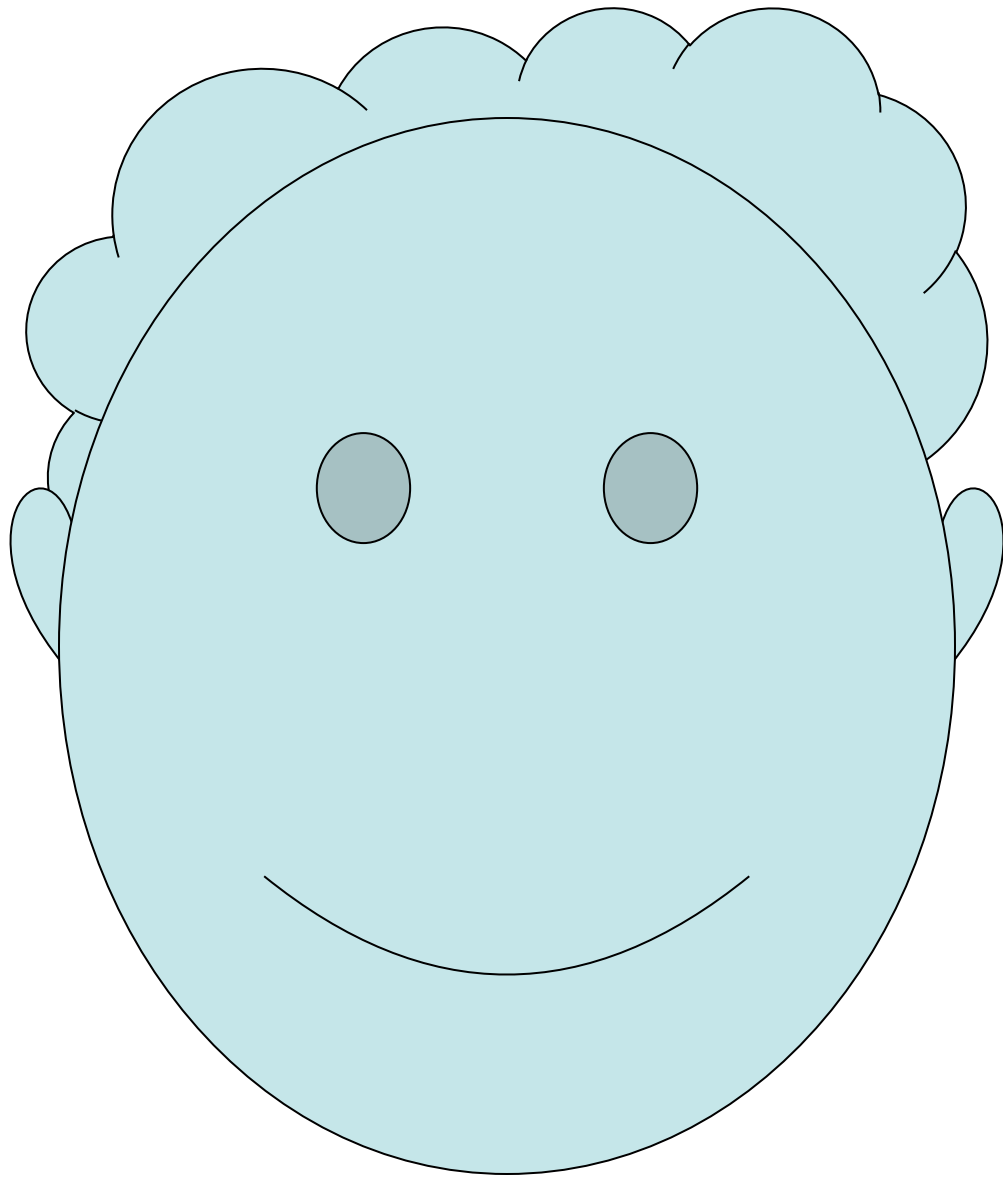


# STRESS FACED BY MOTHERS OF CHILDREN WITH INTELLECTUAL DISABILITY AND ITS IMPACT ON THEIR FAMILY LIFE

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## Introduction:

- All parents expect and plan for a healthy and normal child.
- Very few think of the risk that their child might not be normal.

Parents on being told about having a child with intellectual disability, generally progress through six emotional stages:

1. disbelief,

2. guilt,

3. rejection,

4. shame,

5. denial and

6. a feeling of helplessness.

- parents may experience periods of panic, anxiety and helplessness,
- periods of indifference and anger, depression, apathy and bitterness (Vijesh & Sukumaran 2007).
- Parents of children with intellectual disabilities frequently report symptoms of depression and anxiety.

- Two key factors:
  - the adequacy of social support,
  - and the extent of the child's problem behaviors
  - have been argued to account for much of the distress observed.

- Among the parents, as compared to the fathers,
- mothers face lot of stress because
- they have to spend most of their time with the child with intellectual disability at home
- besides doing all household work and taking care of other non handicapped children.

A study conducted by Marika, (1999) showed that parents, especially mothers of children with disability, have significantly more negative emotional states and also significantly more depressive symptoms

Trute and Murphy (2002) quoted Brinchmann 1998 & Larson 1999 who confirm the importance of assessing familial stress in situations of childhood developmental disability.

- It is important to guide the provision of needed psychosocial, educational, and health services that can strengthen family coping and positive adjustment.
- They suggest that the reduction of parenting stress is paramount in the enhancement of a child's family life and in the child's ultimate integration within society.

This study was designed to find out the stress faced by the mothers of children with intellectual disability and its impact on their family life.

## Objectives of the Study:

To find out

- causes of stress in mothers of children with intellectual disability.
- emotional symptoms of stress.
- physical symptoms of stress.
- impact of stress faced by the mothers of children with intellectual disability on their family life.

- common therapies/strategies available and used to overcome the stress.
- how their coping strategies to overcome their stress is different from the ones used by families in other cultures.
- whether Pakistani families experience similar levels of stress as the families in other cultures of the world.

## **Findings:**

In Pakistani culture like western culture, the major cause of high level of stress faced by mothers of children with intellectual disability is the inappropriate behavior of children with intellectual disability.

1. Majority of the mothers faced high level of stress due to
  - the lack of assessment and therapy facilities,
  - lack of social interaction of their children with intellectual disability.
2. Stress caused the feeling of anger and depression in most of the mothers.

3. Anger and sense of loneliness and depression faced by mothers of children with intellectual disability has a negative impact on their family life.

4. These mothers ignore their other able bodied children because they give more time and pay more attention on their children with intellectual disability.

5. The social support system in Pakistan, because of joint family system, results less stress in parents.

6. Common therapies used by mothers;

- Offering prays,
- watching television and
- chatting with friends on the telephone

- Parents with disabled children in Pakistan due to economical constraints, lack of resources and facilities for their children and also because of lesser therapy facilities for them, have depression symptoms and negative emotional states on a higher level compared with parents of western countries with more resources for their children.

## Discussion:

### Causes of Stress

- Gallagher, etl. (2008) quoted Dunn, Burbine, Bowers, & Tantleff-Dunn (2001), Hastings et al. (2005) and Yirmiya & Shaked (2005) reported
- the parents of children with intellectual disabilities frequently report symptoms of **depression and anxiety**.

- Our study reveals that the **primary cause** of stress faced by mothers is the **inappropriate behavior of such children.**
- Other reasons;
  - **lack of assessment and therapy** facilities,
  - **lack of social interaction** of their children with society,
  - the **concern** of mothers **for the future** of these children.

- When parents go to professionals for help in the diagnosis or treatment of child suspected of being intellectually disabled, they have all too frequently met with disappointment and frustration.
- A number of studies e.g. Baker et al., 2003, Blacher & McIntyre, 2006, Floyd & Gallagher, 1997, Maes, Broekman, Dosen, & Nauts, 2003, Aman, Richmond, Stewart, Bell & Kissel, 1987 also reveal the same results.

- A study by Marika, V. (1999) reveals the negative emotional states in the parents of disabled and non-disabled children.
- Parents of disabled children felt significantly more under pressure, were sorry for their child, worried about the child's future.
- They were also more tired, desperate, and sorry for the children and themselves, and more displeased, sad, depressed, helpless, and embittered.
- The mothers of disabled children had the highest scores in negative emotional states. Mothers were also worried about the child's future, were more sad, tired, helpless, depressed, and nervous than fathers and had higher total score in negative feelings.

- But there are also findings to the contrary.
- According to Anderson (1993) there were no differences between the mean values for parents of mentally retarded and nondisabled children, neither concerning anxiety nor depression.

- For any parent of a child with disability, the most stress producing factor is the child's dependence for daily living activities.
- Once the child attains independence in these activities, the dependence on the mother is reduced, and naturally it will reduce the stress level.
- This gives an important point in managing the child with disability, where the emphasis has to be on attaining independence in daily activities. (Vijesh & Sukumaran 2007).

## Symptoms of Stress

- Our study reveals that the feelings of anger and fatigue are the most common symptoms.
- Similar are the results of other studies conducted in this area.

- Gallagher, etl., (2008) reported that the parents of children with intellectual disabilities registered high depression and anxiety scores, and the majority met the criteria for possible clinical depression and/or anxiety.
- They were more tired, desperate, and more displeased, sad, depressed, helpless, and embittered.
- Analyses of its component dimensions indicated that feelings of guilt held the greatest consequence for depression and anxiety.

- A study by Marika, V. (1999) quoted Holroyd, Brown, Wikler and Simmons (1975) that the parents of children with mental retardation often experience feelings of stress and anxiety.
- Parents of children with intellectual disabilities frequently report symptoms of depression and anxiety.

## Social support

- Social support is important for health and stress relief; it increases resilience, multiplies joy, and softens sorrow. (Scott, E. 2007).
- An important resource for coping with stress is social support, the presence of others in whom one can confide and from whom one can expect help and concern. (Burton, Westen & Kowalski, 2009)

- Burton, 2007 quoted Bolger & Amarel,2007; Salovey, Ruthman, & Rodin,1998.
- Social support system is as important for maintaining physical health as it is mental health  
The magnitude of reaction to stress is considerably less for individuals with good social support from close friends and family members than for individuals with inadequate social support (Lahey, 2002. p 367).

- Social support has long been regarded to mitigate distress (Bailey, Wolfe, & Wolfe, 1994, Dunn et al., 2001).
- A study by Marika, V. (1999) conducted in Estonia located in North Europe reported that, the perception of the social network as inadequate was related to feelings of anxiety.
- A particularly strong correlation was found between anxiety and low number of friends. Individuals with good social support are less likely to react to negative life events with depression, anxiety, and health problems (Lahey, 2002, p 368).

- Marika,V. (1999) quoted Baumeister & Tice, 1990 that the tendency towards social isolation often encountered in families with a child with disability may affect the mother in the form of a real or threatening exclusion from the social environment and may be an important factor in anxiety.

- Gallagher, etl. (2008) reported that the social support has generally been found to be inversely related to depression and anxiety in such parents whereas the child's problem behaviors are positively associated with these symptoms.
- More recently, within the wider care-giving context, sleep quality and caregiver burden have been identified as significant predictors of psychological morbidity.

- These are factors amenable to psychological intervention.
- However, sleep quality and care-giving burden have rarely been examined as possible predictors of depression and anxiety in parents caring for children with intellectual disabilities. Our study reveals that the stress caused the feeling of anger and depression in most of the mothers of children with intellectual disability.

- In Pakistan, where a joint family system is very common, the importance and effects of grandparents as a support can not be neglected.
- An Indian study by Upadhyaya and Havalappanavar (2008) also highlighted the same that is the effect of grandparental support is more evident in the areas of care stress and emotional stress.
- Unlike western countries where there are volunteers working for the families to give some free time to mothers of children with disabilities, Pakistani families don't have such volunteers' support facility so the caring support by the grand parents even to small extent (because of their own health) could be considered as alternate to this.

## Impact of stress faced by the mothers of children with intellectual disability on their family life

- Our study reveals that the sense of loneliness faced by mothers of children with intellectual disability has a negative impact on their family life although they get considerable support by other family members to handle the child with disability.
- They also do not have enough time for any entertainment as they are busy most of the time with their child with disability.

- The results are supported by a study conducted by Hill.F., Newmark. R, and Le Grange. L. (2003) reveals that the mothers have little time for themselves, either because of the demands of childcare or because they choose to spend much of their time with their child with an intellectual disability.
- The same study also noted the isolation that mothers with a child with an intellectual disability tend to experience because of such difficulties as finding an appropriate babysitter when social occasions arise.
- Bumin, Gunal, & Tukul (2008) also stated that “the mother has to undertake too much stress because they are alone with their children in daily life.

## **Common strategies available and used for coping the stress**

- Coping is generally defined as the cognitive and behavioral efforts made to ameliorate demands that tax or overwhelm a person's resources.
- Coping can be seen as the role the individual or social system plays in utilizing physical, social, and psychological resources to manage a stressful situation in the environment (Trute and Murphy 2002).

- Counseling and therapy are another important type of treatment for the mothers of children with intellectual disability to help parents cope with painful feelings about the child's condition and with the extra time and patience needed for the care and education of a special-needs child (Children's Health Encyclopedia n.d.).
- In our study, offering prayers, watching television and chatting with friends on the telephone are the most common therapies used by mothers of children with intellectual disability to cope with the stress.

- Other studies also support these results e.g. Morris & Maisto (2001) quoted Koenig, 1977 that people who attended religious services regularly enjoy better health and have markedly lower rates of depression than those who do not.
- A study by Uchino, Cacioppo, & Kiecolt-Glaser (1996) stated that having a strong network of friends and family who provide social support is lined to good health.

- Barbosa, Chaud, & Gomes (2008) mentioned that  
“the mother overcomes the obstacles that emerge with the disability of the child; sadness and grief are replaced with the feeling of joy and happiness. She intensely lives the successes for her personal and family achievements and growth.”

## Recommendations:

1. The mothers need to have awareness as to how they can overcome their stress.
2. They need to have a positive acceptance of their children with intellectual disability.
3. therapies that can be used by the mothers include;
  - music therapy,
  - aromatherapy,
  - massage and yoga therapy.

### 3. Controlling diets e.g.

- avoiding alcohol, caffeine and sugar,
- using foods containing 'good fats' such as fish, nuts and olive oil can be used to overcome stress.

4. exercises and mediation can improve physical and mental health of these mothers.

6. Mothers facing severe stress need proper medical treatment to lead normal, fulfilling life.
7. These mothers need some time for entertainment e.g. outing, watching movie etc., and during this time the responsibility of their child with intellectual disability can be shared by some family member, neighbors, or volunteers.

8. Siblings and other family members should be encouraged and equipped to;
  - participate in the training and educational process of these children
  - thus helping the mothers to relax and to reduce their anxiety about the future of these children.

9. Parents and families need counseling to create a friendly and optimistic home environment.
10. Formulation of small mothers' groups in the special schools, can provide the mothers a needed platform for expressing their difficulties, sharing their experiences, solving their problems and more importantly, to develop a mutual help system. (Vijesh & Sukumaran 2007).

11. Media can play an important role for the social acceptance of these children.
12. The Government institutes/ hospitals need to provide assessment and therapy facilities for the children with intellectual disability.

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