

Quality of life and burnout among mothers of children with neurodevelopmental disorders

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ABSTRACT

The present study was initiated to understand the relationship between quality of life and burnout symptoms among mothers of children with neurodevelopmental disorders. The participants for the study were randomly selected and consisted of 120 mothers, 30 each with children having intellectual disability, specific learning disability, autism spectrum disorder and attention deficit hyperactivity disorder. The measures like WHO Quality of Life Scale and Maternal Burnout Inventory were used for collecting the data. Correlational analysis of the data revealed the interrelationship between quality of life and maternal burnout. The study also throws light on the importance of providing psycho-social intervention to manage the burnout symptoms among the mothers.

Key words: Quality of life (QoL), maternal burnout, neurodevelopmental disorder (NDD)

1. INTRODUCTION

Neurodevelopmental disorders are a group of conditions with onset in the developmental period. These disorders are usually visible early in development before the child enters grade school. Individuals with neurodevelopmental disorders have deficits in development that results in personal, social, academic or occupational functioning. These are disabilities connected mainly with the functioning of brain and nervous system. Intellectual disability (ID), autism spectrum disorder (ASD), specific learning disabilities (SLD), attention deficit hyperactivity disorder (ADHD) and cerebral palsy (CP) are examples of neurodevelopmental disorder (DSM-V,2013). Some children with neurodevelopmental disorders have more than one of these conditions. They face difficulties in speech and language, motor skills, learning, memory or other neurological functions. Some disabilities are life long, though the signs and symptoms of neurodevelopmental disorders often change or evolve as the child grows up.

In India, the prevalence rate of neurodevelopmental disorders among the children of age 2 to 9 are 12% (Arora, et al., 2018). The present study considered the mothers of children with four types of neurodevelopmental disorders viz., intellectual disability, specific learning disabilities, attention deficit hyperactivity disorder and autism spectrum disorder. Intellectual disability is characterized by deficits in general mental abilities such as reasoning, planning, problem solving, judgment, abstract thinking, academic learning and learning from experiences. The Indian prevalence of intellectual disability is 3% and the rate will vary by age. Specific learning disabilities (SLD) refers to a heterogeneous group of disorders manifested by significant difficulties in the acquisition and use of listening, speaking, reading, writing, reasoning, or mathematical abilities (NJCLD, 1998). The prevalence rate is 5-15% among school age children across different culture and languages (Karande & Kulkarni, 2009). Attention deficit hyperactivity disorder (ADHD) is a brain disorder defined by impairing levels of inattention, disorganization and/or hyperactivity- impulsivity. Disorganization and inattention caused inability to stay on task or losing materials or seeming not to listen at levels that are

inconsistent with age or development level. Hyperactivity- impulsivity involves over activity, fidgeting, inability to stay seated, intruding into other people's activities and inability to wait; symptoms that are excessive for age or developmental level (DSM-V, 2013). Autism spectrum disorder (ASD) is characterized by persistent deficit in social communication and social interaction across multiple context, including deficits in social reciprocity, nonverbal communicative behaviors used for social interaction and skills in developing, maintaining, and understanding relationships. Reported frequencies in recent years for autism spectrum disorder are 1% of population for children and adults (DSM-V, 2013).

Role of the mother in the development of the child is critical, one that is driven logically, not emotionally. Mother is the one who observes the development of her child closely and carefully. So, she has a natural tendency to compare her child with others of the same age. This results in the early identification of children with neurodevelopmental disorders. And these neurodevelopmental disorders have life-long effects on the child and family, especially the mother. Such children require more attention than normal children. This makes the mother more responsible in taking care of the child. It is a challenging task for the mother to mould the child to handle everyday situations and problems. The mothers shoulder the responsibility to prepare the child for the future. The demands of each and every case of neurodevelopmental disorder are different. It varies with the type of disorder and the child. And the mother is the one who is supposed to change accordingly. Research shows that mothers caring for children with disabilities are more likely to report poor health compared with mothers caring for children who do not have any disabilities (Barton, Lethbridge, & Phipps, 2008). The long-term functional limitations of the child along with the requirement of high level of demand could create burden and result in both physical and psychological health issues of the mother.

Quality of Life (QoL) is an area that has been increasingly accepted as a significant outcome measure in caregivers of children with neurodevelopmental disorder and other long-term chronic illness. QoL is defined as "a person's dynamic appraisal of his life in relation to various domains as it relates to his environment" (WHO, 1998). QoL includes the condition that results from the combination of the effect of factors such as those influence one's health, happiness and a satisfying occupation, education, social and intellectual attainments, freedom of actions and freedom of expression. In the case of a mother of children with NDD, due to the stress and workload, she is going through results in lowering of QoL. They face different challenges, such as additional financial burdens for treating their child's condition, dealing with the child's challenging behavior, disability-related stigma (Lecavalier et al. 2006), more physical health symptoms, negative effects, and low mental well-being (Seltzer et al., 2004; Singer, 2006; Ha et al., 2008). There is a strong evidence that mothers of children with developmental disabilities, such as ID and ASD have higher rates of mental health problems (Bailey et al. 2007; Singer 2006) as well as physical health issues and ultimately their wellbeing (Eisenhower et al. 2005).

Chronic stress due to encountering persisting demands from the child and family's needs can result in parental burnout (Procaccini & Kiefaber, 1983). In our culture, it is always the responsibility of the mother to take care of her child, this leads to maternal burnout. They suffer burnout in today's uncertain society owing to insufficient time, money, sleep, space, order and organization. This results in physical and psychological issues in mothers. And at a point, these mothers start to believe that they are the reason behind the challenges and struggles faced by their disabled children. They should overcome the complications and difficulties resulting from

their children's neurodevelopmental impairments. It would be stressful for the mothers if there is impairment in the balance between these inevitable demands and their own social needs. This may lead to several psycho-social problems in mother (Ha et al., 2008).

Mothers of children with neurodevelopmental disorder encounters with innumerable challenges in meeting the demands of their child as well as their personal needs. Families of a child diagnosed with neurodevelopmental disorder are negatively impacted and therefore experience more dysfunction and instability than “normal” families (Watson et al. 2011). Also, she undergoes a lot of sacrifices and sufferings in running her family. This affects both physical and psychological wellbeing of the mother. Studies have revealed that mothers of children with various developmental disabilities experience heightened stress, overburden and marginalization in society, sense of self blame, tiredness or exhaustion. All this leaves mothers of children with disabilities as targets for emotional and physical burnout (Kuhn & Carter, 2006). But limited studies were conducted to explore the QoL of mothers of children with NDD. The present study attempted to understand how the burnout syndrome decides the QoL of these mothers.

2. METHOD Participants

The participants for the present study were randomly chosen mothers of children with four types of neurodevelopmental disorders viz., intellectual disability, specific learning disabilities, attention deficit hyperactivity disorder and autism spectrum disorder. The total number of participants consisted of 120 mothers; 30 each from four types of neurodevelopmental disorders.

Measures

In addition to personal data schedule, the following scale/questionnaire were used for collecting the data.

1. Quality of Life Scale (WHOQOL-BREF, 1998), Malayalam adaptation

This scale was used to assess the perception of individuals in the context of their culture and value systems, and their personal goals, standards and concerns. It is a 26 item Likert scale which measures the domains of general health, physical health, psychological health, social relationships, environmental health and overall QoL. The scale was translated in to the regional language and revalidated by the researchers. The split half reliability of the scale was found to be 0.85 through Spearman-Brown formula and the scale have face validity and content validity as judged by experts.

2. Maternal Burnout Inventory (Abhilash & Jasseer, 2019)

The Maternal Burnout Inventory (MBI) is a 22 item seven-point rating scale developed to measure whether the mother have a risk of burnout syndrome developed as a result of rearing children with NDD. The MBI measures four components viz., emotional exhaustion, depersonalization, personal achievement and overall maternal burnout. The split half reliability of the inventory was found to be 0.82 using Spearman-Brown formula. The inventory has face validity and content validity as judged by experts.

Statistical Technique

Pearson product moment method of correlation was used to examine the relationship between the study variables.

Procedure for data collection

The participants were selected from clinics and special schools after obtaining prior permission from the authorities and strictly followed the ethical considerations. The researchers were briefed about the study to each participant and assured the confidentiality of the data. The scales along with personal data schedule were given to each participant one by one with a brief instruction to mark their responses.

3. RESULTS AND DISCUSSION

In order to explore the relationship between QoL and maternal burnout, Pearson's correlation coefficient was computed. The details were given in the table below. *Table 1: Results of correlation between QoL and burnout (n = 120)*

Variable	General Health	Physical Health	Psychological Health	Social Relationships	Environmental Health	Overall QoL
Emotional Exhaustion	-.429**	-.358**	-.506**	-.381**	-.515**	-.559**
Depersonalization	-.361**	-.441**	-.538**	-.327**	-.601**	-.611**
Personal Achievement	.244**	.223*	.276**	.284**	.346**	.353**
Overall Maternal Burnout	-.391**	-.383**	-.516**	-.325**	-.526**	-.561**

** . Significant at .01 level, * . Significant at .05 level.

The table revealed that the dimensions of quality of life (general health, physical health, psychological health, social relationships, environmental health and overall QoL) had negative correlation with the dimensions of maternal burnout viz., emotional exhaustion, depersonalization and overall burnout. At the same time, all the dimensions of QoL had a positive correlation with personal achievement which was a favorable dimension of maternal burnout.

The variable, general health of mothers had negative correlations with emotional exhaustion ($r = -0.43$, $p < 0.01$), depersonalization ($r = -0.36$, $p < 0.01$) and overall maternal burnout ($r = 0.38$, $p < 0.01$). But, the same variable have a positive correlation with personal achievement ($r = 0.24$, $p < 0.05$). The percentage of variance of these dimensions of maternal burnout on general health were 18.49%, 12.96%, 14.44% and 5.76% respectively.

In the case of the variable physical health, the dimension had negative correlations with emotional exhaustion ($r = -0.36$, $p < 0.01$), depersonalization ($r = -0.44$, $p < 0.01$) and overall maternal burnout ($r = -0.39$, $p < 0.01$). However, this variable have a positive correlation with personal achievement ($r = 0.22$, $p < 0.01$). The percentages of variance of these dimensions of maternal burnout on physical health were 12.96%, 19.36%, 15.21% and 4.84% respectively.

The result of the investigation denoted that the variable psychological health had negative correlations with emotional exhaustion ($r = -0.51$, $p < 0.01$), depersonalization ($r = -0.54$, $p < 0.01$) and overall maternal burnout ($r = -0.52$, $p < 0.01$) and it have a positive correlation with personal achievement ($r = 0.28$, $p < 0.01$). The percentage of variance of these dimensions of burnout on psychological health was 26.01%, 29.16%, 27.04% and 7.84% respectively.

The analysis also revealed that the variable social relations had negative correlation with emotional exhaustion ($r = -0.38$, $p < 0.01$), depersonalization ($r = -0.33$, $p < 0.01$) and overall maternal burnout ($r = -0.33$, $p < 0.01$), whereas the same variable have positively correlation with personal achievement ($r = 0.28$, $p < 0.01$). The percentage of variance of these dimensions of burnout on social relationships was 14.44%, 10.89%, 10.89% and 7.84% respectively.

The result implied that the variable environmental health had negative correlations with emotional exhaustion ($r = -0.52$, $p < 0.01$), depersonalization ($r = -0.60$, $p < 0.01$) and overall maternal burnout ($r = -0.53$, $p < 0.01$) and the same variable have positive correlation with personal achievement ($r = 0.35$, $p < 0.01$). The percentage of variance of these dimensions of maternal burnout on environmental health was 27.04%, 36.00%, 28.09% and 11.20% respectively.

In the case of the overall QoL, negative correlations were observed with emotional exhaustion ($r = -0.56$, $p < 0.01$), depersonalization ($r = -0.61$, $p < 0.01$) and overall maternal burnout ($r = -0.56$, $p < 0.01$), whereas, it have positive correlation with personal achievement ($r = 0.35$, $p < 0.01$). The percentage of variance of these dimensions of burnout on overall QoL was 31.36%, 37.21%, 31.36% and 12.25% respectively.

The research evidences indicated that parents of children with neurodevelopmental disorders, especially mothers, experience difficulties in life (Abhilash & Jasseer, 2019). Their psychological and social life were affected and face greater financial burden than their counterparts as they need to pay for the health care and therapy services for their children (Yau & Li-Tsang, 1999). The parents spend much of their time caring for their disabled children, taking them for assessment, therapy or medical treatment (Ayrault, 2001). These life experiences affect the QoL of mothers which will result in developing burnout symptoms. The result revealed the presence negative relationship between overall QoL and maternal burnout ($r = -0.56$, $p < 0.01$). This may be due to the upbringing a child with NDD is a great deal of work that can result in burden of financial strain, constant supervision and care, pressure on relationship with spouse and other family members. This condition also affected their work life and caused social isolation in mothers (Abhilash & Jasseer, 2019). In a study, Basaran,

Karadavut, Uneri, Balbaloglu and Atasoy (2013) found that having a disabled child has interference on caregivers' QoL and mental health and that results in increased burnout. Another research highlighted that children with disabilities may affect their parents' quality of life (Evans, Dingus & Haselkorn, 1993). The cited studies throw light on the findings of the present investigation.

4. CONCLUSION

The study concluded that there is significant negative relationship established among the dimensions of QoL and burnout in mothers of children with neurodevelopmental disorders. This relationship implies that decrease in quality of life causes burnout symptoms in mothers. They undergo a lot of challenges in meeting personal needs which demanded intervention strategies to maintain the QoL and manage burnout symptoms in mothers.

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