken at this early stage it is difficult to help these people to handle their problems because these psychological problems become the part of his/her life style i.e. his/her personality in later stages.

Chapter 4

Limitations of the study

1. Sample size is small.
2. Study was not compared with other children with similar problems like stuttering, expressive language delay etc.
3. Lack of norms at present.

Chapter 5
Future Direction

1. To develop norms for the questionnaire.
2. To conduct the questionnaire on other children with similar problem.
3. To extend the study for adolescents and adults.

- Achenbach TM. (1991). *Manual for the Child Behavior Checklist/4-18 and 1991 Profile*. Burlington: University of Vermont, Department of Psychiatry.
- Agarwal, K.G. (2006). *Scales Measuring Self Perception*. National Psychological Corporation, Agra.
- Ahluwalia, S.P. (2009). *Children's Self Concept Scale*. National Psychological Corporation, Agra.
- Baker, S.R., Owens, J., Stern, M., & Willmot, D. (2008). Coping strategies and social support in the family impact of cleft lip and palate and parents' adjustment and psychological distress. *Cleft Palate-Craniofacial Journal*, 46(3), 229-236.
- Brand, S., Blechschmidt, A., Muller, A., Sader, R., Schwenger-Zimmerer, K., Zeilhofer, H.F., & Holsboer-Trachsler, E. (2008). Psychosocial functioning and sleep patterns in children and adolescents with cleft lip and palate (CLP) compared with healthy controls. *Cleft Palate-Craniofacial Journal*, 46(2), 124-135.
- Brantley HT, Clifford E. (1979). Maternal and child locus of control and field-dependence in cleft palate children. *Cleft Palate Journal*.;16:183-187.
- Broder HL, Smith FB, Strauss RP. (1992). Rehabilitation of patients with clefts: parent and child ratings of satisfaction with appearance and speech. *Cleft Palate Craniofacial Journal*.;29:262-267.

- Broder, H & Strauss, R.P. (1989). Self concept of early primary school age children with visible or invisible defects. *Cleft Palate Journal*. Vol. 26 (2), 114-118.
- Bull R & Rumsey N. (1988). The social psychology of facial disfigurement. *Journal of Cross Cultural Psychology* .17:99-108.
- Carr T. (1997) Assessment and measurement in clinical practice. In: Lansdown R, Rumsey N, Bradbury E, Carr T, Partridge J, eds. Visibly different: Coping with disfigurement. Oxford: Butterworth –Heinemann; 131-146.
- Cheung, L.K., Pheng Loh, J.S., & Ho, S.M.Y. (2006). Psychosocial profile of Chinese with cleft lip and palate deformities. *Cleft Palate- Craniofacial Journal*, 44(1), 79-86.
- Clifford E. (1978). *The Cleft Palate Experience: New Perspectives On Management*. Springfield, Illinois. 22-30.
- Dion K, Berscheid E, Walster E. (1972). What is beautiful is good. *Journal of Personality and Social Psychology*. 24:285-90.
- Field, A. (2005). *Discovering statistics using SPSS* (2nd ed.). London: Sage.
- Fitts WH. (1972). *The self concept and behavior: Counsellor recordings and tests*. Research Monograph No.1, Nashville, Tennessee. 35-45.
- Glasner, Rabbi S. (1961). Family religion as a matrix of personal growth. *Marriage & Family Living*; 23: 291-293.
- Gupta, R. (2011). *Agnihotri's Self Confidence Inventory*. National Psychological Corporation, Agra.

- Harper DC, Richman LC. (1978). Personality profiles of physically impaired adolescents. *Journal of Clinical Psychology*. 4:636-42.
- Heller A, Rafman S, Zvagulis I, Pless IB. (1985). Birth defects and psychosocial adjustment. *American Journal of Diseases of Children*;139:257–263.
- Hunt O, Burden D, Hepper P, Johnston C. (2005). The psychosocial effects of cleft lip and palate: a systematic review. *European Journal of Orthodontics*. 27:274–85.
- Hunt O, Burden D, Hepper P, Stevenson M, Johnston C. (2006). Self-reports of psychosocial functioning among children and young adults with cleft lip and palate. *Cleft Palate Craniofacial Journal*. 43:598–605.
- Hunt, O., Burden, D., Hepper, P., & Johnston, C. (2005a). The psychosocial effects of cleft lip and palate: A systematic review. *European Journal of Orthodontics*, 27, 274-285.
- Hunt, O.; Burden, D.; Hepper, P.; Stevenson, M. & Johnston, M. (2007). Parent Reports of the Psychosocial Functioning of Children With Cleft Lip and/or Palate. *Cleft Palate–Craniofacial Journal*. 44 (3), 304-11.
- Jha, P.K. (1997). *Perceived Loneliness Scale*. National Psychological Corporation, Agra.
- Kapp-Simon, K. (1986) self concept of primary – age school children. *Cleft palate Journal*. 23 (1).
- Kapp-Simon, K.A. (2004). Psychological issues in cleft lip and palate. *Clinics in Plastic Surgery*, 31(2), 347-352.
- Kinnis, G.C. (1954). Emotional adjustment of the mother to the child with a cleft palate. *Medical Social work*; 3:67-71.

- Kummer, A.W. (2008). *Cleft palate and craniofacial anomalies: Effects on speech and resonance* (2nd ed.). New York: Delmar Cengage Learning.
- Lansdown R, Lloyd J, Hunter J. (1991). Facial deformity in childhood: severity and psychological adjustment. *Child Care Health Development*. 17:165-71.
- Mathur, M. & Aurora, S. (2005). *Manual for Social Skills Problem Behaviour Checklist*. Manovigyan Anusandhan Peeth, Meerut.
- McWilliams, B.J. (1982). Social and Psychological problems associated with cleft palate. *Clinics in Plastic Surgery*. 9(3), 317-326.
- Mohite, P. (2004). *Mohite Home Environment Inventory*. National Psychological Corporation, Agra.
- Murray,L; Arteché, A.; Bingley, c.; Hentges, F.,Bishop, A.V.M.; Dalton, L.; Goodacre, T. & Hill, J. (2010). The effect of Cleft lip on socio-emotional functioning in school age children. *Journal of child psychology and psychiatry*. 51:1, 94-103.
- Noar JH. (1991). Questionnaire survey of attitudes and concerns of patients with cleft lip and palate and their parents. *Cleft Palate Craniofacial Journal*.28:279–284.
- Rai, S.N. & Mehta, C.S. (2010). *Interpersonal Judgment Scale*. National Psychological Corporation, Agra.
- Rai, S.N. (1994). *Manual for Conformity Behaviour*. National Psychological Corporation, Agra.
- Reinherz H.Z., Stewart-Berghauer G, Pakiz B, Frost A.K, Moeykens B.A. Holmes W.M. (1989). The relationship of early risk and current mediators to

- depressive symptomatology in adolescence. *Journal of American Academy of Child Psychiatry*; 28: 942-947.
- Richman LC, Harper DC. (1978). Observable stigmata and perceived maternal behaviors. *Cleft Palate Journal*.; 15:215–219.
- Richman LC, Harper DC. (1978). Observable stigmata and perceived maternal behaviors. *Cleft Palate Journal*. ;15:215–219.
- Richman LC. (1997). Facial and speech relationships to behavior of children with clefts across three age levels. *Cleft Palate Craniofacial Journal*; 34:390–395.
- Ruess, A. L., A (1965). Comparative Study of Cleft Palate Children and Their Siblings. *Journal Clinical Psychology*; 21: 354-360.
- Schneiderman CR, Auer KE. (1984). The behavior of the child with cleft lip and palate as perceived by parents and teachers. *Cleft Palate Journal*; 21:224–228.
- Shah, B. (2010). *Shah Security-Insecurity Scale*. National Psychological Corporation, Agra.
- Sharma, H., Bharadwaj, R.L. & Bhargava, M. (1998). *Comprehensive Anxiety Test*. Pankaj Mapan, Agra.
- Sharma, H.C. & Bharadwaj, R.L. (2007). *Manual for the Scale of Emotional competence*. Pankaj Mapan, Agra.
- Snyder, H., & Pope, A.W. (2009). Psychosocial adjustment in children and adolescents with a craniofacial anomaly: Diagnosis-specific Patterns. *Cleft Palate-Craniofacial Journal*, 47(3), 264-272.

- Snyder, H.T, Bilboul, M.J., & Pope, A.W. (2005). Psychosocial Adjustment in Adolescents With Craniofacial Anomalies: A Comparison of Parent and Self-Reports. *Cleft Palate–Craniofacial Journal*. 42(5), 548-555.
- Spence, S. H. (1995). *Social skills training: Enhancing social competence and children and adolescents*. Windsor, UK: The NFER-NELSON Publishing Company Ltd.
- Spriestersbach, D.C (1961). Counseling parents of children with cleft lips and palates. *Journal of Chronic Diseases*; 13: 244-252.
- Thomas PT, Turner SR, Rumsey N, Dowell T & Sandy JR. (1997). Satisfaction with facial appearance among subjects affected by a cleft. *Cleft Palate Craniofacial Journal*; 34:226–231.
- Tisza, Veronica B, Silverstone, Betty, Rosenblum. G& Hanlon, Nancy (1958). Psychiatric observations of children with cleft palate. *American Journal of Orthopsychiatry*; 28: 416-423.
- Tobiasen JM, Hiebert JM. (1984). Parents' tolerance for the conduct problems of the child with cleft lip and palate. *Cleft Palate Journal*; 21:82–85.
- Turner SR, Thomas PW, Dowell T, Rumsey N, Sandy JR. (1997). Psychological outcomes amongst cleft patients and their families. *British Journal of Plastic Surgery*. 50:1–9.
- Videbeck R. (1960). Self-concept and the reaction of others. *Sociometry*. 23:231-9.