

Relationship between personality and quality of life of caregivers of children with mental disabilities: A review

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ABSTRACT

The number of children with disability is increasing gradually in India. Throughout life's transitions, parents are considered the most important part of a person's life. Parents can play a central role in children's psychological, social, and academic development. For children with chronic disabilities, studies have found that children's welfare and developmental outcomes can be substantially affected by their parents' mental health. Caregiving of persons with mental illness is challenging as sometimes it is demanding and at other times, it is fulfilling to caregivers. In India, family members are the caregivers for persons with mental illness as there are extremely limited alternative facilities and family members are preferred for caring. The changing social milieu in India such as urbanization and nuclear family is placing significant burden on family members. The Quality of Life (QOL) has been noted as one of the major health concerns for parents following a lifelong complex experience such as raising a child with disability. Some studies have examined the difference in QOL between fathers and mothers of children with disability. The results in these studies indicated that mothers tend to have lower QOL levels compared to fathers. The child with disability is considered the most significant factor in quality of life of caregivers. Difficulties in dealing with children with mental disability have the capacity to spill over into various areas of their parents' life leaving them physically and psychologically exhausted. Parents with children with developmental disabilities (DD) encounter a variety of stressors associated with rearing their children. Results showed that parents of mentally retarded children had significantly higher scores only on the neuroticism scale, indicating that they were more emotionally unstable than the parents of normal children.

Key Words : Relationship, Caregivers, Children, Mental disabilities

INTRODUCTION

Care giving can be dichotomized into different types. This is based on the types of caregivers, *i.e.*, formal caregiving vs informal caregiving. Formal caregiving is provided by nurses and trained staff in either a hospital setting or in the home of the disabled person and in the case the caregiver is paid for his /her service, while informal caregiving, also known as family caregiving, is provided by the disabled person's family members, friends and neighbors, out of affection duty and obligation. Other types of caregiving are based on duration, such as short term or long term. In India, caregiving is largely by the family members as there are extremely limited alternative institutional facilities and welfare supports for those with long-standing illnesses such as mental disability and chronic illnesses.

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In addition, in India, most families prefer to care for the ill person at all stages of illness. However, the larger societal changes in the country are placing significant demands on the caregivers. Two of the changes making caregiving difficult are living in urban areas and living in nuclear families. The lack of a supportive community in urban areas and the limited resources in a nuclear family make caring a demand on the caregivers and places their mental health at risk.

Intellectual disability is not a single, isolated disorder. It often originates before the age of 18, and is characterized by significant limitations both in intellectual functioning and in adaptive behaviour (AAIDD, 2007). In recent years, the American Association of Intellectual and Developmental Disability (AAIDD, 2007), Diagnostic and Statistical Manual for Mental Disorders (DSM- 5, 2013) have adopted the new terminology, 'Intellectual Disability' instead of 'mental retardation'. The World Health Organisation (WHO) in the yet-to-be-published 11th edition of the International Classification of Diseases (ICD-11) has also agreed to revision of the name to 'Intellectual Disability' (Salvador-Carulla *et al.*, 2011). The life and survival of a child with disability depends on a number of external and internal factors. The internal factors are supported and nourished by various external factors. For persons with intellectual disability the situation is more complex. Internal factors are less supportive to survival because intellectual disability results in partial or full incapacitation of one's intellectual capabilities. Among the external factors, the role of families, particularly of the parents, is crucial (IASSID, 2012). Hence, the role of support mechanisms in the form of family services is the most integral component when it comes to the wellbeing of a child with intellectual disability (McConkey, 2005; Hill and Rose, 2009).

Intellectual disability as a disorder has wider negative impacts on the family and the caregivers than any other form of disability (Baxter *et al.*, 2000). There is overwhelming evidence that caregivers experience multiple types of emotional distress on diagnosis of intellectual disability in their children. Shock, disbelief, anger, grief, guilt, embarrassment, depression, withdrawal, ambivalence and fear of stigma are common manifestations (Blacher, 1984; Marsh, 1992; Marvin and Pianta, 1996). In India, Singh *et al.* (2008) found negative impacts among one-fourth of the parents in their study sample; these included difficulties in meeting extra demands for physical care of the child, health-related problems, making career adjustments, experiencing loss of support from their spouses, etc. Studies also point out that parents may experience the impacts of disability in different ways. For example, mothers of children with disabilities were found to exhibit increased depression (Olsson and Hwang, 2001), increased caregiver burden (Heller *et al.*, 1997) and increased stress (Herring *et al.*, 2006), as compared to fathers. Studies also reveal that it is not just the presence or absence of disability which causes the negative impacts on the family, but the child's maladaptive behaviour and various care needs (Neely-Barnes and Dia, 2008).

Felce and Perry (1995, p. 60) define quality of life, as:

"Quality of life is defined as an overall general wellbeing that comprises objective descriptors and subjective evaluations of physical, material, social, and emotional wellbeing together with the extent of personal development and purposeful activity, all weighted by a personal set of values."

Rapley (2003) explains that the Felce and Perry model by explaining that firstly, quality of life is the same for all human beings with or without disabilities. Secondly, people understand the world differently and through their perceptions they define happiness in different ways. Individuals' needs reform the meaning of quality of life. Quality of life is about enrichment of everyday life. Moreover, there is emphasis on the individuals' choices and needs but life quality is also influenced by environmental factors. Basically the framework has three fundamental features: the subjective and

objective measurement, life domains, and the influence of personal values (Shearer, 2010, p. 207).

Cummins (1997, p. 6) argues that “*quality of life is both subjective and objective.*” According to him both the objective and subjective axes should be investigated. The axes compound seven domains that cover the spectrum of the concept of quality of life are: material well-being, health, productivity, intimacy, safety, community, and emotional well-being. The objective axis shows the people’s real living conditions and the subjective the individual’s personal evaluation of the domains of his life (Exenberger and Juen, 2014).

Eckermann (2012, as cited in Exenberger and Juen, 2014) states that there are two common areas in the definitions regarding quality of life. Firstly, it is to adapt a common understanding about the good life and secondly to integrate subjective and objective indicators in the concept of quality of life. Subjective indicators apply to personal feelings, opinions, beliefs and objective indicators are measurable things (Sirgy *et al.*, 2006, as cited in Exenberger and Juen, 2014).

The main focus of this paper is to throw light on the way personality of the caregivers of children with mental disabilities are associated with QOL. In general, we agree that people tend to response the life circumstances differently because of individual differences. These differences are due to the fact that personality in itself is a product of interaction between genetic and environmental factor, and due to individual differences, the qualities of life experienced are different. Since what we achieve, expect for the future and even our general health are influenced by our personality.

Personality should be understood as unique combination of patterns that influence behavior, thought, motivation, and emotion and drives individuals to consistently think, feel, and behave in specific ways; in essence, it is what makes each individual unique. Over time, these patterns strongly influence personal expectations, perceptions, values, and attitudes. Personality is thought to affect the QOL of the people because it influences the way they approach and react to stressful situations. Over the past several decades, researchers have acknowledged the importance of examining the quality of life (QOL) of caregivers of the children with disabilities because researchers have found that the responsibilities of caring for a child with a disability may negatively influence parents’ mental health (Dellve *et al.*, 2006; Glenn, Cunningham *et al.*, 2009; Pisula, 2007). There have been numerous demographic factors (e.g., poverty, minority status, single-parent status) that have been identified as possible risk factors for parents as they strive to achieve lives of quality (Brandon and Hogan, 2004; Honberg *et al.*, 2009; Rosenberg *et al.*, 2008; Welterlin and LaRue, 2007).

Relationship between personality and QOL of caregivers of children with Disabilities:

- Deepak Ganjiwale, Jaishree Ganjiwale, Bharti Sharma, and Brajesh Mishra (2016) have conducted a study to assess the quality of life (QOL) and coping mechanisms used by the carers of physically challenged children. In this cross-sectional study, all the 116 children from a school for children with special needs in Anand, Gujarat and their carers were included. Significant differences were found in QOL of the caregivers of physically challenged children based on the type of disability of the child.
- Masako Suzuki Atsurou Yamada, Misuzu Kato, Miyoshi Suzuki, *et al.* (2012) have carried out a study which was aimed to evaluate the quality of life (QOL) of parents caring for their children with pervasive developmental disorders (PDDs). The study concluded that the mothers of children with PDDs had lower QOL scores than those of the Japanese general population especially in mental domains. Impairment of the maternal QOL was

significantly associated with the personality tendency of the parents and relationships with their partners.

- Diego Mugno, Liliana Ruta, Valentina Genitori D'Arrigo and Luigi Mazzone (2007) conducted a study which was aimed: (i) To evaluate QOL in parents of children affected by Pervasive Development Disorder (PDDs), Cerebral Palsy (CP) or Mental Retardation (MR) as compared to a control group (CG) (ii) To evaluate QOL of parents of patients with different types of PDDs, namely Autistic Disorder (AD), High Function Autism/Asperger Syndromes (HFA/AS) and Pervasive Developmental Disorder Not Otherwise Specified (PPD-NOS) and (iii) To compare the level of impairment in QOL of mothers and fathers within PDDs, CP, MR groups and between AD, HFA/AS, PDD-NOS sub-groups. The study revealed that Compared with parents of healthy children, parents in the PDDs group reported impairment in physical activity and social relationships and worse overall perception of their QOL and health. Scores in the physical, psychological and social relationships domains and in the physical and social relationships domains were lower compared to the MR group CP group respectively. Little differences were observed between MR, CP and control groups. The level of impairment of physical and psychological well-being were higher in mothers than in fathers in the PDDs and CP groups, respectively; in the other groups, and across all the other domains of QOL impairment was similar. There were no statistically significant differences in the scores between the AD, HFA/AS and PDDNOS sub-groups, but parents in the HFA/AS sub-group seemed to display a lower QOL compared to the AD sub-group.
- Allik *et al.* (2006) examined the health related QOL (HRQOL) in 31 mothers and 30 fathers of children with Asperger Syndrome (AS) or high-functioning autism (HFA) in comparison to a control group of mothers and fathers of age-matched typically developing (TD) children. It was found that mothers of AS/HFA children have poorer physical health than mothers of children in the control group; however, there were no differences in reported mental health, in addition to no differences in the mental or physical health between the fathers of the AS/HFA and control groups. Maternal physical health was poorer than paternal physical health in the AS/HFA group. Parental HRQOL was not found to be related to the child's autism symptom severity as measured by parent or teacher, while higher maternal physical health was related to higher teacher-reported pro-social behaviours, and higher maternal mental health was related to higher parent-reported pro-social behaviour and lower parent-reported hyperactivity and conduct problems. It was concluded that mothers of children with AS/HFA are more likely to experience impairment of HRQOL than mothers of typically developing children, and child behaviour problems in AS/HFA are associated with poorer maternal mental health.
- Mugno *et al.* undertook a study in 212 parents of children with PDDs, cerebral palsy and intellectual disability, aiming to evaluate the QOL in these parents in comparison to a control group of 77 parents of TD children, as well as to compare QOL between the disability groups. Result found was that mothers and fathers of children with PDD reported poorer perception of overall QOL, health, social relationships and psychological wellbeing in comparison to the parents in the control, cerebral palsy, and intellectual disability groups. When the PDD group was analyzed separately as AS/HFA, AD and PDD-NOS groups, comparison to the control group found the same. When comparing these PDD groups with one way ANOVA and post-hoc comparison, no significant differences emerged except for

lower perceived overall health in fathers of HFA/AS children than PDD-NOS children. The results of this study thus suggest parents of children with PDD were more likely to perceive poorer QOL than parents of children with other disabilities or TD children.

- Lee *et al.* (2009) compared the HRQOL in 89 parents of children with high-functioning ASD to that of a control group of 46 parents of TD children. Finding revealed that both mental and physical domains were significantly poorer in parents of children with HFA. Similarly, stress, coping and resources were found to be poorer in the study group when compare to that of the control group.
- Cecilia Yuen Shan Leung and Cecilia Wai Ping Li-Tsang (2003) has explored the QOL among parents who have children with or without disabilities and found that Social relationships and environmental domains of QOL differed significantly between the two groups of parents, but there were no significant differences in physical health and psychological domains of QOL between the two groups. Parental QOL and the disability levels of their children were positively correlated. Parents who have children with more severe disabilities were found to have lower scores in physical, psychological, and environmental domains. Children with severe disabilities are more physically demanding of their parents, who might feel more stress when taking care of them. Parents' physical and psychological well-being might directly affect their children. (My ppr 3)
- Eloise H. Tew, Sharon L. Naismith, Marilia Pereira, and Simon J. G. Lewis (2013) formulated a study with aim to look at the relative contribution of caregiver personality on their quality of life, specially attempting to identify those traits, which may be protective or harmful. The result obtained showed that conscientiousness was associated with enhanced psychological quality of life and openness positively predicted benefits in the environmental domain. Neuroticism was associated with reduced quality of life in the psychological domain. Thus, screening for neuroticism may help identify those caregivers who would benefit from intervention strategies, which could in the long term help reduce the need for nursing home placement of Parkinson's disease patients.
- Montalbano and Roccella (2009) examined the impact on QOL of the families of 54 children with PDD. It was demonstrated that both mothers and fathers felt that their lives had been impacted, with 59.3% of fathers and 51.9% of mothers indicating that their social contacts were affected, 66.7% of fathers and 72.2% of mothers indicating that family activities were affected, 46.3% of fathers and 50% of mothers indicating more arguments at home. No significant differences between maternal and paternal concerns were found.
- Benjak (2011) investigated the subjective quality of life (SQOL) and health status of 177 parents of 105 children with autism who were primary caregivers, in comparison to 169 parents of children with no disability. The results showed that parents of children with ASD report poorer general health. The author concluded that parents of children with ASD are a vulnerable population group at risk of poorer SQOL and self-perceived health.
- Khanna *et al.* (2006) compared the HRQOL of 304 parents who were main caregivers of children with autism to that of caregivers in the general US population, They concluded that caring for a child with ASD has a significant impact upon QOL, which intervention approaches need to address.
- Yamada *et al.* (2007) examined the QOL in 269 mothers and fathers of children with PDDs. In mothers, a range of QOL domains were found to be significantly poorer than that of the general population, including role physical, general health perception, vitality,

social functioning, role emotional, mental health, as well as overall mental component summary. In fathers, however, only vitality was found to be poorer than that of the general population. It was found that neuroticism was associated with poorer mental health in both mothers and fathers. Lower levels of care in the relationship were associated with poorer maternal physical health, while higher levels of control were associated with both poorer maternal mental health and paternal physical health. Increased work hours in fathers was associated with better physical health, while increased time spent with children was associated with better paternal mental health. While many other studies have shown that QOL is poorer in parents of children with PDDs, this is the only study reviewed which has considered the effect of parental personality traits, which the authors suggest may be used to personalize interventions.

- Suzumura evaluated the HRQOL in 30 mothers of children with high-functioning PDD in comparison to a control group of 30 mothers of TD children, in addition to the child characteristics which contributed to QOL. Result of the study indicated that mothers in the PDD group had poorer general health, vitality, social functioning, and overall mental health than the mothers in the control group, but no difference in overall physical health. On step wise regression, it was found that increased difficult behaviours, rather than child IQ or autism severity, contributed to poorer physical and mental health-related QOL. The authors concluded that caring for a child with high-functioning PDD had an impact on maternal health related quality of life, which is influenced by child behaviours rather than autism symptomatology.

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