Original Research Article

Burden on Families of Children with Hearing Impairment and Intellectual Disability

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ABSTRACT

Aim: The immediate families and/or caregivers of persons with disabilities often experience lifestyle changes that may manifest in the form of financial burden, restricted or dysfunctional family interactions, altered physical and mental health, etc. Similar problems are also faced by parents who have a child with disability. Though there are reports of changes in the lifestyle of parents of a child with an impairment/s, it is important to quantify and characterize the burden. This would, in turn, help in counseling.

Objective: To quantify third party burden in parents of children with intellectual disabilities and parents of children with hearing impairments, and to compare the groups.

Methods: Sixty-five parents were interviewed using the Family Burden Scale developed by Pai and Kapur (1982). Twenty-one parents had typically developed children, twenty-three parents had children with intellectual disabilities, and twenty-one parents had children with hearing impairments. The mean age of the children was 4.7, 6, and 4.8 years, respectively. Statistical analysis involved MANOVA to compare group data across subcategories and total scores, with Bonferroni-corrected post hoc tests applied as needed.

Results: Parents of children with disabilities suffer significantly more burden than parents of typically developing children. Parents of children with intellectual disabilities face more burden than parents with hearing impairment. Among the various contributors to the burden, the financial burden was found to be the highest.

Conclusion and implications: Parents of children with disabilities have to be made aware of the possible impact of having a child with disability in their family and how to handle such an impact. It is of utmost importance for any professional to look for the possibility of referring the parents to a psychologist.

Keywords: Low- and Middle-income countries, Central America, Disability, Community-Based Inclusive Development, Community-Based Rehabilitation

INTRODUCTION

Third-party disability (TPD) was a term coined by the World Health Organization (WHO, 2001) to describe the experiences or burdens of the immediate family or caregivers of a person with disability which manifests as 'a range of activity limitations and participation restrictions due to their partner's physical impairment, including a variety of stresses involving lifestyle changes, communication difficulties, and emotional consequences'. This is seen in the form of financial burdens, reduced social interaction, strain in relationships, and overall quality of life. Similar burdens have been reported by spouses of individuals with other conditions, such as traumatic brain injury, aphasia, dysphagia, etc. Changes in social interaction, bitterness and irritability towards the partner, difficulties with activities of daily living and household chores for themselves, and communication difficulties are most commonly reported by these individuals (Malone et al., 1970; Webster & Newhoff, 1981; Coutts & Sayed, 2023). Scarinci et al. (2011) reported that 98% of spouses of older adults with hearing impairments reported TPD, with a majority reporting mild disability. TPD was assessed in close partners of persons with hearing impairments scheduled for cochlear implant surgery. The authors concluded that third-party burden was persistent even 6 months post-cochlear implantation (Völter et al., 2023). Studies show that the spouses of individuals with hearing impairments have to take an additional role, in addition to the communication problems that arise due to hearing impairment (Anderson & Noble, 2005; Piercy & Piercy, 2002). This leads to distress and reduced quality of life for them. The extent of TPD in these individuals is affected by the degree of hearing impairment of their spouses (Nandurkar & Shende, 2020). Partners of individuals with tinnitus also report TPD, the extent of which is influenced by their partners' tinnitus severity, anxiety, and hyperacusis (Beukes et al., 2023). Sen and Yurtsever (2007) reported that parents also face similar problems when concerned with a child with disability. The parents reported that their social life, work life, financial situation, and family relationships were negatively affected.

Parents of children with intellectual disabilities perceived greater financial burden, disruption in family routine, reduced social interaction, and greater negative effects to mental and physical health than parents of healthy children (Singhi et al., 1990). Mothers of children with intellectual disabilities also reported increased perception of family burden and decreased life satisfaction compared to mothers of typically developing children (Akarsu & Kostak, 2022). Though there are reports of changes in the lifestyle of parents of children with impairments, it is necessary to quantify and characterize the burden. This would be useful in counseling. Moreover, parents of children with different disabilities undergo different levels of lifestyle changes.

Further, studies that imply the TPD in the Indian context are scarce. The Indian population has more differences from the studied populations, as India is a developing country with a culturally diverse population. Furthermore, there is a lack of insight into this topic concerning children with hearing impairments and their parents. Hence, it is essential to quantify and also know which group of parents is likely to suffer more, which in turn would help to track the reasons and, thus, the possible solutions. It is, thus, important to quantify third-party burden on parents of children with intellectual disabilities and parents of children with hearing impairments and compare with the parents of typically developing children, and also between the parents having children with two different disabilities.

METHODS

Study area

The family burden in terms of financial, interpersonal relationships in the family, physical and mental health of the family members of a child with hearing impairment, or a child with intellectual disability, in comparison to family members of a typically developing child, is assessed in this study.

Design

This study employed a non-experimental standard group comparison design.

Population and sampling technique

Non-random purposive sampling was done to select the participants. A total of 65 parents were selected and interviewed. Out of which 21 were parents of children with hearing impairments, 23 were parents of children with intellectual disabilities, and 21 were parents of typically developing children. All the children with intellectual disabilities or hearing impairments had a disability greater than 40% and were attending a preschool for children with special needs.

Instruments of data collection

The Family Burden Scale, developed by Pai and Kapur (1982), was adopted to assess the parents. The questionnaire was adapted to suit the demographics of the population interviewed.

Data collection procedures

Parents of children with hearing impairments, children with intellectual disabilities, and typically developing children were interviewed using the Family Burden Scale. The questionnaire has a total of 24 questions under 6 sub-categories. These subcategories are financial burden-6 questions, disruption of routine family activities-5 questions, disruption of family leisure-4 questions, disruption of family interaction-5 questions, effects on physical health of others-2 questions, and effects on mental health of others-2 questions. The number of questions under each category is not the same. The questionnaire also has a question that facilitates obtaining an open-ended response that can also contribute to the family burden, not included in the questionnaire. Each of the responses was assigned a score for analysis, i.e., 0 for 'No', 1 for 'Moderate burden', and 2 for 'Severe burden' as recommended by the authors. Thus, participants who scored higher reported a greater extent of disability. The overall score for each participant was calculated along with the percentage of burden in each group. The contribution of each subcategory to the overall family burden for each group was also calculated.

Analysis

Statistical analysis was carried out using SPSS version 26 software. MANOVA was done to compare the data obtained across the groups for each subcategory and the total scores obtained. Post hoc comparisons with Bonferroni corrections were used when appropriate to identify the groups' differences.

Ethics

Informed consent was obtained from the participants prior to questionnaire administration. Privacy and confidentiality of the participants and their data were assured.

RESULTS

The mean ages of the children were 4.7, 4.8, and 6 years in the normal, the group with hearing impairment, and the group with intellectual disability, respectively. The demographic details of the children are given in Annexure 1. The parents' ages ranged from 30 - 40 years. The mean scores for each subcategory and the total scores obtained in each group are given in Figure 1. Inferential statistical analysis results to see the significant difference across the groups are given in Table 1. The results showed a statistically significant increase in the burden on parents of children with disabilities when compared to the typically developing children. However, the mean total score was higher in the parents of children with intellectual disability group (11.95) than in the children with hearing impairment group (9.04). This was much greater than the mean total score of the typically developing group (0.35), which is negligible. The partial Eta squared values for the comparisons indicate that, with the exception of 'disruptions to family interactions,' which demonstrated a medium effect size, all other categories in the questionnaire showed large effect sizes (Table 1). The contributions to the burden are financial burden, disruption of routine family activities, disruption of family interaction, disruption of family leisure, effects on physical health, and effects on mental health, in descending order of contribution to the overall burden. This can be seen in Fig. 1. The financial burden was the major factor that contributed to the family burden than other factors. Parents of children with hearing impairments scored more in expenditure related to treatment and additional arrangements that they had to make. In contrast, parents of children with intellectual disabilities are equally affected in all parameters considered under financial burden, while effects on physical health were the least contributing factor, which mainly focused on the effect of family members' health. This was similar in both parents of children with intellectual disabilities and children with hearing impairments. Both groups of parents were reported to be similarly affected by the respective disability in the disruption of routine family activities and the disruption of family leisure time parameters. However, the contribution of the above-mentioned factors was more for parents of children with intellectual disabilities than for children with hearing impairments. With respect to the disruption of family interaction, both the parent groups with children with disabilities performed equally. The subcategory on the effect on mental health of family members revealed that parents with children with intellectual disabilities are affected more than parents with children with hearing impairments. Table 2 shows the post hoc comparisons of the scores obtained between any two groups.

The questionnaire also had a section where parents had to share other factors that can potentially increase the risk of family burdens that were not listed. Most of the parents of both groups raised similar issues. They expressed their feeling about not being able to focus on their career, not being able to take care of other kids, fluctuation in blood pressure, stress, and sleeplessness. However, parents of children with intellectual disabilities also reported concerns about the future of their child and not being able to care for their spouse and family members.

Annexure: Table containing the demographic details of the children with normal abilities, children with hearing impairment, and children with intellectual disability. HI- Hearing Impairment, ID- Intellectual Disability, NA- Not applicable

S.No.	Age (in years	Age of Onset	Gender	Disability	Informant	Type of family
1	5	Congenital	Male	HI	Mother	Joint
2	7	Congenital	Male	HI	Mother	Nuclear
3	6	Congenital	Male	HI	Mother	Joint
4	4	Congenital	Male	HI	Mother	Nuclear
5	4	Congenital	Female	HI	Mother	Nuclear
6	6	Congenital	Female	HI	Mother	Nuclear
7	4	Congenital	Male	HI	Mother	Joint
8	6	Congenital	Male	HI	Mother	Joint
9	5	Congenital	Male	HI	Mother	Joint
10	4	Congenital	Female	HI	Mother	Joint
11	5	Congenital	Male	HI	Mother	Joint
12	3	Congenital	Male	HI	Mother	Joint
13	4	Congenital	Male	HI	Mother	Nuclear
14	3	Congenital	Male	HI	Mother	Joint
15	5	Congenital	Male	HI	Mother	Nuclear
16	6	Congenital	Female	HI	Mother	Nuclear

17	4	Congenital	Male	HI	Mother	Nuclear
18	4	Congenital	Female	HI	Mother	Nuclear
19	6	Congenital	Male	HI	Mother	Nuclear
20	4	Congenital	Female	HI	Mother	Joint
21	6	Congenital	Male	HI	Mother	Nuclear
22	6	Congenital	Male	ID	Mother	Joint
23	4	Congenital	Male	ID	Mother	Joint
24	6	Congenital	Male	ID	Mother	Nuclear
25	7	Congenital	Male	ID	Mother	Joint
26	6	Congenital	Male	ID	Mother	Joint
27	8	Congenital	Male	ID	Mother	Joint
28	7	Congenital	Female	ID	Mother	Joint
29	7	Congenital	Male	ID	Mother	Nuclear
30	7	1 year	Male	ID	Mother	Joint
31	6	7 months	Male	ID	Mother	Nuclear
32	4	2 years	Male	ID	Mother	Nuclear
33	5	1.5 years	Female	ID	Mother	Nuclear
34	7	9 months	Female	ID	Father	Joint
35	9	1 year	Male	ID	Mother	Nuclear
36	8	1.5 years	Female	ID	Mother	Nuclear
37	6	1 year	Male	ID	Mother	Nuclear
38	6	1.5 years	Female	ID	Mother	Nuclear
39	6	Congenital	Male	ID	Mother	Nuclear
40	5	Congenital	Male	ID	Mother	Nuclear
41	4	1.5 years	Male	ID	Mother	Joint
42	5	9 months	Female	ID	Mother	Joint
43	3	1 year	Female	ID	Mother	Nuclear
44	6	NA	Male	Normal	Mother	Nuclear
45	4	NA	Male	Normal	Mother	Nuclear
46	4	NA	Male	Normal	Mother	Nuclear
47	6	NA	Female	Normal	Mother	Joint
48	4	NA	Female	Normal	Mother	Nuclear
49	6	NA	Male	Normal	Mother	Nuclear
50	5	NA	Female	Normal	Mother	Joint
51	4	NA	Female	Normal	Mother	Joint
52	5	NA	Female	Normal	Mother	Nuclear
53	3	NA	Female	Normal	Mother	Nuclear
54	6	NA	Male	Normal	Mother	Joint
55	4	NA	Female	Normal	Mother	Nuclear
56	6	NA	Female	Normal	Mother	Joint
57	5	NA	Male	Normal	Mother	Joint
58	4	NA	Female	Normal	Mother	Nuclear
59	6	NA	Male	Normal	Mother	Nuclear
60	5	NA	Female	Normal	Mother	Joint
61	4	NA	Female	Normal	Mother	Joint
62	5	NA	Female	Normal	Mother	Nuclear
63	3	NA	Female	Normal	Mother	Nuclear
64	5	Congenital	Male	HI	Mother	Joint

Table 1: F value with the degrees of freedom, significance level, and the partial Eta squared values for the total scores and the scores for each subcategory across the groups.

Category	Degrees of freedom (df)	F value	Significance value	Partial Eta Squared
Total score	**2,60**	**16.802**	**0.000**	**0.359**
Financial Burden	2,60	19.330	0.000	0.392
Disruption of routine family activities	2,60	11.732	0.000	0.281
Disruption of family leisure	2,60	12.357	0.000	0.292
Disruption of family interaction	2,60	2.825	0.067	0.086
Effect on the physical health of others	2,60	11.221	0.000	0.272
Effect on the mental health of others	2,60	12.391	0.000	0.292

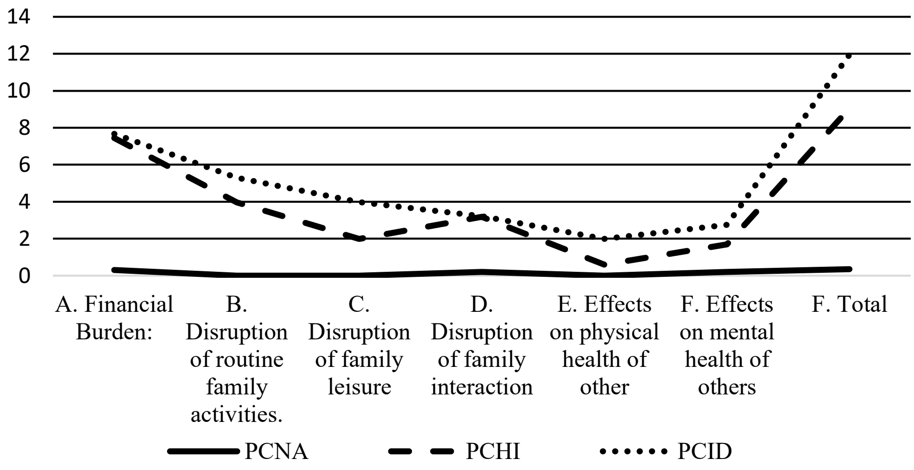

Figure 1: Score of the parents of normal children (PCNA), parents of children with hearing impairment (PCHI), and parents of children with intellectual disability (PCID) on the subcategories of the Family Burden Scale.

Table 2: Post hoc comparisons with Bonferroni corrections for the total score and the scores of the subcategories between the parents of children with normal abilities (PCNA), parents of children with hearing impairment (PCHI), and parents of children with intellectual disability (PCID).

Category	Comparison	Mean difference	*p* value
Total score	**PCNA-PCHI**	**8.69**	**0.000***
	PCNA-PCID	**11.60**	**0.000***
	PCHI-PCID	**2.90**	**0.480***
Financial Burden	PCNA-PCHI	7.12	0.000*
	PCNA-PCID	7.35	0.000*
	PCHI-PCID	0.22	1.000
Disruption of routine family activities	PCNA-PCHI	3.96	0.003*
	PCNA-PCID	5.30	0.000*
	PCHI-PCID	1.33	0.710
Disruption of family leisure	PCNA-PCHI	1.98	0.051

	PCNA-PCID	3.97	0.000*
	PCHI-PCID	1.99	0.043*
Disruption of family interaction	PCNA-PCHI	2.96	0.136
	PCNA-PCID	3.01	0.120
	PCHI-PCID	0.04	1.000
Effect on the physical health of others	PCNA-PCHI	0.59	0.539
	PCNA-PCID	1.98	0.000*
	PCHI-PCID	1.39	0.006*
Effect on the mental health of others	PCNA-PCHI	1.47	0.017*
	PCNA-PCID	2.53	0.000*
	PCHI-PCID	1.05	0.120

*- significant difference; $p< 0.05$

DISCUSSION

Parents of children with a hearing impairment or intellectual disability showed significantly greater family burden than parents who had typically developing children. Similar findings were reported by Singhi et al. (1990). They mentioned that families with children with disabilities experienced more financial burden, disruption of family routine and leisure, affected social interaction, as well as negative impacts on their physical and mental health in comparison to the families of typically developing children.

Parents of children with intellectual disabilities faced more burden than parents of children with hearing impairments. This was observed on all the sub-categories of the scale. Children with hearing impairments are physically and intellectually able to be independent, with only communication being affected. However, children with intellectual disabilities are more dependent due to reduced intellectual ability. The former can also perform daily activities independently compared to the latter. Thus, a lower psychosocial impact on the parents of children with hearing impairments than on parents of children with intellectual disability is expected.

Financial burden was the major contributor to the overall burden in the parents of both the disabled groups. Families with children with disabilities often sacrifice their earning capacity to care for the child's needs. Forty-three percent (19/44) of the families in this study gave up at least one of the parents' salaried jobs to look after their children. This, and the extra expenditure on account of the disability, increases the financial implications on the family (Baldwin, 2015; Hung et al., 2010).

Families of children with disabilities faced disturbed functioning of the family. This can be seen in the disruption of family activities, leisure, and interactions. This has been reported in the form of seclusion of the family by extended family members, and abandonment of recreational/ leisure activities of the family members to accommodate the child's needs.

From the data, we can also see that the physical health of the parents was the factor that contributed minimum to the overall burden. This is because their child's disability may increase psychological stress; however, it may not contribute significantly to deteriorating their physical health. They remain in similar health as they were before.

CONCLUSIONS

When a child is born with a disability, parents are negatively impacted since they are concerned about what they should do and the future of their child. These parents need to be counseled regarding the disorder and the difficulties faced by their children (Leung & Li-Tsang, 2003). They should also be provided with adequate information on all the rehabilitation options and feasible vocational training available to them. This should be with a compassionate approach by professionals, thereby making them feel supported. The outcome of these results can help decide/modify the government policies to better suit the needs of the hour.

The parents do not receive adequate support, which may affect the functioning of the family and the individual's physical and mental health. Support for these families can be provided by professionals in terms of adequate knowledge regarding the disability, and/or psychological counseling. Support groups can also be established at the local and regional levels to provide a platform for parents to share experiences, coping strategies, and emotional support. Comprehensive psychological counseling services should be made accessible to parents to address the mental health impacts. Parent training programs or workshops can be organized that focus on caregiving skills, stress management, and effective communication strategies. These programs would help empower the parents and educate them about the disability specific challenges and solutions. Further, raising public awareness about third-party disability can reduce stigma and foster a more inclusive environment for families with disabled members.

Governments and non-profit organisations can expand financial aid programs, such as subsidies for medical treatments, therapy sessions, and assistive devices. Providing tax benefits or incentives for families with disabled children could also help alleviate the financial burden. Information regarding vocational training and the available setups for vocational training to make the children independent should also be provided to the parents. This addresses a significant portion of the parents' concerns and anxiety regarding the child's future prospects. Rehabilitation using a family-centered approach may also help these parents. Additional information gathered under the open-ended subsection also highlights the need for modification of questionnaires.

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Conflict of interest statement:

The authors do not have any conflicts of interest to declare.

*Data availability statement: *

The data supporting this study are not publicly available due to confidentiality and privacy constraints.

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