Scholars Journal of Applied Medical Sciences (SJAMS)
Abbreviated Key Title: Sch. J. App. Med. Sci.
ISSN 2320-6691 (Online)
ISSN 2347-954X (Print)
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A Unit of Scholars Academic and Scientific Society, India
www.saspublishers.com

Speech and Hearing

Issues faced by Parents of Children with Cochlear Implant in Everyday Life

Mrs. Garima Dixit[1*], Mrs. Mittali Joshi[2], Ms. Priyanka Dubey[3]
[1,2]Assoc. Prof, Sri Auribindo Institute of Speech and Hearing, Indore, India
[3]Clinical Supervisor, Sri Auribindo Institute of Speech and Hearing, Indore, India

Original Research Article

***Corresponding author**
Mrs. Mittali Joshi

Article History
Received: 02.12.2018
Accepted: 11.12.2018
Published: 30.12.2018

DOI:
10.36347/sjams.2018.v06i12.027

Abstract: The current study is observational study was conducted on a total of 100 participants. The participants were parents (from either parents or both) of children with cochlear implant. The data was collected from subjects who had enrolled in different government schemes (MBSY, ADIP, RBSK) for receiving free of cost pre and post cochlear implant services. Two groups of Life Stress after CI & Depression after CI with Mean 1.92 & 2.23 & S.D 0.63 & 0.46 respectively among the response of the questionnaire 16 responses out of 28. The current study described parent's everyday problems that are associated with raising children who undergo CI. So while planning intervention to children we need work upon the issues which parents of children with CI are going through and could at the same time empower parents to acquire specific competencies in efficiently solving problems and coping with various parenting demands.
Keywords: Cochlear Implant, Children, Auditory.

INTRODUCTION

Cochlear implants evolvement has served as boon for many children with moderately severe to profound hearing loss as a one of the auditory habilitation option. The effectiveness of cochlear implant depends on various factors such as the cause of hearing loss, age of implantation, previous usage of hearing aid, number of electrodes inserted into cochlea, mapping, effective speech and language therapy and motivation of the parents. The motivated parents are one of the candidacy requirements previously considered mandatory to the process of cochlear implantation as per FDA guidelines.

The continuous parental efforts are required to achieve optimum results from the cochlear implant device post implantation [1-4]. There are various challenges that parents has to go through which might lead to many problems and stress in the life of parents of children with cochlear implant [5].The literature is brimming up with the reports day by day on parental support and stress related to rearing children with cochlear implant. The parental involvement is required not only in acceptance of the hearing loss and in selecting appropriate habilitation but also in continuous long term habilitation process. Overall, many studies have demonstrated higher stress levels in the parents of children with cochlear impalnts [6, 7]. On contrary, studies have also reported a good level of personal and social adjustment by parents of children with cochlear implant[1]. Sarant & Garrad, 2013 presented a finding that stress experienced by the parents with bilateral implants is lesser in comparison to the parents of children with unilateral implants[6]. The results of the study are explained on the basis of advantages of binaural hearing. Research studies have also attempted to identify stressors related to child as well as family like age of child, degree of hearing loss, social & financial support or parental income.The parent child stress has a significant effect on developmental skills such as language, social and communication skills of children with cochlear implant. Hence, it becomes important to identify any such factor and take appropriate measures to alleviate it[8].

India is a diverse nation and there are variations in culture, socioeconomic status, quality of life in comparison to the western countries. Hence, direct application of results of studies based on western population may not be justifiable. Previously, in Indian context few studies in this regard have been reported. A study by Prakash, G.R, Ravichandran[9] Susan, Alex, 2013 compared stress levels in mothers of children with hearing aids to those children using cochlear implants. The results revealed higher stress levels in both the groups. However, more stress levels in mothers with children using cochlear implant as shown on Parental stress Index. Kumar, Kumar S, Singh & Mohan, 2017 [[10]]. Evaluated parents expectation from children with cochlear implanted reported that their expectations

are higher in the children with cochlear implant. It was a questionnaire based study and comprised of only two questions related to parental stress. Hence, it is important that this aspect should be evaluated more in depth. On the similar lines, Desai and Karmadhari, 2017 compared and measured pre and post cochlear implant maternal stress and depression [11]. The authors gave preliminary evidence of higher maternal stress levels in the mothers of children with cochlear implantation. However, study served a major drawback of having very few no. of subjects (a total of 5). Thus, it is required to evaluate parental stress in larger group of sample in order to arrive at conclusive results. The present study aims to measure and also identify different stressors in the life of parents of the children with cochlear implant. The findings of the study might be helpful in understanding the problems faced by parents of children with cochlear implant and in providing professional support. This in turn will result into effective interventions strategies and positive outcome from the children with cochlear implant.

METHODS

The current study was conducted on a total of 100 participants. The participants were parents (from either parents or both) of children with cochlear implants. The data was collected from subjects who had enrolled in different government schemes (MBSY, ADIP, RBSK) for receiving free of cost pre and post cochlear implant services. The demographic details were recorded from the parents regarding age of child, gender, Mother's & father's age, their literacy levels, occupation of parents, number of siblings, number of affected children, place of living (urban/rural), type of family (nuclear or joint) & family support (adequate or inadequate). The children were in the age range of 3 to 10 years (Mean age = 6.5 years) out of which 62 were males and 38 were females. The minimum education level of mother's & fathers of children with cochlear implant was 5th grade. Except two families, others had only 1 of their children affected with hearing loss. A total of 38 families resided in urban and 62 remaining in the rural areas. All the families were using Hindi language as a language spoken at home and at other places. The families residing in nuclear set up were 60 and 40others resided in joint family. Also, the families were asked to report whether support that they received from their family members was adequate or not. The detail of the records shows 42 families reporting adequate support and remaining 58 reporting it to be inadequate.

Following demographic data, a questionnaire was given to the participants. The Burden scale for family caregivers (BSFC) [15]. Was used to evaluate the subjective issues faced by parents while rearing a child with cochlear implants. The present study is the first to use BSFC with parents of children with cochlear implant. This scale has been used previously as valid assessment tool in evaluating burden faced by a caregiver in practice and research. It has been made available in 20 European languages. The scale comprised of a total of 28 questions where participants had to put a cross mark to an option for each statement and options were Strongly agree, agree, disagree, & strongly disagree the one which is apt for their situation. As the questionnaire was in English language, to help parents it was translated in Hindi language and they were asked to mark accordingly. The scoring and interpretation was done as mentioned in the manual of BSFC. The scale used has been attached in the appendix. The scores obtained were subjected to the statistical analysis.

RESULTS

Table-01: Gender & Age wise distribution of Mothers & Fathers

Gender	Frequency	Percentage %
Female	38	38%
Male	62	62%
Age Group of Mothers	Frequency	Percentage %
20-25	23	23%
26-30	36	36%
31-35	22	22%
36-40	19	19%
Age Group of Fathers	Frequency	Percentage %
20-25	01	01%
26-30	31	31%
31-35	32	32%
36-40	36	36%

Table-2: Occupation Distribution of Mothers & Fathers

Mothers- Occupation	Frequency	Percentage %
Farmer	03	03
Housewife	93	93
Maid	01	01
Political leader	01	01
Teacher	01	01
Worker	01	01
Fathers- Occupation	Frequency	Percentage %
Business	04	04
Compounder	02	02
Driver	01	01
Employer	01	01
Factory	01	01
Farmer	20	20
Worker	37	37
Labourer	04	04
Marketing job	01	01
Mechanic	01	01
Private job	02	02

Table-03: Education Distribution of Mothers & Fathers

Mothers- Education	Frequency	Fathers- Education	Frequency
5th pass	12	5th pass	08
6th pass	01	6th pass	03
7th pass	03	7th pass	01
8th pass	20	8th pass	15
9th pass	02	9th pass	03
10th pass	26	10th pass	30
11th pass	01	11th pass	01
12th pass	29	12th pass	29
M.Com	02	B.Com	03
B.E.	02	B.A.	01
Uneducated	01	IMT	01
		LLB	01
		M.A.	01
		M. Tech	01
		Uneducated	01

Table-04: Mean & SD score after CI

Variable	Mean	SD
Life Stress after CI	1.92	0.63
Depression after CI	2.23	0.46

DISCUSSION

Teja Deepak Dessai *et al*. Parents of children with hearing impairment tend to exhibit “depression” a known stress related response [1, 2]. In addition, mothers are found to be less successful in cultivating language and psychological development of their children. The study aimed to measure pre and post cochlear implantation (CI) levels of maternal stress & depression. Total of Five mothers were supplied through Parental Stress Scale & Centre for Epidemiologic studies Depression Scale adapted in Kannada Language pre and post CI of their children. No significant difference in mean levels of stress & depression pre & post CI ($p<0.05$) was observed. The results provide beginning evidence those mothers of children with hearing impairment experience higher levels of stress & depression[11].

Spahn, C. *et al.* To evaluate satisfaction with life among mothers of pediatric cochlear implant candidates in relation to implant operation and socio demographic Factors Mothers of 160 pediatric patients with profound sensorineural hearing loss who underwent unilateral cochlear implant surgery were included. A questionnaire form elicited items on sociodemographic-familial characteristics and

Satisfaction with Life Scale (SWLS) were applied via face-to-face interview method before and 12 months after the implant surgery.

SWLS scores significantly improved after the implant surgery (from 19.1(7.0) to 28.9(4.0), p<0.000). Being unemployed vs. employed (17.9(6.9) vs. 24.0(5.3), p=0.000), having another child with hearing disability (13.5(5.7) vs. 19.7(6.9), p=0.001), younger (12-24 month) vs. older (>24 months) age of the child at the time of implant surgery (7.1(0.4) vs. 19.7(6.6), p=0.001), absence vs. presence of regular follow up visits (13.0(0.0) vs. 19.4(7.1), p=0.002) and presence vs. absence of change in social life after the diagnosis of disease (17.3(6.5) vs. 20.9(7.1), p=0.001) were associated with significantly lower SWLS scores among mothers. SWLS scores were positively correlated with patient's age at the time of implant surgery (r=0.206, p=0.009), whereas negatively correlated with the number of household members (r=-0.406, p=0.000) and number of children (r=-0.310, p=0.000).

In conclusion, our findings revealed association of cochlear implantation with a significant increase in mother's life satisfaction, despite the unemployment, presence of another child with hearing disability and crowded household. Our findings emphasize the consideration of family systems with special attention to mothers' emotional experiences and occupational competence in the intervention programs [12-14].

Little attention has been focused on stress levels of parents of children with cochlear implants (CIs). This study examined the stress experience of 70 parents of children with CIs by comparing stress levels in this group of parents to those in parents of children without disabilities, identifying primary stressors, examining the relationship between parent stress and child language, and comparing stress in parents of children with bilateral and unilateral CIs. Parents completed a parent stress questionnaire, and the receptive vocabulary and language abilities of the children were evaluated. Results indicated that these parents had a higher incidence of stress than the normative population. Parent stress levels and child language outcomes were negatively correlated. Child behavior and lack of spousal and social support were the prime causes of parent stress.

CONCLUSION

The Burden scale for family caregivers (BSFC) [15] was used to evaluate the subjective issues faced by parents while rearing a child with cochlear implants. The current study described parent's everyday problems that are associated with raising children who undergo CI. So while planning intervention to children we need work upon the issues which parents of children with CI are going through and could at the same time empower parents to acquire specific competencies in efficiently solving problems and coping with various parenting demands.

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