



Burden and Social Support of the Caregivers of Children with Hearing Impairment

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ABSTRACT:

A child with physical, intellectual or behavioral problems presents unique and diverse challenges to the family unit. The stress levels of parents of children with disabilities are typically higher than those of parents of nondisabled children. Having a child with hearing impairment is a traumatic event for the mother. The aim of the study was to examine family burden and social support of the mothers of children with hearing impairment and compare the results with that of mothers with normal children. For the purpose of the study the sample consisted of a group of 30 mothers of children with hearing impairment and 30 mothers of normal children with age range of 3 years to 10 years and 20 years to 40 years of mothers has been taken. The tools used are Burden assessment schedule and Berlin Social Support Scales. The study results shows that the mothers of children with hearing impaired are showing more burden when compared with mothers of normal children and no significant difference in social support for mothers of children with hearing impaired and mothers of normal children.

Key words: *Burden, Social Support, Mental Health & Hearing Impairment*

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INRODUCTION:

Families are the foundation for a child's development, socialization and formation of his or her values and beliefs. Families can be source of greater happiness, as well as stress. Parenting is highly stressful job and becoming the parent of a child with a disability is one of the most stressful life events that can occur (Rose, 1987). How parents react to this stress depends on a variety of factors which may be individual, family related or environmental factors. Some families may view the situation as uncontrollably threatening while others may view the added stress challenged and become stronger in the process. In our traditional society, mothers are often their child's main caregivers. Consequently they are more exposed to illness related situations than fathers and may therefore experience more psychological stress than fathers. As caregivers they may experience a range of natural emotions in response to their child's disability. These feelings include frustration, anger and fear, feelings of failure, shame, self-blame, social stigma and sadness.

A child with physical, intellectual or behavioural problems presents unique and diverse challenges to the family unit (Sherman, 1988). Family relationships may be weakened by the added and unexpected physical, emotional and financial stress imposed on them (Shelton, Jeppson, Johnson, 1987). The stress levels of parents of children with disabilities are typically higher than those of parents of nondisabled children (Bradley, 1991). Research concluded that mother of children with autism and mental retardation are experiencing same level of stress and using more of active coping, positive reframing, planning and acceptance as the coping strategies to cope with their child's disability (Spandana et al., 2013). In other hand, mothers of children with mental retardation are experiencing more caregiver's burden in the form of general stain, disappointment, and emotional involvement and seeking more social support than the mothers of normal children (Kerenhappuch & Sridevi, 2014). The mothers of children with mental retardation experience more psychological distress than the mothers of children with autism in relation to age and gender of the children, severity of disability and educational back ground of the mother (Sridevi, Sriveni & Rangaswami, 2013). Many factors influence the reactions of family members; the emotional stability of each individual, religious values and beliefs, socio economic status, the severity of the child's disability, to identify a few. So, there is a need to understand the family burden and social support of the parents of children with disabilities. Mothers of children with autism are showing significant expressed emotions than the mothers of children with autism in the form of warmth and over-involvement towards their children in relation to the age level and gender of the children, and educational background of the mothers

and severity of the disability of the children (Sridevi, Sriveni & Rangaswami, 2013). In general population, loneliness and depression was experienced by widows and widowers and gender difference was also found (Bharathi, Sridevi & Kumar, 2015). The significant death depression, geriatric depression and suicidal ideation was experienced in non-institutionalized elders but there is no significant difference in death anxiety among institutionalized and non-institutionalized elders (Sridevi & Swathi, 2014; Sridevi, 2014; Sridevi et al., 2015; Sridevi & Shyam, 2014; Sridevi, Shyam & George, 2014).

Hearing impairment is a full or partial decrease in the ability to detect or understand sounds caused by a wide range of biological and environmental factors, loss of hearing can happen to any organism that perceives sound. The birth of an infant with conspicuous congenital defect or abnormality throws parents into a kind of emotional shock (Blacher, 1984). The expected or fantasized child whom the parents and other family members had anticipated does not arrive (Chinn, Winn and Walter, 1978). Deafness often installs a sense of mourning in parents/caregivers (Kampfe, 1989; Koeste & Meadow-Orlans, 1990)

Having a child with hearing impairment is a traumatic event for the mother. Many mothers due to constant care giving demands on the part of their disabled child suffer 'burnouts' and at times deliberately distance themselves from other house hold responsibilities. (Schlesinger and Meadows 1972). The burden on Families ranges from economic difficulties to emotional reactions to the deaf, the stress of coping with disturbed behavior, the disruption of house hold routine and the social activities(WHO 1980). The term family burden generally refers to the consequences for the family of close contact with a person who is severely disabled. The time immediately after the diagnosis of hearing loss is usually perceived as the most stressful. Parents report this period as a burden and it brings about the greatest loss of quality of life to parents (Burger et al, 2005). Mothers of infants in the false-positive group did not report increased stress or impact and the mothers of infants with HL reported greater financial impact, total impact, and caretaker burden compared with mothers of infants in the control group (Vohr , 2008). Parents of the disabled children were severely burdened in terms of financial burden and mental health (Laskar, 2010). Social support plays a crucial role in parent's ability to cope with deafness. Increased social support was shown to have a positive effect on stress in families of children with disabilities, specifically those with children who have hearing loss (Lederberg, 2002). Using social networks, support groups and even social services, many issues of education, finance and childcare can be overcome for the hearing impaired child and their family structure.

Mothers of children with disabilities need the therapeutic intervention to reduce their stress and burden and CBT can help them very effectively. CBT is evidence based talking therapy which focuses on present difficulties including symptoms, emotions, behaviour and negative thoughts. CBT seeks to develop both cognitive and behavioural skills to cope with current stressors, making it particularly suitable to the complex demands and stresses of the caregiving role. CBT may help to modify the maladaptive anxiety so that caregivers may be motivated to adopt a more positive attitude toward their caregiving tasks (Au, Li & Lee, 2010; Katona & Livingston, 2009; Liu, Wang & Gray, 2008). CBT techniques are effective in the treatment of the symptoms of depression and anxiety (Tripathi & Sridevi, 2014) and CBT intervention is widely studied and empirically validated treatments for anger and aggression in youth. The research was also concluded CBT was effective to reduce 60% in the existing symptoms of emotional problems with an adopted adolescent girl (Tripathi & Sridevi, 2016) and also CBT techniques are very effective for Dhat syndrome and co-morbid conditions (Tripathi & Sridevi, 2014). Parent education and skills training program for parents of young children newly diagnosed with autism provides significant improvements in parental mental health and adjustment, justifying its addition to early intervention programs at least for parents with mental health problems (Tonge et al., 2006). One more study was evaluated in a training course for parents, designed to help them understand the problems of children with disability and research also found that the training course was well received by parents and had a measurable effect on both parents' and children's communication skills (McConachie, 2005). Solomon et al., (2008), conducted evidenced based treatment called parent –child interaction therapy. They investigated the role of shared positive affect during the course of therapy on child and parent outcomes. Shared positive affect in parent child dyads and parent positive affect increased between the initial and final phases of the therapy. A review survey conducted on parent–child interaction therapy (PCIT) and concluded that it is a psychosocial treatment for preschoolers with conduct, behavioral problems and their parents. PCIT is an evidence-based behavioral parent training program and it is proved to be effective with parents and their young children (Sridevi, Debashis & Rangaswami, 2017). An intensive early intervention is critical in maximizing outcomes for children with behavior problems and evidence suggests that the earlier the intervention, the better the outcome. Research also found that a multidisciplinary approach (Sridevi, Sriveni & Rangaswami, 2013) and an early intervention (Sridevi & Saroj Arya, 2014) can improve adaptive and personal-social behaviors of children with autism.

METHODOLOGY

Aim:

The aim of the present study was to examine family burden and social support of the mothers of children with hearing impairment and compare the results with that of mothers with normal children.

Sample:

For the purpose of the study the sample consisted of a group of 30 mothers of children with hearing impairment and 30 mothers of normal children. The age range of children with hearing impairment and normal children is between 3 years to 10 years. The age range of mothers of hearing impaired children and normal children is 20years to 40 years. The mothers of hearing impaired children were recruited from Sweekaar Rehabilitation Institute for Handicapped, situated at Secunderabad, A.P. Mothers of normal children were recruited from normal school St. Marks School, situated in Secuderabad, A.P.

INCLUSION CRITERIA

1. Mothers of children with hearing impairment
2. Mothers of normal children were examined.

EXCLUSION CRITERIA

1. Mothers with chronic physical or mental illness.
2. Children with hearing impairment with behavior problems, physical problems and psychiatric problems.
3. Children with chronic neurological conditions such as cerebral palsy, epilepsy etc.
4. Widowed, separated or divorced mothers.
5. Children above 10 years.

TOOLS USED:

1. Demographic data sheet designed for the purpose of this study.
2. Burden assessment schedule.
3. Berlin Social Support Scales.

PROCEDURE:

The mothers recruited for the study after obtaining the written consent were interviewed to elicit the relevant socio-demographic details and were administered Burden Assessment Schedule and Berlin Social Support Scale individually. Subject requiring any clarifications was attended by the researcher.

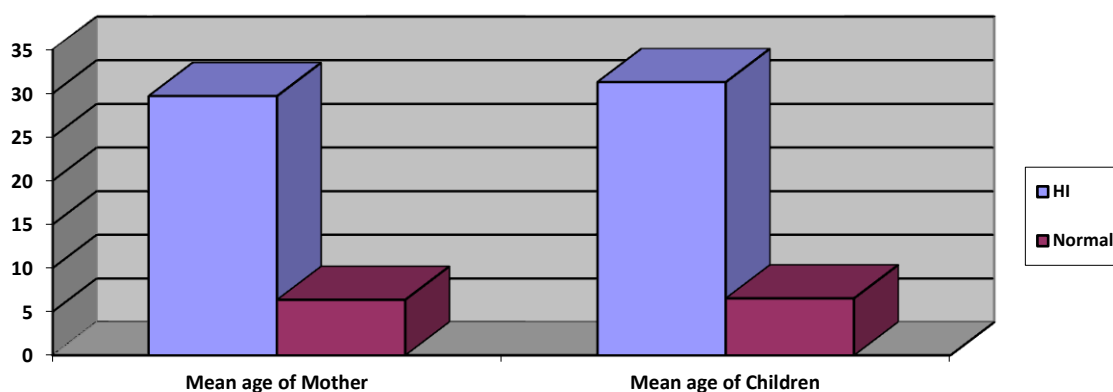
STATISTICAL METHOD USED:

Keeping in view the objectives and hypothesis of the study the data collected on the two groups i.e. the mothers of hearing impaired and mothers of normal children were subjected to statistical analysis. The means and standard deviations for scores on different variables under study were calculated for the two groups separately. Further ‘t’ test was used to find out the significance of difference between the groups for various variables selected for the study.

RESULTS

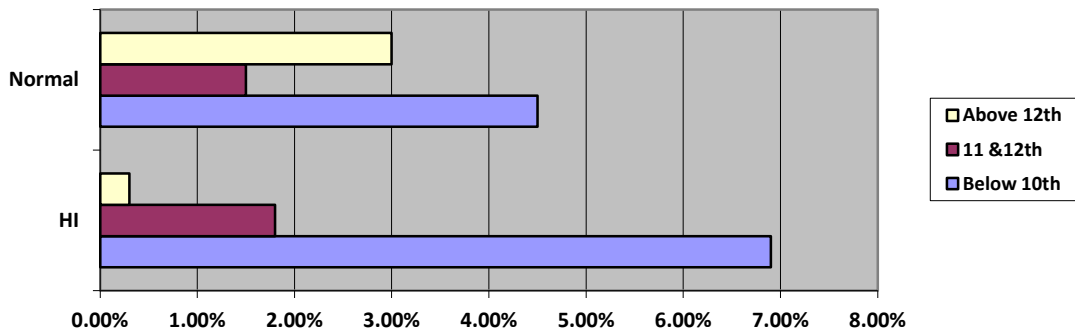
The present study was aimed at assessing the burden assessment and social support of mothers of children with hearing impaired and comparing the finding with normal children. This was a cross sectional study conducted on the hearing impaired children at and normal children at with maintaining all inclusion and exclusion criteria. In the present study, below graphs gives the socio demographic data of mothers of children with hearing impaired (30) and mothers with normal children (30) respectively.

Graph-1: Mean age of mothers and children with HI and Normal



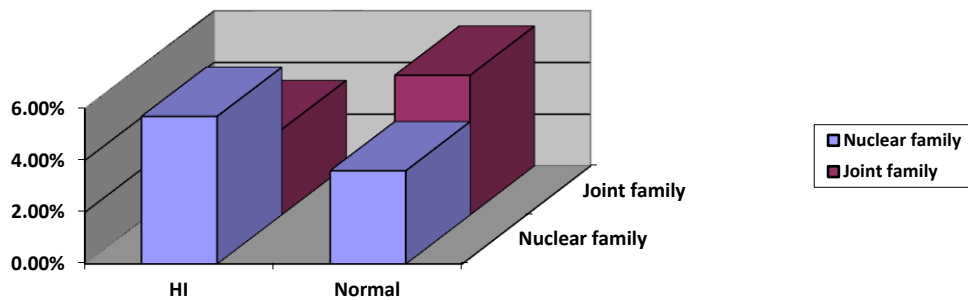
Graph-1 gives mean age of mothers and mean age of children with HI and normal. It shows the mean age of the mothers of hearing impaired (HI) was 29.70(±4.90) and children was 6.36(±2.39), the mean age of mothers of normal children was 31.30(±4.20) and children was 6.53(±2.81).

Graph-2: Education of mothers of children with HI and normal



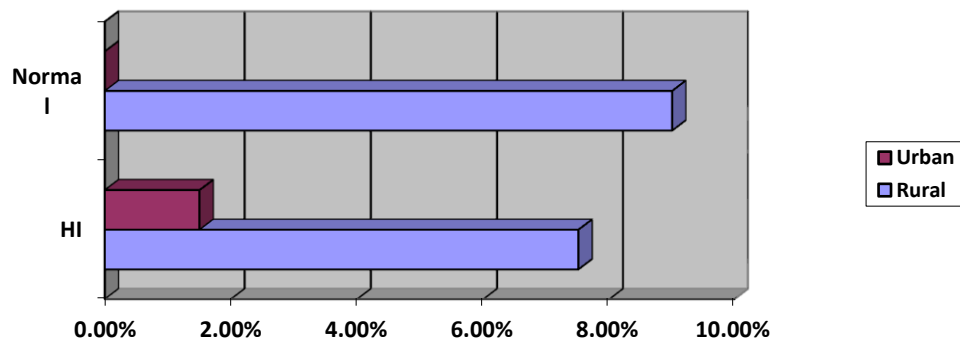
The above graph gives the educational background of the mothers of children with HI and normal. The percentage value of mother's education of children with hearing impaired group; below 10th std, 11-12 std and above 12 std are 6.9%, 1.8%, and 0.3% respectively and in normal group are 4.5%, 1.5%, 3% respectively.

Graph-3: Family type of children with HI and Normal



The graph-3 gives the family type of children with HI and normal. In hearing impaired children, 3.3% belonged to joint family background and 5.7 % have nuclear family background and in mothers of normal children 5.4% belonged to joint family background and 3.6% belonged to nuclear family background.

Graph-4: Domicile of children with HI and normal



The above graph gives the domicile of the children with HI and normal. In domicile about 7.5% of hearing impaired mothers belongs to rural and 1.5% belongs to urban, and 9% of normal children's mothers belong only to urban.

Table –1: Mean (\pm SD) Score on Burden Assessment Schedule (BAS) for mothers of HI and Normal children (N=30/group).

BAS	HI	N	“t”	“p”
SR	6.13(0.97)	6.06(0.36)	0.35	0.72
PM	12.06(2.61)	6.80(1.12)	10.14	.001***
ES	8.93(2.81)	7.76(1.94)	1.86	.06
CR	8.00(1.57)	6.70(1.70)	3.06	.003**
SP	5.60(0.89)	5.16(0.64)	2.14	.03*
TR	6.00(1.89)	3.00(0.00)	8.67	.001***
OR	10.36(1.58)	10.16(1.01)	0.58	.56
PB	9.10(1.82)	5.83(1.48)	7.59	.001***
CS	9.66(1.82)	6.60(1.58)	6.94	.001***

*= $p < 0.05$ level, **= $P < 0.01$ level, ***= $p < 0.0001$

SR- Spouse Related, PM- Physical & Mental Health, ES- External Support, CR- Caregiver’s Routine, SP- Support of Patient, TR-Taking Responsibility, OR-Other Relations, PB-Patient’s Behavior, CS-Caregiver’s Strategy.

The scale taken for the study was burden assessment schedule. This scale is a 40- item scale, which measures 9 different areas of burden. In Table -1, there is a significant difference in the following subscales physical and mental health; the Mean (\pm SD) scores of mothers of children with HI are 12.06(\pm 2.61) whereas Mean (\pm SD) of mothers of normal children are 6.80(\pm 1.12). The “t” value is 10.14 and it is significant at 0.01 level. It shows that mothers of children with hearing impaired are experiencing more Physical and mental health burden.

In the sub scales of Caregiver’s Routine; the mothers of children with HI Mean (\pm SD) is 8.00(\pm 1.57) and mothers of normal children is 6.70(\pm 1.70) respectively. The “t” value is 3.06 and it is significant at 0.01 levels. There is difference in mothers of hearing impaired in caregiver’s routine.

In the subscale of Support of Patient; the mothers of children with HI Mean (\pm SD) is 5.60(\pm 0.89) and mothers of normal children is 5.16(\pm 0.64) respectively. The “t” value is 2.14 and it is

significant at 0.05 level. It shows that there is a burden of support of patient on mothers of children with hearing impaired than in mothers of normal children.

In the subscale of Taking Responsibility; the mothers of children with HI Mean (\pm SD) is 6.00(\pm 1.89) and mothers of normal children is 3.00(\pm 0.00) respectively. The “t” value is 8.67 and it is significant at 0.01 level. It indicates that the mothers of children with HI are feeling burden for taking the responsibility of their children.

In the subscale of Patient’s Behavior; the mothers of children with HI Mean (\pm SD) is 9.10(\pm 1.82) and mothers of normal children is 5.83(\pm 1.48) respectively. The “t” value is 7.59 and it is significant at 0.01 level. It shows that the mothers of children with HI are feeling more burden because of the patient’s behavior than the mothers of normal children.

In the subscale Caregiver’s Strategy; the mother of children with HI Mean (\pm SD) is 9.66(\pm 1.82) and mothers of normal children is 6.60(\pm 1.58) respectively. The “t” value is 6.94 and it is significant at 0.01 level. Hence there is more burden in mothers of children with hearing impaired than in mothers of normal children.

Table-2: Mean (\pm SD) score on Social Support Scale for mothers of HI and normal children (N+30/group).

SSS	HI	N	“t”	“p”
PS	26.30(\pm 3.83)	27.30(\pm 2.57)	-1.18	0.24
NS	12.26(\pm 2.17)	12.73(\pm 1.99)	-0.85	0.39
SS	18.03(\pm 2.17)	17.33(\pm 1.88)	1.33	0.18
AS	47.63(\pm 4.75)	48.93(\pm 3.41)	-1.21	0.22

PS- Perceived Available Support, NS- Need for Support, SS- Support Seeking, AS-Actually Received Support.

The other scale is Berlin Social Support Scale this scale is a four- point Likert-type scale consisting of 4 subscales. In the above table on social support scale; for mothers of hearing impaired and normal children shows that there is no significant difference in getting social support. The mothers of children with hearing impaired and mothers of normal children are

getting almost same in all the subscales such as perceived available support , need for support , support seeking , and actually received support.

CONCLUSION

The mothers of children with hearing impaired showed significantly difference on burden than the mothers of normal children in the areas of physical and mental health, caregiver's routine, support of patient, taking of responsibility, patient's behavior and caregiver's strategies. It reveals that mothers of hearing impaired children are having more burden than the mothers of normal children. And there is no significant difference in social support for mothers of children with hearing impaired and mothers of normal children. It reveals that the mothers of children with hearing impaired and the mothers of normal children are experiencing almost same social support.

IMPLICATION OF THE STUDY:

Assessment of burden and social support helps in counseling mother to reduce the mother's burden and to guide her to deal with children appropriately. This will help the parents to accept children as they are. They may not unnecessarily reject, punish, and show hostility towards their children. It will also help to improve the quality of life, and take positive steps to handle the children more constructively.

LIMITATIONS OF THE STUDY:

1. Sample size is not large enough to generalize the results.
2. This study is limited to hearing impaired and normal children, it would be better to have an additional comparison group such as children with other disabilities and children with behavior problems.

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