

## RELATIONSHIP OF HOPELESSNESS, DEPRESSION AND QUALITY OF LIFE IN MOTHERS OF PERSONS WITH DISABILITIES

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**ABSTRACT:** The present study was carried out to investigate the relationship among hopelessness and depression with quality of life in mothers of hearing & orthopedic impaired. One hundred fifty disabled children's mothers were included in this study. They belonged to nuclear, urban literate families of Chandigarh. The findings of this study indicated that mothers of hearing and orthopedic impairment have high level of hopelessness and depression which affects their quality of life. The effective rehabilitation programs should provide sufficient opportunities for repeated follow-up interviews which offer not only information on the children's disabilities but also psychological support for the mothers.

**KEYWORDS:** Depression, hopelessness; mothers have disabled children; quality of life; Orthopedic Handicapped; Hearing Impaired; Person with Disabilities.

### 1 INTRODUCTION

Parent experiences difficulties when trying to raise a disabled child which can lead to feelings of incompleteness, inadequacy and frustration (Koester & Meadow, 2011). Review of literature provides evidence that parents of children with disabilities or illnesses experience more psychological distress and anxiety as compare to parents of healthy children. However, parents who accepted their children's differences were more likely to adapt better than parents who experienced emotional struggles in accepting perceived disabilities in their children (Meadow et. al, 1995; Watson et. al, 1990).

When children are diagnosed with developmental delays, their parents may experience psychological trauma similar to that experienced by suicidal individuals (Ellis, & Hirsch, 2000). In such a situation the most affected person in the family is usually the mother. Mothers of children with disabilities or children with prolonged illness often experience more stress and emotional demands than do mothers of normal children (Smith et al., 2008). Mothers have to undertake too much stress because they are alone with their children in daily life. Not all mothers of children with disabilities have difficulties of adaptation and in adjustment with their disabled child even when they have to face highly stressful life situations. However, it has been explained that children and mothers are at risk of stress related problems when mothers are overburdened by demands of care giving, earning for living and other responsibilities (Ganong et al., 2010).

Gupta (2007) examined the relation between parenting stress and type of disabilities in children. It was found that parents of the children with disabilities reported highest amount of stress in distractibility and adaptability domain while acceptability scores were the highest for children with developmental delay and mood scores were highest in the medical domain. Higher scores in parent domain were reported when there are sources of stress related to parent functioning. The level of stress in parents of children with special needs is determined by overall nature of the disorders with the parents of children with ADHD and developmental disabilities reporting higher level of parenting stress than children with HIV infection, asthma and healthy controls.

Children with different disabilities cause different levels of stress in their mothers. Mothers of children with hearing impaired show increased levels of expressed emotion towards their children. Maternal over-involvement being significantly positively correlated with maternal stress suggests that concern and worry about children with disabilities is an extra burden for mothers (Hodes et al., 1999), also orthopedic child had the significant impact on the mothers' depression symptom (Mu & Chang, 2005). The mothers of children with orthopedic impairments are more depressed as compared to mothers of hearing impaired children (Rudolph et al., 2003). Parents of hearing impaired children have described stressful conditions in their families (Sanders J.L., & Morgan S.B., 2009) hopelessness and depression was significantly higher among the mothers of psychotic children (Brandt B., 2010). It was demonstrated that the mothers of children with hearing impairment experienced higher levels of stress than mothers of healthy children (Manuel et al., 2003).

Maternal mental situations affect the quality of life in mothers. Quality of life is an overall sense of well-being with a strong relation to a person's health perceptions and ability to function. On a larger scale, quality of life can be viewed as including all aspects of community life that have a direct and quantifiable on the physical and mental health of its members (Gerberding J.L., 2002).

The aim of our study is to determine the relationship among hopelessness and depression with quality of life in mothers with disabled children.

## 2 HYPOTHESES

1. It is expected that there will be negative relation between hopelessness and quality of life in mothers of children with hearing and orthopedic impairment.
2. It is expected that there will be negative relation between depression and quality of life in mothers of children with hearing and orthopedic impairment.

## 3 DESIGN

The present study was carried out to investigate the relationship among hopelessness and depression with quality of life in mothers of hearing & orthopedic impaired. One hundred fifty disabled children's mothers were included in this study. They belonged to nuclear, urban literate families of Chandigarh. The psychological tools were used to assess BDI, BHS and WHOQOL.

Participation was voluntary and data was handled confidentially. The procedures and purpose of study were described in detail to the mothers and written informed consents were obtained. The mothers were solicited for participation through special education and rehabilitation centers, in the different regions of Chandigarh.

## 4 TESTS AND TOOLS

Standard scales were used each of which have been described briefly.

**Beck Hopelessness Scale (BHS)**, is 20 item self report inventory developed by Dr. Aaron Beck that was designed to measure three major aspects of hopelessness: feelings about the future, loss of motivation and expectations. The test is designed for adults, age 17-80. It measures the extent of the respondent's negative attitudes or pessimism about the future.

**Beck Depression Inventory (BDI)**, created by Dr. Aaron Back, is a 21 question multiple choice self-report inventory, one of the most widely used instruments for measuring the severity of depression. When the test is scored, a value of 0 to 3 is assigned for each answer and then the total score is compared to a key to determine the depression's severity. The standards cut-off ranges show 0-9: indicates minimal depression, 10-18: indicates mild depression, 19-29: indicates moderate depression, 30-63: indicates severe depression. It is used to measure depression. This widely used instrument consists of 21 symptoms or attitudes commonly seen in patients suffering from depression (e.g. sadness, negative self-concept, sleep and appetite disturbances).

**Quality of Life (WHOQOL)**, measurement tool is a generic multi-dimensional QOL instrument. This tool has been developed across 15 international field centers. It is designed for cross-cultural subjective assessment and it can be used in any country where people can read and understand English language. It is possible to derive six domains (areas) scores, 24 specific facets (features) scores and one facet score that measures "overall QOL and general health". Each facet is represented by four items with a 5-point Likert-type response scale. Domains and facets scores range from 0 to 100, with higher scores indicating better QOL.

**5 DATA ANALYSIS**

The data was analyzed using SPSS. Variables were presented with descriptive statistics and analyzed with Pearson Correlation Coefficient.

**INCLUSION CRITERIA**

1. The mothers of children with hearing and orthopedic having age range between 22-40 years.
2. The mothers of children with hearing and orthopedic having graduation.
3. The mothers of children with hearing and orthopedic who comes under middle income group.
4. The non-working mothers of children with hearing and orthopedic impairment.
5. The families having one disabled child either orthopedic or hearing impairment.

**EXCLUSION CRITERIA**

1. Working mothers.
2. Mothers having education qualification less than graduation.
3. Families who having normal children only.

**6 RESULTS**

Mean age of the children in this study was 10.2 with a 6.5 standard deviation. There were 75% girls and 75% boys in the children. Children having orthopedic impairment & hearing impairment were included.

**Table 1: Sample Scores of BDI, BHS, WHOQOL**

Variables	Mean	SD	Median	IQR*
BDI	14.24	13.01	12.0	6.0-18.0
BHS	48.2	7.84	48.0	42.0-53.0
WHOQOL				
EL	25.91	25.68	20.20	0.0-40.0
PM	18.61	16.37	12.8	0.0-38.0
Sleep	41.57	37.67	32.2	0.0-62.66
SI	25.3	27.72	21.50	0.0-40.00
PAIN	32.56	31.92	34.00	0.0-56.22
ER	23.76	28.06	12.7	0.0-37.5

*\*Interquartile Range*

The Mean score for the study sample on BDI was 14.24 (SD=13.01). Results represents minimal to mild depression in the mothers of both groups. Results represent especially higher hopelessness in the sample group. The highest mean score was 48.2 in BHS. The highest mean score in WHOQOL was in sleep with 41.57 and pain with 32.56.

**Table 2: Correlation between BDI, BHS, WHOQOL**

	BDI	BHS	SLEEP	PM	EL	SI	PAIN	ER
BDI	1							
BHS	.346**	1						

<b>SLEEP</b>	.413**	.264**	1					
<b>PM</b>	.421**	.145	.233*	1				
<b>EL</b>	.426**	.256*	.156	.588**	1			
<b>SI</b>	.622**	.153	.426**	.355*	.344**	1		
<b>PAIN</b>	.687**	.278**	.456**	.439**	.576**	.657**	1	
<b>ER</b>	.465**	.173	.286**	.687**	.456**	.259**	.367**	1

\* $p < 0.05$ , \*\* $p < 0.01$

Bivariate Pearson Correlation Co-efficient among BDI, BHS and WHOQOL has been shown in above Table. There was a significant correlation between BDI and all WHOQOL sections: sleep ( $r = 0.413$ ), PM ( $r = 0.421$ ), EL ( $r = 0.426$ ), SI ( $r = 0.622$ ), ER ( $r = 0.465$ ) and pain ( $r = 0.687$ ) significant at 0.01 levels. Between TAI and BDI ( $r = 0.346$ ) correlation coefficient was significant at 0.01 level. BHS was positively correlated with sleep ( $r = 0.264$ ) and ER ( $r = 0.456$ ) at 0.01 level. Between WHOQOL sections, almost every section was positively correlated with each other. Sleep was correlated with SI ( $r = 0.426$ ), ER ( $r = 0.286$ ) and pain ( $r = 0.456$ ) at 0.01 level, and with PM at 0.05 level. There were significant correlations between PM and EL ( $r = 0.588$ ), SI ( $r = 0.355$ ), ER ( $r = 0.687$ ) and pain ( $r = 0.439$ ) at 0.01 level. EL was correlated with SI ( $r = 0.344$ ), ER ( $r = 0.456$ ) and pain ( $r = 0.576$ ) at 0.01 level. SI was significantly correlated with ER ( $r = 0.259$ ) and pain ( $r = 0.657$ ) at 0.01 level. There was a relation between ER and pain ( $r = 0.367$ ) significant at 0.01 level.

## 7 DISCUSSION

Disability brings different experience for the child and his/her parents. Sometimes there are feeling of guilt, sorrow, hopelessness and helplessness. When children are diagnosed with developmental delays, their parents may experience psychological stress. On the other hand, obligation in dependent daily living activities is stressful among family members. Different responsibilities cause stress, anxiety and depression. The most affected person in the family is usually mother who take cares of their children. Mostly, mothers have to undertake too much stress because they are alone to take care of their children. Though most of the studies shown that father and mother both have gone through same level of stress and it depends upon the nature of disabilities.

The mothers of children with special needs are compressed with profound sense of grief. This grief would result from their loss of initial hopes, dreams and expectations. These feelings can be similar to any trauma when we encounter any significant loss such as death of loved one. Recent research has indicated that mothers of children with special needs may even experience feelings and symptoms of depression, particularly at the time of their child's diagnosis. Mothers may be worried that expressing their feelings of anger, depression or fear may not be tolerated by those around them. They may feel even pressure from family and friends to be "strong" or to remain positive, leaving those feelings of grief without a place for expression (Krisitin Resinsenberg, 2012).

The findings of this study indicated that the feeling of hopelessness among mothers of person with disability consistent and they have high risk towards depression and low quality of life. Hopelessness and depression affect negatively quality of life of mothers. Giving birth to and bringing up a child with a physical handicap may give shock, denial, guilt, sorrow and helplessness. Spending more time with disabled children increase the anxiety among all family members (Brandt et al., 2010) and often depression accompanied with hopelessness in mothers. In our study, a significant correlation was found between depression scores and hopelessness scores. Constantly, researchers found hopelessness and higher level of depression in mothers of children with disabilities (Baxter et al., 2002).

In this study, significant correlation was found between depression scores and all subscales of quality of life. In case of increased depression scores, we found increased emotional reactions in mothers of both groups. Similarly, Baxter found higher scores both of emotional scores and depression scores in mothers of child with disabilities (Baxter et al., 2002). In our study, we found significant correlation between depression and social isolation in mothers. The multivariate analyses revealed that variables such as distress, hopelessness and financial situation were more important in explaining the reduced quality of life than parental gender and the presence/severity of the children's with disability (Lawoko et al., 2003, Boslton et al., 2010). Severity of disease, age and gender of the child, social and financial conditions are identified as factors that affect quality of life in most of the studies. Studies showed that neither the child's gender nor the age had affected the quality of life in mothers of children with disability, but severity of disease affected quality of life in mothers (Wagner et al., 1991). In our study, we found a positive correlation between pain and depression. Similarly, recent studies indicated that depression was accompanied with pain (Geerlings et al., 2002). Results revealed that energy level and physical activity level decrease, in case of decrease depression score (Wallander et al., 2010). However, sleep disturbance was seen when depression scores

were higher. The findings of this study indicated that mothers with disabled children have high level of depression. Increased depression and anxiety level affected with badly in mother's quality of life. We thought that effective rehabilitation programs should provide sufficient opportunities for repeated follow-up interviews which offer not only information on the children's disabilities but also psychological support for the mothers.

Several psychological characteristics, in contrast, are known to be associated with the distress reported by a family member caring for a loved one with a disability and many of these have considerable implications for psychological interventions. Researches concluded that cognitive appraisals of stress and growth (Hastings, 2002; Kronenberger & Thompson, 1992; Pakenham, 2001), effective social problem-solving abilities (Dreer, Elliott, Fletcher, & Swanson, 2005; Dreer, Elliott, Shewchuk, Berry, & Rivera, 2007; Noojin & Wallander, 1997; Rivera, Elliott, Berry, Grant, & Oswald, 2007) and satisfaction with familial relationships (Glidden & Floyd, 1997; Lightsey & Sweeney, 2008) are predictors of distress reported by family members who are in caregiver roles to care severely disabled children.

The system is not helping people with a disability, which is the reason that most people with disabilities are not empowered. The basic need for people with disabilities is to provide better infrastructure so that they can go outside and live like any other citizens. A lot more need to be done for implementation and getting basic rights. Researchers have found that disability in India, particularly in rural areas it is often seen as a punishment for a person's misdeed in a past life. We need to provide mental health services more and tackle the stigma and taboo associated with it.

In addition to diagnostic and management skills, persons with disabilities and their parents need social support and also need skilled counseling by psychologist. It may influence the ongoing care of the disabled; implications for health professionals include a need for thorough psychological assessment of affected child and their parents. At individual level an important step in this regard is to follow the guidance offered by people with disabilities in India on interaction with disabled people.

Few Important useful tips which need to be followed include: Listen to the person with the disability. Do not make assumptions about what the person can or cannot do. When speaking with a person with a disability, talk directly to that person, not through his or her companion. Extend common courtesies to people with disabilities as you would to anyone else. Shake hands or hand over business cards. If the person cannot shake hand with you or grasp your card, they will tell you. Do not be ashamed of another attempt. Offer assistance to a person with disability, but wait until your offer is accepted before you help. It is okay to feel nervous or uncomfortable around people with disabilities, and it is okay to admit that. When you encounter these situations, think "person" first instead of disability and you will eventually feel relaxed.

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