

## Psycho-Physiological Complaints among Mothers of Disabled Children: An Exploration.

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**ABSTRACT:** *The mind and body are closely linked and their relationship can exert influence on health. Studies highlight that psychological problems are more commonly seen among mothers having a disabled child, since the mothers play the major role in child care. Due to the lack of studies addressing on the psycho-physiological issues of the mothers of developmentally disabled children we focused to explore whether there will be any physical complaints specific to these mothers and if their emotion will have any role to these problems and what all are the social issues faced by these mothers. The purpose of the study is to explore the psychological, physiological, and social issues of the mothers of disabled children. The participants are the mothers having child with a developmental disability (Mental Retardation, ADHD, Autism and Cerebral Palsy). The sample consisted of 20 mothers of age ranging from 20 to 60 years. The data was collected through semi- structured interview method and it was analysed using thematic analysis.*

**KEY WORDS:** *disabled child, mothers, psycho-physiological complaints and thematic analysis.*

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### I. INTRODUCTION

The mind and body are closely linked and their relationship can play a central role in all aspects of our health. Research shows that by taking care of our psychological well-being we can sometimes prevent medical illness and often speed our recovery when we do get sick. Some physical or medical problems can be strongly influenced by psychological factors such as stress, emotion, or personality. These medical problems are generally called psychosomatic or psycho-physiological disorders. The term psycho physiological means "interaction of psychological and physiological variables." Consequently, a psycho physiological disorder occurs when psychological and physiological variables interact to produce a pathological state. Common types of psycho-physiological disorders are: migraine headache, tension headache, peptic ulcer, irritable bowel syndrome, insomnia, and essential hypertension. These problems share a common etiological theory, which is often called the diathesis-stress model. The term diathesis refers to a constitutional vulnerability toward over activity in a particular biological system (e.g., cardiovascular or gastrointestinal systems). The diathesis-stress model postulates that stress, worry, anxiety, etc. interact with the vulnerable system to produce a specific psycho physiological syndrome. Research evidence supporting the diathesis-stress model is somewhat mixed and is stronger for some psycho physiological disorders than others. (Donald, Williamson, Barker, & Guidry, 1994).

Disability is not a disease, but a permanent condition. This long lasting condition affects the life of the mothers since they play major role in child rearing. Mothers are the primary caregiver and person responsible for the child's daily needs, health, development and participation in over 95% of family situations (Montes & Halter man, 2007). Past research findings have suggested that having a child with a disability may be one risk factor, interplaying with other risk factors, for the development of negative health outcomes. The international literature points to the risk of negative mental and physical health outcomes among parents, as well as negative consequences for family composition and functioning, the risk of social deprivation and low socio-economic status (Bailey et al. 2007). Having a child with a disability seems to affect the mother's health to a greater extent than it does the father's (Burton, Lethbridge, and Phipps, 2008). Research findings shows that the parents of children with a disability were at risk of developing negative health outcomes; this was especially apparent among mothers of such children (Hedov, Anneren & Wikblad, 2000). The duties of mothers who care for a child with a disability call for the highest level of health research consistently shows that many mothers report poor subjective mental health and, or high stress (Bailey, Golden, Roberts & Ford, 2007). Biomedical studies now provide irrefutable evidence that some mothers experience very high stress levels, potentially making them more susceptible to depression, anxiety and cellular aging beyond their years (Epel et al., 2004).

Studies regarding the physiological complaints stemming from the psychosocial problems of the mothers having a disabled child are rare in the literature. In order to address the gaps in the current researches , the present research focuses on exploring the psycho-physiological complaints and social issues faced by the mothers of disabled children.

## II. METHODS

### Participants

The participants selected for the study were mothers of disabled children. The investigators focused mothers of children with developmental disabilities like Mental retardation, Autism, ADHD, Cerebral Palsy since these are the conditions limiting the capabilities of individuals and affects the life of caregivers. The mothers educational background varies from illiterate to under graduation and their age ranged from 26 to 56 years and the ages of their children ranged from 7 to 20 years. Convenient sampling method was used for selecting participants.

### Measures used

The investigator used semi-structured interview method for data collection and it was analysed qualitatively using thematic analysis.

### Procedure

The investigator obtained permission from the authority of a disability clinic to invite the mothers to take part in the interview. Informed consent was obtained from the mothers before the interview. And an interview schedule was devised to explore participants physical health, psychological health and their social issues. The interviews lasted between 20 to 30 minutes. The questions employed in the interviews were always more open-ended to begin with, followed by some semi-structured questions keeping the key points relevant to the research objective.

### Analysis

The method of data analysis chosen for the present study was a qualitative approach of thematic analysis. Generally, thematic analysis is the most widely used qualitative approach to analysing interviews. The conceptual framework of the thematic analysis for the interviews was mainly built upon the theoretical positions of Braun and Clarke (2006).Thematic frame work was developed and used to classify and organize data according to key themes. Key themes were developed from the research objective and from the responses of the participants

## III. FINDINGS

The responses of the participants are categorized according to the themes. The themes are already set as physiological complaints, psychological complaints and social issues. After repeated reading of the transcripts, Sub themes are developed and coded. The details of the findings are given below in the tables.

**Table 1:** Physiological complaints.

A.Complaints related to sleep	Frequency	Percentage
1.Initial insomnia	2	10 %
2.Disturbed sleep	3	15%
3.Sudden awakening	7	35%
4.Decreased sleep	6	30%
5.Increased sleep	3	15%
6.Night mare	2	10%
7.Sleep drunkenness	3	15%
8. Crying during sleep	1	5%

B.Complaints related to pain	Frequency	Percentage
1.Tension Head ache	7	35%
2.Migraine head ache	7	35%
3.Back pain	5	25%
4.Body pain	2	10%
5.Chest pain	1	5%

C.Gastrointestinal complaints	Frequency	Percentage
1.Gastroble	8	40%
2.Stomach upset	3	15%
3.Burning stomach	6	30%
4.Decreased appetite	3	15%
5.Constipation	2	10%

6.Ulcer	2	10%
<b>D. Respiratory complaints</b>	<b>Frequency</b>	<b>Percentage</b>
1.Palpitation	9	45%
2.Asthma	2	10%
3.Cold	1	5%

<b>E. Other complaints</b>	<b>Frequency</b>	<b>Percentage</b>
1.Fatigue	12	60%
2. High BP	2	10%
3. Head spin	1	5%
4.Heaviness in head	1	5%

**Table 2: Psychological complaints**

<b>A.Complaints related to Cognition</b>	<b>Frequency</b>	<b>Percentage</b>
1.forgetting	13	65%
2.Suicidal thought	2	10%
3.Loneliness	5	25%
4.Not interested in living	1	5%
5.Expectations lost	1	5%
6.Uncertainty about future	1	5%

<b>B.Complaints related to emotion or feeling</b>	<b>Frequency</b>	<b>Percentage</b>
1.Grief	14	70%
2.Sad	9	45%
3.Aloof	1	5%
4.Frozen mind	1	5%
5.Worry	1	5%
6.Guilty	3	15%
7.Pessimism	1	5%
8.Anxiety	15	75%
9.Depression	2	10%
10.anger	9	45%

**Table 3: Social issues**

1.Blaming	5	25%
2.Staring	4	20%
3.Questions	1	5%
4.Contempt	1	5%
5.Ridicules	6	30%
6.Social withdrawal	7	35%
7.Social isolation	2	10%
8.Lack of empathy	2	10%

#### IV. DISCUSSION

During the analysis the physiological complaints were categorised into five major themes such as complaints related to sleep, complaints related to different types of pain, Gastro intestinal problems, complaints related to respiratory system and other complaints. And these themes further divided into sub themes. The psychological complaints are categorised as complaints related to cognition and emotion. The social issues are blaming from extended family members, Staring of others when attending social functions, unbearable questions about the child's condition and behaviours, contempt from others, ridicules when observing the child's inappropriate behaviours in social gatherings, social withdrawal, social isolation and lack of empathy towards the mother of children were the social issues explored.

#### **Physiological complaints**

Majority of the mothers shared their experiences related to sleep disturbances. This may be because of the psychological problems experienced by them. This is also consistent from previous studies. Exposure to prolonged psychological distress has shown to result in negative health outcomes ranging from impaired sleep to negative psychological and physiological well-being. When the body is unable to respond effectively to stressful challenges, this ineffective response is believed to produce a harmful effect due to activation of neural, endocrine and immune systems (Mc Even, 1998). Impaired sleep often occurs when an individual experiences psychological stress as adaptation or coping responses to stressors. (Cohen et al., 2007) that has been associated with negative health outcomes, such as low quality of life. (Zammit, Weiner, Damato, Sillup & Mc Millan, 1999).

The participants explained that they experience gastrological problems and the problems related to respiration during the days when they suffer more stress. The stress may be due to the misbehaviour of the child or the problems related to the social issues. One of the mother shared, "I feel like something is blocked the pathways of my throat and can't take breath properly which often experience immediately after my child behave inappropriately in social functions."

### **Psychological complaints**

While responding to the questions related to psychological complaints all of the participants explained about the stress they are experiencing. Most of the mothers have deeply rooted grief when thinking about the condition of their child. Since the problem of their child is incurable the mothers are helpless. This is also clear from the previous finding that the mental health issues experienced by mothers of children with disabilities have been assumed to be due to grief and sadness related to child's disability (Green, 2007).

The participants were anxious about their own health as well as the future of their child. The mothers anxiety was expressed through the quoting like, "I used to pray every day to the God to take the soul of my son even a day before taking mine..." and she concluded that she is not hating the child, but loved him very much but when thinking a day of my child without my help is impossible. No one will look after him like as I care my boy, her face becomes red and cried, ventilating what was inside her heart. During the interview it was found that the older mothers were the most concerned about the child's independence. Mothers who had unsupportive extended family members were highly concerned about the child's future.

The mothers complained that they are troubled with increased forgetting, mind is scattered and couldn't get concentration. Most of the time thinking about the condition of the child and engaged with helping him in daily activities weakened the mothers both physically and mentally. Behavioural problems, along with disabilities (Minnes, 1998) cause extra stress in parents than the child's disability alone (Walker, Van Slyke, & Newbrough, 1992). When these stresses reach the extreme level, one may think about ending the life itself. One of the mother reported that she had thought about killing the child and ending her life is better than this. She said "I am living now, only because the religion doesn't permit suicide".

Anger is one of the other psychological complaints explained by the participants. They get easily disturbed and increasing their anger day by day. When asking about the expression of anger one of the mother replied that "I get angry when things are not going well, then most of the time expressed to the child and feel guilty after that."

### **Social issues**

Mothers explained about a lot of problems they are experiencing in the society. The social issues are categorized into two themes. One is the issues when participating or attending social functions outside home and the other is the blaming from family members.

#### **• Issues faced outside the family**

Staring and ridicules from others in social gatherings are one of the important social issue faced by these mother. Mother having a child with Down syndrome reported that "People stare at him with eyes full of sympathy like "what is wrong with him", When people ridicule him, I am deeply saddened, I feel hurt."

Mother of an autistic child shared her experience from a marriage function of a relative that, a lady staring at her boy and commented that "what a pity condition, this may be due to not getting a proper medical treatment. Why should you consult an expert doctor?". The mother with a feeling of helplessness looked at the eyes of the investigator and said, "Only we (a mother having a disabled child) can understand these feelings". Most of the mothers reported they are not interested to attend the social functions due to these problems.

#### **• Issues faced within the family.**

In Kerala culture most of the women live with her husband's family and the parents of husbands are the authority figures. Blaming from mother in law and sisters in law are reported as the issues faced by the mothers of disabled children within the family. During the analysis it was noted that mothers who lived in a joint family experiencing more issues related to the problems of disabled child. Following are the live examples of mothers pointing to their problems.

A mother of child with autism explained, "my mother-in-law blamed me for the inappropriate behaviour of my child that, this may be due to false parenting and the child had no problems till the babyhood." Actually major symptoms of autism noticed only after two or three years when social interactions started. She explained that "now I am physically and mentally tired by caring this child, taking the household works and along with this I have to hear the scolding and blaming from in laws.

Another mother, a parent of a child with ADHD shared her problems she facing in the joint family. Her words, "my son is hyper active, he is restless most of the time, sometimes he takes food from other's plate with his dirty hands. Sister-in-law scolded me for not teaching the manners. Most of the time my child makes disturbances by troubling the children of sister-in-law or brother-in-law. What can I do? , they can't

understand his condition. Actually now I am not interested in living, thinking about killing my child and ending my life...". Ended the explanation with sobbing.

One of our participant have a child with autism and the following quote illustrates how she and her daughter were disowned by her mother in law ( her eyes becomes red and started crying while explaining). "When we were ready to attend the marriage function of my sister in law's son, my mother in law said me not to attend the function with the child, relatives will know about the child and it will be a dishonour to our family." But the mother attended the function with the child and during the function a lady enquired about the child. "Who's child is that, what is wrong with her? ".Hearing this mother in law pointed at me and replied like a stranger "that lady's child (instead of saying my grandchild). She continued "these words pierced into my heart like an arrow"

A mother shared her experience bitterly, my sister in law advised me "Should be kept hidden the disabled child", when her son- in- law visit our house.

The aspect of motherhood was seen as stressful because mothers were often blamed for their child's condition by close family and friends, including by their parents as well as spouses at times. This impacted mothers' health (khanlou, Musthafa, Maria, Davidson & Yoshida, 2017)

## V. CONCLUSION

The mothers of a disabled child endure with a plenty of problems. The mothers are physically weak along with psychological complaints. And also they are facing issues from the society and from extended family members .The physiological complaints may be the manifestation of these psychological disturbances stemming from the social exclusion experienced by these mothers due to the disabled children. The negative attitudes expressed by society seemed to be related to lack of understanding of the nature of disability and a response to the physical and behavioural manifestation of the disabled children

Current findings highlight the importance of a strong need to change the social stereotype in the society to create a positive model of a special child and his or her family as a whole. So it is our responsibility as researchers to develop intervention programmes to make a good understanding about the condition of the disability and create a positive attitude of "differentially abled "instead of "disabled ".

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