

**“NEED AND EFFICACY OF SPEECH THERAPY FOR CLEFT LIP AND PALATE CHILDREN
AFTER SURGERY; PARENTS’ PERSPECTIVE”**

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ABSTRACT

The current study was carried out to investigate the awareness of parents of children with orofacial cleft regarding the need and effectiveness of speech therapy. The main objective of the study to find out the awareness of timely treatment of speech problems in parents, the information provided to parents in general settings and to suggest some ways to guide parents about the positive impact of speech therapy programs on speech and language of congenital orofacial cleft children. It also investigate the importance of home assignments, carryover exercises and parental counselling from parental aspects. The study focused on parents of cleft children because by their efforts and motivation the speech related issues of their cleft children can be addressed. The children with orofacial cleft need a long term treatment plan for their treatment, there is a need of complete cleft care unit. The availability of a comprehensive cleft care unit from where the parents receive guidance to minimize the problem faced by their children can be helpful for the patients and their parents.

KEYWORDS: Cleft Lip and Palate, Speech Language Therapist, Therapeutic Interventions

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Chapter I: Introduction

Introduction

Cleft lip and palate are birth defects that develop when the baby's lip or mouth do not form properly during pregnancy. These birth defects are called orofacial clefts. It is a group of conditions that includes cleft lip, cleft palate, or both together. One in 700 babies are born with a cleft globally. Clefts cause difficulties eating, breathing, hearing and speaking. Experts say that the highest incidents of clefts are among Asians, approximately one in 500 births. No exact cause is known, but most experts agree that the causes of Cleft lip and palate are multi factorial and may include a genetic predisposition as well as environmental issues or malnutrition. In Pakistan, 24 children everyday and 9000 children per year are born with cleft. A small cleft palate adds risk for a wide range of speech disorders and language delays that commonly include hyper nasality, nasal emission or articulation errors such as compensatory articulation. The burden for individuals, with craniofacial conditions, and their parents can be tremendous. The parental awareness and perception about the child needs is very important for the wellbeing of the child. The cleft related problems is provided by interdisciplinary Cleft teams (Crockett and Gordy, 2014). The intensive and complex treatment sports increase pressure on the family life ((Akinbami, 2016).

(Myhre, Agai, Dundas and Feragin , 2019) were among the first to investigate parents perspective on multi multidisciplinary craniofacial teams using an emic perspective.

Even with early surgical repair, a majority of pre-schoolers demonstrate delays in speech sound development.

Around half of all children with cleft palate need some form of speech and language therapy; this explains the important of parental involvement in treating the children with cleft palate.

Previous studies focused on the speech and language problems of patients with cleft lip and palate, the importance of parental awareness and perception to deal with this situation is often ignored.

This study is conducted in a cleft unit hospital in Karachi, Pakistan. In Karachi this is the only comprehensive cleft unit that provides all available treatments of orofacial cleft including surgery, orthodontic treatments, speech therapy, psychological treatments and social integration of cleft patients. Qualitative research can respond to this limitation by providing in depth information and insight about the

parental awareness and expectations about the efficacy of speech therapy. A questionnaire is used to investigate parents using a set of themes that might be appropriate to detect in depth experiences, Harris, (1976) Sutton and Austin). Surveys are conducted in outpatient department of cleft unit as well as speech therapy department of the Centre.

Its purpose includes to align parental concerns about the appropriate development of verbal communication and the provided ways to foster speech language at home. Counselling of CP children and their parents is part of the clinical assessment process. Speech programme goals may include counselling of parents about early development. It is observed that parents of patients who are enrolled in a speech programmes are much more aware and positive than the parents of cleft patients in general settings.

Emotional Experiences of Having A Child With A Cleft

In research views around the diagnosis of a child with a cleft, discourses of 'loss, 'mourning,' and 'correction' have been frequent, informed by the assumptions of preceding theoretical perspectives. Parents' sentiments of astonishment, wrath, sadness, and fear have been reported in surveys and qualitative research both pre- and post-natally, across nations and cultures. In-depth qualitative study, on the other hand, has shown a broader range of experiences, such as parents' joy at a child's birth or opinions of a child's cleft as ordinary or unusual.

However, the quality of both quantitative and qualitative studies in this body of work varies, with half of them failing to give response rates and a quarter failing to document the ages of the children. Most studies omit fathers and concentrate solely on collecting cross-sectional data. Furthermore, quantitative studies include samples as small as 25 people and utilise few validated measures, whereas qualitative research rarely thoroughly explains its methodology or conclusions.

Attachment theory has informed studies of the early development of the relationship between parents and children with clefts, suggesting that infants with clefts may be as securely attached to their mothers as those without clefts, with a potentially less sensitive interplay between the two due to possible disruptions in communication cues.

Further, it is evident through research that parents have expressed concerns about social difficulties such as a child's acceptability by classmates, teasing experiences, finding a life partner, and gaining work.

Parents' discomfort was noted as a result of their child's reported experiences of teasing or bullying at school or while entering new and unfamiliar environments, according to the

study. This research also revealed the conflict that parents have in trying to safeguard their children while still encouraging their independence.

Through survey, it has been observed that across all other countries, between 15% and 68 percent of parents said their kid's self-confidence had been harmed by having a cleft, and between 50% and 68 percent said their child had been teased because of it.

Problem of the Study

In Pakistan, 24 children every day and 9000 children per year are born with a cleft. Speech problems are very common among these patients; quite often parents do not understand the need of timely therapeutic treatment of speech that compromises the speech intelligibility of the child. This problem should be resolved by giving awareness of the importance of getting the child help for speech difficulties as soon as possible.

Scope of the Study

The study is focused on parents of cleft lip and palate patients. It is conducted in a comprehensive cleft set up. The data was collected from parents of patients of cleft lip and palate above two years.

For gathering the data parents of children with cleft lip and palate were interviewed through a questionnaire at a cleft care unit.

The parents of children enrolled in therapy program were asked in detail about their understanding, thinking and efficacy of speech therapy

Objectives of the Study

- To investigate the awareness regarding speech therapy among the parents of cleft children.
- To investigate the perception regarding speech therapy among the parents of children who are taking sessions.
- To find out the parent's opinion on the effectiveness of therapy
- To assess overall expectations of parents from the therapist and the treatment.
- To find out the importance of carry over exercises and home assignments
- To find out the effect of parent and therapist coordination on therapy outcomes.
- To find out the importance of counseling according to parents..

Definition of Technical Terms

Speech and Language Therapists: Children and adults with communication, eating, drinking, and swallowing problems might benefit from speech and language therapy. You'll

assist those who have difficulty speaking and communicating due to physical or psychological issues. (Google)

Speech Therapy: Speech therapy is the assessment and treatment of communication problems and speech disorders. It is performed by speech-language pathologists (SLPs), which are often referred to as speech therapists. (Ref: <https://www.healthline.com/health/speech-therapy>)

Cleft Lip and Palate: Cleft lip and palate are birth abnormalities that occur when the lip or mouth of a newborn does not develop normally during pregnancy. These congenital malformations are collectively known as "orofacial clefts.". (Google)

Therapeutic Interventions: A therapeutic intervention is an attempt by people or organisations to enhance the well-being of someone else who is either in need of assistance but refuses it or is otherwise unable to initiate or accept it. (Google)

Limitations of the Study

The research is restricted to unit of a specific hospital of Karachi. Moreover, the research is restricted to these variables that are employed in the study. However there are various factors that should be considered to research. The sample size that is employ in study is also restricted the research. The time that is required to conduct the research is another limitation. Furthermore, the resource that is available to conduct the research is also limited; therefore, the research is conducted in the Karachi.

Chapter II: Review of the Literature

Literature Review

In this chapter, we will be looking at the need for speech therapy for cleft lip and palate after surgery and how effective it is perceived by parents.

Speech therapy is a kind of therapy that helps kids with special needs in improving their speech, understanding language, and communicating in ways other than verbal. Speech therapists treat the swallowing and communication problems of these kids with speech disorders. Kids that are born with a cleft palate or lips may need speech therapy after surgery to help them with problems like articulation disorder, nasal fricatives, glottal stops, hyper nasality, and hypo nasality; to name a few.

A Speech therapist helps these kids in establishing correct articulation, putting pressure on the right places during sound production, and establishing new motor speech patterns.

Parent support plays an important part in the successful completion of these therapies. Parents who are actively involved in this process find their kids completing the therapy quickly and with long-lasting results.

What is Cleft Lip and Palate

According to the U.S department of health science (Facts about Cleft Lip and Cleft Palate, 2020), a cleft palate happens if the tissue of the roof of the mouth did not join between the sixth and ninth months of pregnancy. In some babies, both front and back parts are open while in others only one part is open. Cleft deformity can be classified into three different types: Cleft lips, cleft palates, and sub mucous cleft palate. ((Sullivan, 2010).

Surgery Impact on Child Speech

According to (O'Gara, 1987), children having cleft deformities find it difficult to produce some sounds, especially high-pressure consonants. They also face velopharyngeal insufficiency which is the main reason for deviant speech production. In velopharyngeal insufficiency, air escapes through the nose instead of the mouth; resulting in improper closing of the soft palate. (Abdel-Aziz, 2008).

After studying various researches done on cleft palates, it can be concluded that the first step in the formation of adequate speech is cleft surgery. The main purpose of this surgery is to provide these children with typical speech development chances. (Agrawal, 2011).

A lot of research and debates were conducted to find out the optimal time of cleft palate surgery so that it can provide maximum benefit to speech development strategies.

Need of Speech Therapy after Surgery

According to the research conducted by (Morris, 1962), children with cleft lips and palate find it extremely difficult to communicate on their own especially after surgery. The result of this study shows that cleft lips and palate are not just anatomical defects. Therefore, parents should pay special consideration to their language development.

Chapman is of the view that speech can be improved not by surgery only but it can also be improved through speech therapy and language development.

Nasal resonance and articulation play an important part in the outcome of speech in children suffering from cleft palates. (al. P. e., 1996). The main reason for speech error is the lack of proper velopharyngeal sphincter closure. When velopharyngeal sphincter is not closed off properly, speech sounds come out from the nose instead of the mouth. These irregular articulation patterns are also known as Compensatory articulation disorder (CAD) (Guerrero, 1996).

If after surgery, parents opt not to take their child to a speech therapist, this may result in improper handling of situations once they enter adulthood. It is to be noted that not all children with cleft lips and palates need speech therapy. It is up to the parent's discretion whether to take their child to therapy or not. Parents should keep a close eye on their child's speech development.

A study was conducted by (Carvalho, 2020) in which emotional and social experiences of parents whose children have cleft deformities were questioned and how they dealt with them.

The participants were made to fill out a questionnaire in which they were asked to describe their feelings as soon as they heard about their child cleft deformity. Around 36% reported fear and 14.6% reported shock and sadness.

This study shows that the emotions felt by the parents were in line with the researches that have been conducted so far. The top most emotion was fear followed by feeding problems. Feeding care is one of the most important concerns as parents cannot feed baby directly from the mouth due to the abnormalities in face formation. (Pamplona, 2000)

Since this is also a shock for parents and caregivers as they don't know how to take care of their baby's different needs. The whole family along with the child needs care and continuous guidance and clarification from experts in this field. Because of these factors, it is necessary that initial therapy and counselling should be performed with the parents and caregivers to extend psychological support to the family. (Tabaquim, 2013)

The first and foremost treatment is performing surgery on these kids after 4-5 weeks. After surgery, parents should consider taking their kids to speech therapy in order to improve their communication skills at an earlier stage. Since children at this age are really adaptive, so they can easily improve their communication skills and articulation problems. (JA, 2012)

The main limitation and drawback of this study was that the participants were selected according to convenience sampling. Therefore, the impact of age, ethnicity, and other external factors were not properly taken into account while conducting this study.

Further, most of the cleft research has focused on parents' information requirements and experiences at the time of diagnosis, with fewer studies examining these concerns over the age ranges of children.

However, parents' need for accurate and balanced information about clefts and their causes has been reported (Cleft Lip and Palate Association 1996; Young et al. 2001), as has a lack of readily accessible information at diagnosis (Davalbhakta & Hall 2000); (Nusbaum et al. 2008).

According to studies, the majority of parents prefer to get their knowledge verbally from specialists at this time (Strauss et al. 1995; Byrnes et al. 2003).

While the health policy of different countries encourages parents and children to participate in decisions about their care, there is little research on parents' experiences in making decisions regarding their child's cleft therapy. Over a third of parents in one small survey (n = 42) , specifically in the United States wanted to be more involved in treatment decision-making (Pannbacker & Scheuerle 1993), and surveys in different countries have also suggested that some parents do not feel involved in decisions and would like more involvement.

Different researchers investigated that 'satisfaction' with the organisation and delivery of cleft services (Kramer et al. 2007). The results suggest high ratings among parents (Jeffery & Boorman 2001); However, because most articles fail to clearly explain how satisfaction is understood, it has been addressed very simplistically in this research.

Some refer to 'care and attention' satisfaction (Williams et al. 2001); some to the 'level' of care (Jeffery & Boorman 2001), and yet others to the 'way' of care offered (Semb et al. 2005).

Despite the good feedback from parents, issues such as limited access to and coordination of services have been highlighted. However, these surveys have a broad range of sample sizes (between 30 and 495), are almost exclusively cross-sectional, and, with the exception of the biggest research, are conducted in single centres. Furthermore, the study tools used in this body of work are varied, and validated measurements are few.

According to research, parents trust cleft clinicians because of their specialisation and are concerned about the lack of knowledge among general healthcare personnel.

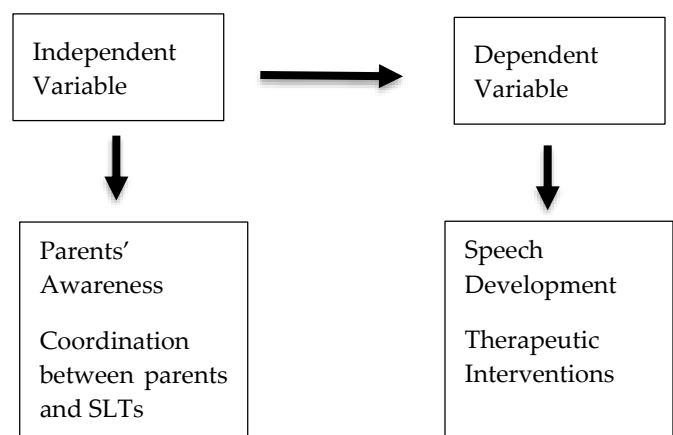
Parents have stressed the importance of having practitioners who communicate well and are sensitive , as well as continuity of care from specialist cleft clinicians.

Parents' satisfaction with the outcomes of their children's cleft therapy has also been studied utilising the important criteria of face appearance, function, and psychological well-being. These trials, too, have consistently indicated high levels of treatment satisfaction. Some studies have discovered broad agreement between parents and their children while others have revealed divergent perspectives on various variables (Berger & Dalton 2009).

Findings on psychosocial consequences have also been mixed, with some claiming that children with clefts have low self-confidence and are subjected to a lot of mocking ((Semb et al. 2005; Noor & Musa 2007).

Others claim that their cleft affects their children less emotionally and socially than their parents believe, or that they have more social but fewer emotional consequences. The discrepancies in these findings might be explained by a lack of longitudinal data or multidimensional ways to measuring satisfaction with treatment results in a particularly sensitive circumstance, or by varied personal/cultural expectations on the outcomes of care.

Conceptual Framework



Chapter III: Design of the Study

Research Design

The research was carried out in the cleft unit of a hospital in Karachi. The present study was an exploratory research and was analyzed through qualitative and quantitative methods. The sample of the study consists of parents whose child children have congenital orofacial cleft and selected through convenient sampling method..

Target Population

Target population of this research are the parents of whose child/children have congenital cleft lip and palate and are of two years and above, interviewed in a cleft care unit of a hospital

Sample Technique

Self-structured questionnaire was used as a tool for collecting data. The respondents were requested to fill the questionnaire.

Sample Size

Sample size for the research is 30 which consists of a group of parents of have congenital cleft lip and palate and are of two years and above.

Instrument

The study was carried out with the help of a structured questionnaire. The questionnaire was designed for the parents of cleft children, it consisted of five sections. The first section collects general information. The second section was used to investigate the parent's perception regarding speech therapy. The third section was designed to determine the level of satisfaction of parents regarding speech therapy. The fourth section noted the coordination between the parents and the therapist. The fifth section investigates understand the parent's expectations regarding speech therapy. The questionnaire also included a few open ended questions to get more in depth idea of the parent's opinions.

Hypothesis

Considering the objectives of our study, the following hypothesis have been developed:

H0: There is no significant relationship between parents' awareness about need of speech therapy and speech development of the child, neither coordination between parents and SLPs leads to realistic expectations of therapeutic interventions.

H1: There is a significant relationship between parents' awareness about need of speech therapy and of speech development of the child.

H2: Coordination between parents and SLPs leads to realistic expectations of therapeutic interventions

Hypothesis Testing Technique

Considering the sample size of our target population, Z-test is appropriate to evaluate the significance of null hypothesis and research hypothesis.

Z-Test

A Z-test is a statistical test in which the test statistic's distribution may be approximated by a normal distribution under the null hypothesis. The mean of a distribution is tested using Z-tests. The Z-test has a single critical value for each significance level in the confidence interval, making it more practical than other hypothesis tests, whose critical values are determined by the sample size.

In our survey, we have applied Z-test (one tailed)

P-Value

The p-value in statistics is the likelihood of getting outcomes at least as severe as the observed results of a statistical hypothesis test, given the null hypothesis is valid. A lower p-value indicates that the alternative hypothesis has more evidence supporting it.

We have assumed P value $\alpha = 0.05$ as level of significance, for which, the critical value of Z (one-tailed) = -1.645 to +1.645.

Procedure for Data Collection and Analysis

The data was collected through interviews and the responses were recorded on the spot. The results of responses collected through the questionnaire was analyzed using SPSS description statistics. The results have been compiled in the



■ Unintelligible Speech ■ Normal speech
■ Some Problem

form of tables and graphs. Further, for the purpose of evaluating significance of null hypothesis and research hypothesis, Z-test has been applied using SPSS, the results of which have been interpreted in the next sections.

Chapter IV: Interpretation of the Results

Results of Demographic Details

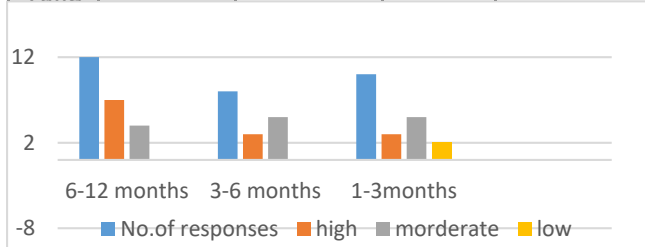
The data was collected from thirty parents, of which twenty four were mothers and six fathers of children, above two years, with cleft lip and palate.

Awareness among Parents

Amongst the thirty children/n; fifteen were found to have Unintelligible Speech (representing 50%), seven with Mild Speech issues (representing 23.3%) and the rest eight with Normal Speech (representing 26.7%).

Data Range	Frequency	Percent	Cumulative Percent
Unintelligible Speech	15	50%	50.0
Normal speech	8	26.7%	76.7
Some Problem	7	23.3%	100.0
Total	30	100.0	

Data Range	Frequency	Percent	Cumulative Percent
High	14	46.7	46.7
Moderate	14	46.7	93.4
Low	2	6.7	100.0
Total	30	100.0	



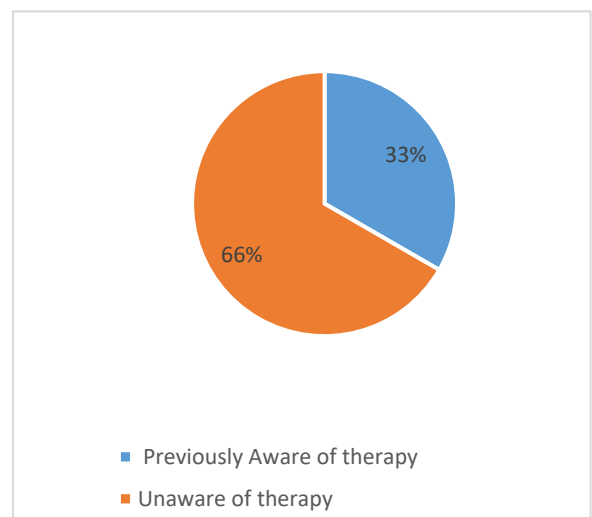
While considering the responses about parental awareness of speech therapy mentioned in Table 4.1.1.2 below, the result concludes that the majority of the parents representing 66% of the sample size are unaware of the speech therapy, whereas, only 33% are aware of it.

Data Range	Frequency	Percent	Cumulative Percent
Aware of therapy previously	10	33	33.0
Unaware of therapy previously	20	66	100.0
Total	30.0	100.0	

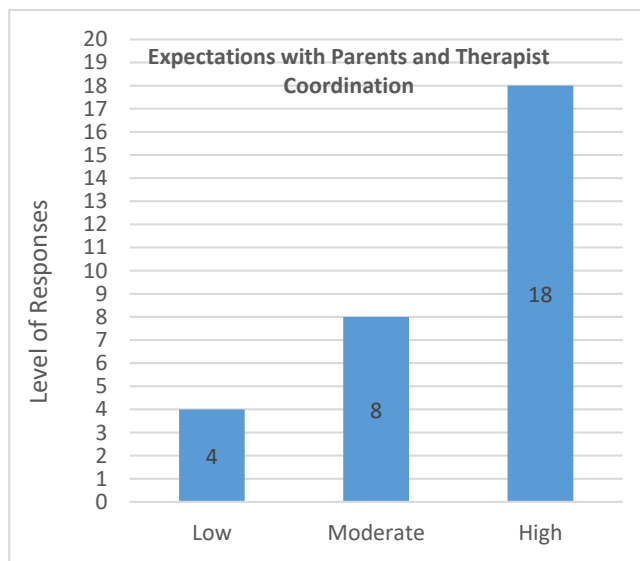
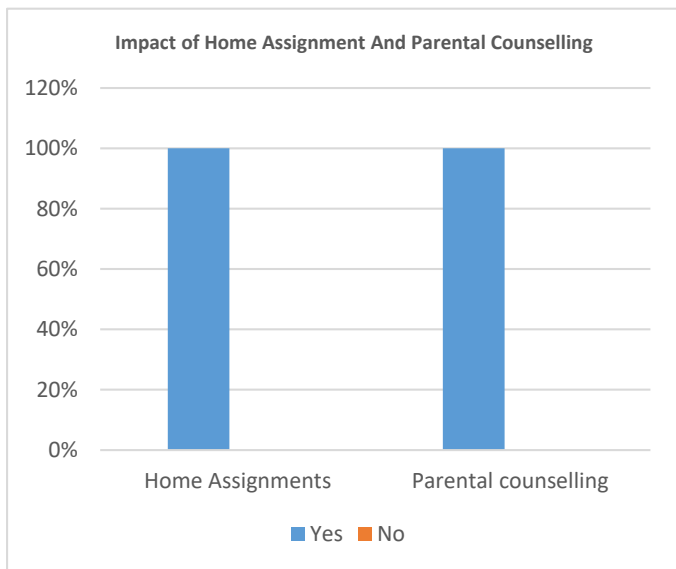
Male	6
Female	24

Effectiveness of Therapy

The responses against the Effectiveness of therapy represents that the effectiveness of therapy results in high and moderate level during the duration of 3-6 months and 6 – 12 months (representing 46.7% each), whereas, only 2% represents the low level of effectiveness of therapy.



Impact of Home Assignment And Parental Counselling



The responses about impact of home assignment and parental counselling reflected 100% positive results, as shown in the Table 4.1.2.2 below:

Expectations with Parents and Therapist Coordination

The responses against expectation for coordination between parents and therapists represent 60% high level of realistic

results, 26.7% moderate level and only 13.3% of low level of results.

Table 4.1.3.1

Expectations with Parents and Therapist Coordination		Frequency	Percent	Cumulative Percent
Table 4.2.1				
Statistical Results				
	Parents' Awareness and Speech Therapy		60.0	60.0
			26.7	86.7
Mean	3.8		13.3	100.0
Known Variance	4.372414			
Observations	30		100.0	
Hypothesized Mean	0			
Z	9.951288533			
P(Z<=z) one-tail	0			
z Critical one-tail	1.644853627			
z Critical two-tail	0.000045			

Interpretation

Interpretation

After applying Z test on the responses collected of the sample size against the self-structured questionnaire, the following results have been obtained:

As per the outcome of Z-test, it has been interpreted that the calculated Z value is greater than the Z (one tailed) critical value i.e. 1.645 ($9.95 > 1.645$) as well as the P-value obtained

through the hypothesis testing is less than the level of significance i.e. 0.05 ($0.000045 < 0.05$), which shows that the null hypothesis is rejected and alternatively, the developed hypothesis have been accepted.

Chapter V: Summary, Discussion, Conclusion and Recommendations

Summary and Discussion

The present study investigates the perception of parents of children with cleft about speech therapy, its usefulness and about the fact that the combined effort of parents and therapists can make a big difference in children's speech and language development.

The themes identified from the structured questionnaire are:

1. Awareness among parents.
2. Effectiveness of therapy.
3. Coordination of parents and therapist and realistic expectations.

Awareness among Parents

This theme of awareness among parents is an important factor. It lays the foundation for the solution of the child's speech and language deficits. If the parents were unaware of how and where the child's speech problems are addressed then the child would not have received any help. Parents should be given guidance regarding speech therapy along with surgical treatment for cleft.

By the information collected through the research, it was found that 50% of the children had unintelligible speech, 23% have intelligible speech with few errors and about 26.6% of children have normal speech.

With this extent of therapeutic need 66% of parents were unaware about speech therapy and 33% had prior knowledge about speech therapy.

The theme clearly identifies that there is a need to increase awareness among parents about the usefulness of speech therapy for their child.

Effectiveness of Speech Therapy

The parental view about how their children are progressing with the help of therapy programs is in favour of speech therapy. According to parents whose children are enrolled in speech therapy program for 6-12 months 6.66% of parents think that therapy is highly effective, from those parents with children that had been enrolled for 3-6 months 62% acknowledged the effectiveness of speech therapy on

moderate level. Among the parents of children enrolled in speech therapy for 1-3 months, 30% found the program highly effective, 50% found it moderately effective and 20% thought the progress was on a lower level.

The findings of the theme indicated that children's speech and language progressed on different levels with the help of therapy. The home assignments and carry over exercises at home boosted their progress. All of the 30 parents realised that assignments and practice at home are very useful for the speech and language development of their children.

Coordination between Parents and Therapists

The speech and language development of children requires a combined effort from the therapist, the parents and the child. Children with cleft lip and palate demonstrate improvement on different levels, it is a slow and time taking process. The patience demonstrated by parents plays a very important part in this process. Visiting the therapist twice a week and manage it with jobs is not an easy task, many often come from distant areas and travel for hours via buses to reach the centre.

The parental counselling keeps them motivated and hopeful. 100% of the parents realised the importance of the counselling done by the therapist. It also plays a role in the successful coordination between therapists and parents. The coordination allows parents to form realistic expectations as they witness the slow progress in their child's speech. Among the group of parents that had strong coordination with the therapist 75% were realistic and positive about the therapy program.

All of these themes identifies the role of parents for the timely intervention of child's speech and language development.

Conclusion

The study identifies the importance of parents' awareness about the need of speech therapy and speech development of the child. Generally the parents were unaware of the importance of timely intervention with their child's speech and language deficits.

1. The efficiency of speech therapy depends on multiple factors:

- i) The duration and intensity of therapy.
- ii) Continuous practice with the help of home assignments and exercises.
- iii) Guidance given to parents about using different therapy techniques.

2. The study reflects that all above factors positively impact therapy outcomes. The study indicates that coordination between parents and therapists lays down a strong foundation of realistic approach, that the advancement of the child's speech and language development would be slow and would take time and effort but would gradually improve the child's speech and language.

References

Adhikary, G., Shawon, M., Shamsuzzaman, M., Ahmed, S., Shackelford, K., & Uddin, M. J. (2019). Factors influencing patients' satisfaction at different levels of health facilities in Bangladesh: Results from patient exit interviews.

Aikins, E. A., & Akinbami, B. O. (2019). Perceptions, expectations, and reactions of caregivers to cleft lip and palate repair in a tertiary hospital. *Odonto-stomatologie Tropicale = Tropical Dental Journal*,

Bessell, A., Sell, D., Whiting, P., Roulstone, S., Albery, L., Persson, M., et al. (2018). Speech and language therapy interventions for children with cleft palate: A systematic review. *The Cleft Palate-craniofacial Journal*: Bleich, S. N., Ozaltin, E., & Murray, C. K. (2009). How does satisfaction with the health-care system relate to patient experience? *Bulletin of the World Health Organization*

Bonner, A., & Tolhurst, G. (2019). Insider-outsider perspectives of participant observation. *Nurse Researcher*, 9, 7-19. Brown, S. W., Nelson, A. M., Bronkesh, S. J., & Wood, S. D. (2018). *Quality service for practice success. Patient satisfaction pays*. Maryland: Aspen Publication.

Carroll, C. (2019). "It's not every day that parents get a chance to talk like this": Exploring parents' perceptions and expectations of speech-language pathology services for children with intellectual disability. *International Journal of Speech-language Pathology*,

Cartwright, J., & Magee, H. (2006). *The views and experiences of patients living with disfiguring conditions and health professionals involved in their care*. Picker Institute

Recommendations

The study was conducted in a cleft care unit, the future research about parent's perception and awareness can be done in general settings which might produce different results.

1. The parents' pre and post therapy opinions were not recorded during this research. A long-term study is required to record the parents' opinion before and after therapy.
2. It is observed that there is a need of establishing a comprehensive cleft care unit where the issues related to orofacial cleft i.e. surgery, feeding, dentition, psychological, speech and language problems are properly addressed.

Corbin, J., & Strauss, A. (2008). *Basics of qualitative research Techniques and procedures for developing grounded theory* (3rd ed.).

Costa, M. A., Yao, C. A., Gillenwater, T. J., Taghva, G. H., Abrishami, S., Green, T. A., et al. (2015). Telemedicine in cleft care: Reliability and predictability in regional and international practice settings. *The Journal of Craniofacial Surgery*

Europe. Cohn, E., Miller, L. J., & Tickle-Degnen, L. (2019). Parental hopes for therapy outcomes: Children with sensory modulation disorders. *The American Journal of Occupational Therapy: Official Publication of the American Occupational Therapy Association*,

J. J. & Sandy, J. R, 2001, Cleft lip and palate care in the United Kingdom – the Clinical Standards Advisory Group (CSAG) Study. Part 2: dentofacial outcomes and patient satisfaction. *The Cleft Palate-Craniofacial Journal*, 38, 24-29

K. & Snyder, H. T. (2005) Parenting stress in infancy and psychosocial adjustment in toddlerhood: a longitudinal study of children with craniofacial anomalies. *The Cleft Palate-Craniofacial Journal*, 42, 556-559.

Martin, V. (2005) Prenatal cleft lip and palate parent programme – phase 1. *British Journal of Midwifery*, 13, 90-95.

Mildinhal, S., Murphy, T., Sell, D., Shaw, 2001, Cleft lip and palate care in the United Kingdom – the Clinical Standards Advisory Group (CSAG) Study. Part 2: dentofacial outcomes and patient satisfaction. *The Cleft Palate-Craniofacial Journal*, 38, 24-29

Mossey, P. A. & Little, J. (2002) Epidemiology of oral clefts: an international perspective. In: *Cleft Lip and Palate: From Origin to Treatment* (ed. D. F. Wyszynski), pp. 127-158. Oxford University Press, New York, NY, USA.

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Semb, G., Brattstrom, V., Molsted, K., Prahl-Andersen, B., Zuurbier, P., Rumsey, N. & Shaw, W. C. (2005) The Eurocleft study: intercenter study of treatment outcome in patients with complete cleft lip and palate. Part 4: relationship among treatment outcome, patient/parent satisfaction and the burden of care. *The Cleft Palate-Craniofacial Journal*, 42, 83–92.

Strauss, R. P., Ramsey, B. L., Edwards, T. C., Topolski, T. D., Kapp-Simon, K. A., Thomas, C. R., Fenson, C. & Patrick, D.

L. (2007) Stigma experiences in youth with facial differences: a multi-site study of adolescents and their mothers. *Orthodontics & Craniofacial Research*, 10, 96–103.

Williams, A., Bearn, D., W. C., Murray,. (2001) Cleft lip and palate care in the United Kingdom – the Clinical Standards Advisory Group (CSAG) Study. Part 2: dentofacial outcomes and patient satisfaction. *The Cleft Palate-Craniofacial Journal*, 38, 24–29.

Pope, A., Tillman, (2005) Parenting stress in infancy and psychosocial adjustment in toddlerhood: a longitudinal study of children with craniofacial anomalies. *The Cleft Palate-Craniofacial Journal*, 42, 556–559.

Young et al. 2001; Cleft Lip and Palate Association (2007) Regionalisation of cleft lip and palate services: has it worked? A report on users' perspectives of cleft care. Available at:

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Appendix

Business Research Method

Questionnaire on

“Need and Efficacy of Speech Therapy for Cleft Lip and Palate Children after Surgery; Parents’ Perspective”

The key objective of this study is to evaluate the parents’ perspective with respect to need and efficacy of speech therapy for cleft lip and palate children after surgery. This questionnaire is divided into a number of sections covering the following;

1. Independent Variables
 - (i) Parents’ Awareness
 - (ii) Coordination between parents and SLTs

2. Dependent Variables
 - (i) Speech Development
 - (ii) Therapeutic Interventions

For all the questions, you have multiple options. Please answer each question by marking (a) against the option that best describes your opinion.

If you do not have enough information to answer a question, please leave it blank.

Section A: “Demographic Details”

Name of child: _____

Age of child: _____

Name of parent: _____

Age of Parent: _____

Address: _____

Phone number: _____

Total number of children: _____

Section B: “Questionnaire”

Q1. Which child was your cleft child: _____

Also specify the type of cleft

Lip Both Complete

Palate Incomplete

Q2. Do you have a family history of cleft?

Yes, mother side Yes, father side

Yes, sibling. No

Q3. When was your child treated for

1. _____ Date _____

2. _____ Date _____

3. _____ Date _____

Q4. How do your children communicate?

Gesture Verbal Single word

Two words Sentences Pointing

Sign

Q5. How is your child developing?

Age-appropriate Delay

Q6. What is the voice quality?

Pitch Low Resonance low

High High

Normal Normal

Q7. Is your child's speech intelligible?

Yes No Most of the time

Sometimes Only family understands

Q8. If not, how do you think it will be solved?

By surgery With time

With therapy Don't know

Q9. Have you heard anything about speech therapy?

Yes No Don't know

If yes, then what _____

Q10. Do you think your child needs any therapy?

Yes No Don't know

We will do it by ourselves It will get better after surgery

Q11. If your child is enrolled in speech therapy what do you think will the results be?

Start talking Speech will become good Speech will be better

No need for therapy Don't know

Q12. Is your child taking speech therapy sessions?

Yes No

Q13. How long has your child been taking speech therapy?

- Less than one month Less than three weeks
 3 to 6 months One year

Q14. Have you observed any change in your child's communication after starting therapy?

- Yes A little bit Very improved
 Don't know No improvement

Q15. Do you think therapy is important for cleft children?

- Yes, very important Important
 Not very important Not important

Q16. At what age did your child start taking therapy?

- 2 to 3 years 3 to 4 years 4 to 5 5 to 6
 6 to 7 7 to 8 9 to 12 12 to 15

Q17. How long do you think that therapy will be needed?

- One month 3 to 6 months One year
 Don't know Other: _____

Q 18. At what age should therapy be started?

- 3 to 4 4 to 5 5 to 6 6 to 8
 9 to 12 12 to 15 Don't know No need

Q19. How was your experience with speech therapy?

- Excellent. Good Fine
 Okay Not good Bad

Q20. How do you think the therapy works?

- (.) By therapist. (.) By parents and therapist
(.) By parents (.) By child (.) By all

Q21. Do you think that counselling and guidance provided by therapist is an important part of the therapy?

- (.) Yes (.) We already understand. (.) No

Q22. Do you think that duration of the therapy session is enough for your child?

- (.) Yes (.) No (.) Don't know

Q23. Are you satisfied with the therapy session provided to your child , Grade i?

- (.) Very good (.) Good (.) Fair
(.) Normal (.) Don't know (.) Not working

Q24. Do you think the therapy helps in your child speech intelligibility?

(.) Yes (.) To some extent (.). Yes (.) Don't know

Q25. Do you want to give some advice that helps the therapist to improve?

1. -----

2. -----

3. -----

4. -----

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