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Quality of Life among Parents of Children with Intellectual Disabilities

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Abstract

The particular difficulties faced by parents of children with intellectual disabilities might have a detrimental effect on their quality of life. They have to take care of their child's needs in addition to managing the household money, which can be a difficult undertaking. Research have indicated that compared to non-caregivers, caregivers are more likely to face physical and mental health problems.

In order to address this problem, a study was carried out in Lucknow, India, to look at the quality of life of parents of children with intellectual disabilities. In addition to comparing the quality of life of parents to that of usually developing children, the study sought to identify the difficulties experienced by parents, evaluate coping mechanisms, examine the influence of cultural and socioeconomic factors, and explore the function of support services and resources.

The WHO Quality of Life Scale (BREF) was used to evaluate a sample of 50 parents whose children had been diagnosed with intellectual impairments. The findings demonstrated that, in comparison to healthy parents of children who develop normally, the parents of children with intellectual disabilities had a poor quality of life, with notable inequalities.

It is critical that mental health providers acknowledge and treat the difficulties parents of children with intellectual disabilities encounter. Caregivers can enhance their quality of life and more effectively manage their obligations by having access to resources and support services. As a society, we have an obligation to take care of this vulnerable group and make sure their needs are being satisfied.

Keywords: *Intellectual disabilities, Quality of life, children's health, care-givers.*

I. Introduction

The well-being of parents with children who have intellectual disabilities (ID) has become a significant concern regarding their quality of life. The demands of modern society and the collapse of the traditional Indian family system exacerbate this stressful situation. Intellectual disability is characterized by significant deficits in cognition and adaptive behavior. The terminology used to describe this condition has evolved over the years due to social and political imperatives, primarily to reduce stigma. For instance, terms like "mental retardation" have been replaced by "intellectual disability" in most English-speaking countries (Chavan & Rozatkar, 2014).

The global prevalence of intellectual disability is reported to be approximately 2.3% (Franklin & Mansuy, 2011), while in India, it is estimated at around 2% for mild intellectual disability and 0.5% for severe intellectual disability (Srinath & Girimaji, 1999). There are numerous factors that can cause intellectual disability; however, in at least 30-50% of cases, physicians are unable to identify an etiology despite thorough examination (Armatas, 2009).

Intellectual disability has a significant social impact, affecting not only individuals but also their families and society as a whole. Parents react differently upon learning that their child has a disability, experiencing emotions such as shock, denial, remorse, grief, rejection, and acceptance. Questions like "Why me?" arise without providing answers. Some parents may experience intense sadness, guilt, set unreasonable expectations for themselves, or wish to escape from the responsibility, which eventually results in having a child. A study by Jani (1967) confirmed that parents' feelings are influenced by their future anxiety. Families with an intellectually disabled child may also experience negative impacts on other siblings, psychological stress, decreased interaction with neighbors and relatives, family misunderstandings, and financial loss.

The definition of an individual's quality of life (QOL) has been the subject of considerable debate over the past three decades, with various researchers offering different definitions (Brown, 1997; Felce, 1997). Schipper et al. (1996) describe quality of life as a multifaceted construct that includes key dimensions such as material state, physical state and functional capacity, social interaction, and emotional well-being. Regardless of the methodology, components of an individual's quality of life include overall well-being, constructive social interaction, and the opportunity to reach one's full potential (Schalock et al., 2002). Researchers agree that various facets of life, as well as life in its entirety, should be included in determining one's quality of life (Felce & Perry, 1997; Schalock et al., 2002).

In recent decades, research on quality of life has primarily focused on healthy individuals and, subsequently, on the quality of life of children with disabilities (Molavi, Nojoomi, & Anbari, 2008). Over the past three decades, there has been a proliferation of studies on quality of life (QOL), attracting interest from various scientific disciplines (Schalock, 2000). According to Medvedev et al. (2017), quality of life is a multifaceted term with no universally accepted definition, potentially signifying different things to different people. Nonetheless, most authors concur that quality of life is a multifaceted concept with both objective and subjective aspects. Felce and Perry (1995) define quality of life as overall well-being, encompassing both objective and subjective measures of one's physical, material, social, and emotional well-being, as well as activities that are goal-oriented and personal growth-oriented. Verdugo et al. (2012) identify domains of quality of life as self-determination, involvement, rights, emotional, physical, and material well-being, and personal growth.

Consequently, the topic of family quality of life (FQOL) has garnered significant interest among academics across various fields (Brown et al., 2006), particularly concerning families of individuals with intellectual disabilities (Brown, Schalock, & Brown, 2009; Mactavish et al., 2007; Wang & Brown, 2009). It is widely recognized that parents of children with disabilities are more likely than parents of typically developing children to experience various mental health issues (King et al., 1999), which may negatively impact their quality of life. Understanding the factors that influence a family's quality of life may enable communities to develop stronger support systems for these families, serving as a guide for relevant organizational change and as a measure of support provider outcomes (Hu, Wang, & Fei, 2011).

Previous research has shown that parents of children with disabilities experience feelings of failure, helplessness, and guilt (Dervishaliaj, 2013). Additionally, the birth of a child with disabilities can negatively affect the relationship between parents (Leutar & Oršulić, 2015). The added burden and strain of changing family dynamics especially affect mothers, who usually carry most of the responsibility of caring for their children. As a result, they often face feelings of incompetence and failure and experience more depressive symptoms than their husbands (Bristol, Gallagher, & Schopler, 1988). Aras (2014) found that mothers of hearing-impaired children performed worse than fathers on the SF-36 Health Status Questionnaire, indicating poorer health-related quality of life both socially and physically. In such cases, there is the potential for social isolation and exclusion of the mother from the social environment (Veisson, 1999). Dervishaliaj (2013) found that parental stress affects children with disabilities; the more frustrated parents are, the less they are able to meet their children's needs. Of particular note is the heavy burden on parents of financial hardship often experienced by parents of children with disabilities (Singer & Farkas, 1989).

Further difficulties arise for parents from a lack of social support services and loss of basic rights (Byrne & Cunningham, 1985; Jones & Passey, 2005). Several studies have shown that support services and resources in general have a protective effect against increased stress (Meppelder et al., 2014). Lin et al. (2009) found that poor quality of life for caregivers of children with intellectual disabilities is caused by factors such as lack of social potential (Schalock et al., 2002). Researchers agree that quality of life assessments should consider various facets of life and not just individual aspects (Felce & Perry, 1997; Schalock et al., 2002).

In recent decades, research on quality of life has primarily focused on healthy individuals and, later, on children with disabilities (Molavi, Nojoomi, & Anbari, 2008). Over the past three decades, the study of quality of life has expanded across multiple scientific disciplines (Schalock, 2000). Medvedev et al. (2017) argue that quality of life is a complex term with no universally accepted definition, varying across individuals and cultures. However, most scholars concur that quality of life consists of both objective and subjective dimensions. Felce and Perry (1995) define quality of life as overall well-being, encompassing both objective and subjective indicators of physical, material, social, and emotional well-being, along with goal-oriented and personal growth-related activities.

Verdugo et al. (2012) outline quality of life as encompassing several domains, including self-determination, involvement, rights, and emotional, physical, and material well-being. This has led to increasing scholarly interest in the concept of family quality of life (QOL) (Brown et al., 2006). Families with individuals who have intellectual disabilities are particularly affected (Brown, Schalock, & Brown, 2009; Mactavish et al., 2007; Wang & Brown, 2009). Research suggests that parents of children with disabilities are more likely than parents of typically developing children to experience various mental health issues (King et al., 1999), which can negatively impact their quality of life. Understanding the factors that influence family quality of life may help communities develop better support systems for these families, serving as both a guide for organizational change and a measure of support service outcomes (Hu, Wang, & Fei, 2011).

Prior research has shown that parents of children with disabilities often experience feelings of failure, helplessness, and guilt (Dervishaliaj, 2013). Additionally, the birth of a child with disabilities can negatively affect parental relationships (Leutar & Oršulić, 2015). The increased burden of care primarily falls on mothers, who often assume the majority of caregiving responsibilities. As a result, mothers frequently experience feelings of incompetence and failure, leading to higher rates of depressive symptoms compared to fathers (Bristol, Gallagher, & Schopler, 1988). Aras (2014) found that mothers of hearing-impaired children scored lower on the SF-36 Health Status Questionnaire, indicating poorer health-related quality of life, both socially and emotionally. These challenges contribute to social isolation and exclusion from social environments (Veisson, 1999).

Parental stress has a direct impact on children with disabilities. Dervishaliaj (2013) found that frustrated parents are less capable of meeting their children's needs. Furthermore, financial hardship significantly burdens parents of children with disabilities (Singer & Farkas, 1989). Additional challenges include a lack of social support services and the loss of basic rights (Byrne & Cunningham, 1985; Jones & Passey, 2005). Several studies suggest that support services and resources play a protective role in mitigating stress among these families (Meppelder et al., 2014).

Lin et al. (2009) found that the poor quality of life among caregivers of children with intellectual disabilities is attributed to factors such as lack of social support, financial strain, inadequate respite care, and the child's challenging behaviors. The study also highlights the need for targeted interventions, including counseling, support groups, financial assistance, and training programs for managing challenging behaviors. These interventions are crucial for improving the well-being of caregivers and, consequently, the quality of life for children with intellectual disabilities.

Most recent research on the quality of life of parents of children with intellectual disabilities has been conducted in Lucknow, Uttar Pradesh, India. However, there is a lack of similar research in other Asian countries. The present study aims to compare the quality of life of parents of children with intellectual disabilities in Lucknow with that of parents of typically developing children. Additionally, the study examines how gender and educational attainment influence the quality of life of parents raising children with intellectual disabilities.

Objective

- To explore the Socio-demographic status of parents of children with intellectual disability in Lucknow, India.
- To identify the challenges faced by parents of children with intellectual disability in Lucknow that affect their quality of life.
- To compare the quality of life of parents of children with intellectual disability in Lucknow with that of parents of typically developing children.

II. Methodology

A descriptive cross-sectional study was conducted among 50 parents of children with intellectual disabilities.

2.1 Participants

The purpose of the study was to compare and contrast parents of ordinarily developing children with those of children with intellectual disability. 50 parents—25 mothers and 25 fathers—of children with intellectual disabilities and 50 parents—25 mothers and 25 fathers—of children with typical development served as the control group. The kids were all in elementary school, and their ages ranged from seven to fifteen. Parents of children with intellectual disabilities were 38.6 years old on average (SD = 6.1), while parents of children who were developing normally were 39.5 years old on average (SD = 0.1). The mean age of the parents in the two groups did not differ statistically significantly (t = 0.74, p = 0.46). Two elementary schools in Lucknow and one primary school in Aliganj provided the parents for the recruitment. Depending on how educated they were, parents of kids with intellectual disabilities were split into two groups. Guardians who have completed their education in elementary or high school as well as junior college or university

.2.2 Tools

The following tools were used in the current study.

Sociodemographic performance:

We collected sociodemographic details about the subjects using performers designed specifically for this study. WHO. Quality of Life (BREF):

WHOQOL-BREF (Agnihotri et al. 2010) is a shortened version of WHOQOL-100. This is a self-administered scale with 26 items and 4 domains.

Psychological domain - Measures self-awareness and cognitive abilities. Body Areas - Measures physical problems such as joint pain, hearing, vision, and sleep disturbances. Social domain - measures levels of social life, personal relationships, social support, family acceptance, and social interaction. Environmental domain - measures living conditions, safety, availability of medical assistance, recreational opportunities and facilities. Apart from these four domains, there are two separate questions that assess the individual's overall quality of life and health. A confidence score of 89 or higher indicates good distinctiveness and content validity.

2.3 Data Collection Procedure

Parents were invited to a school assembly where the researcher explained the purpose of the study. It was emphasized that participation was voluntary and that data would be evaluated anonymously. Participants then underwent a QOL questionnaire. A completed questionnaire was collected two weeks after her.

2.4 Statistical analysis

For the purposes of this study, we used descriptive and inferential statistics. To assess differences in QOL between parents of children with intellectual disabilities and those of normally developing children, we performed independent t-tests and calculated the Cohen coefficient d as a measure of effect size. Did. A two-factor analysis of variance was performed to examine the effects of gender and professional education on her QOL. Alpha level was set to 0.05 for all tests. Data were analyzed with the computer program SPSS v.13 for Windows.

III. Result

Objective 1: To explore the Socio-demographic status of parents of children with intellectual disability in Lucknow, India.

Table 1 Showing Socio-demographic details of the Parents of children with intellectual disabilities and Parents of typically developing children.

Variable	Item	Parents of children witl intellectual disabilities (N=50) N (%)	Parents of typically developing children (N =50) N (%)
Age	**Mean± SI**	34±7	30.92±3
Gender	Male	8 (16%)	---
	Female	42(84%)	50(100%)
Residence	Urban	45(90%)	28(56%)
	Rural	5(10%)	22(44%)
Marital status	Married	50(100%)	50(100%)
	Unemploye	7(14%)	1(2%)
Occupation	Housewif	40(80%)	43(86%)
	Salaried	2(4%)	5(10%)
	Business\self employment	1(2%)	1(2%)
Religion	Hindu	49(98%)	49(98%)
	Sikh	1(2%)	1(2%)
	Illiterate	20(40%)	1(2%)
Education	< Secondar	22(44%)	28(56%)
	> Secondar	8(16%)	21(42%)
Family type	Joint	20(40%)	27(54%)
	Nuclear	30(60%)	23(46%)

Table 1 suggests that the mean age of Parents of children with intellectual disabilities was (34±7) and Parents of typically developing children was (30.92±3). Majority of female respondents was included in both the groups. Similarly majority of study population was from urban areas. Housewives were found more in present study. Majority of respondents were from Hindu religion.

Mostly respondents were educated less than secondary. In family type majority of study population was from nuclear family system.

Objective 2: To identify the challenges faced by parents of children with intellectual disability in Lucknow that affect their quality of life.

Table 2: Showing differences in study and Parents of children with intellectual disabilities and Parents of typically developing children of lifescale.

Variables	Parents of children with intellectual disabilities (N=50) (Mean ± SD)	Parents of typically developing children (N=50) (Mean ± SD)	t	P
Physical	42.58±8.13	75.36±6.33	-22.488	.000*
Psychological	41.80±6.75	75.72±4.63	-29.262	.000*
Social	62.96±12.86	76.44±3.74	-7.114	.000*
Environment	52.58±9.21	67.32±4.20	-10.286	.000*

* Significant at < .0001

Table 2 found that mean score of control study population was found to be high in terms of quality of life in comparison to Parents of children with intellectual disabilities , which is statistically significant at .001 level. It suggests that quality of life (Physical, psychological, social and environment) of parents having normal children was high than parents having children with intellectual disability.

Objective 3: To compare the quality of life of parents of children with intellectual disability in Lucknow with that of parents of typically developing children.

Table 3. Mean Quality of Life Scores for Parents of Children with Intellectual Disabilities and Parents of Children with Normal Development

Parents	M	SD	t-test	Cohen'd
Parents of children with intellectual disabilities	98.3	14.1	4.93*	-0.99
Parents of typically developing children	110.4	10.1		

Note: *p<.001; n=100.

As can be seen from Table 3, parents of normally developing children report much better quality of life than parents of children with intellectual disabilities. In addition to the statistical significance of the scores, the Cohen'd coefficient effect size was also large.

In practice, this means that parents of normally developing children reported QOL scores nearly one standard deviation higher than those of parents of children with intellectual disabilities.

Second, we wanted to assess the effects of parental gender and educational level of a child with intellectual disability on her QOL score. The crosstab means are shown in Table 2.

Table 4. Mean scores on QOL in relation to gender and educational level in parents of children with intellectual disability

Gender	Level of education	M	SD	N
female	Elementary/high school	86.0	21.8	10
	College/university	96.9	10.5	15
	Total	92.5	16.5	25
male	Elementary/high school	99.0	8.1	10
	College/university	107.5	5.6	15
	Total	104.1	7.8	25
total	Elementary/high school	92.5	17.4	20
	College/university	102.2	9.9	30
	Total	98.3	14.1	50

A two-factor analysis of variance revealed a statistically significant effect of gender on quality of life (F(1.46) = 11.2; p<0.01) and a statistically significant effect of education level on quality of life (F(1.46) = 7.5; p < 0.01). However, there was no statistically significant interaction between gender and education level on QOL (F(1.46) = 0.2; p = 0.74). As can be seen from Table 2, fathers had a higher quality of life for her than mothers, and well-educated parents had a higher quality of life.

IV. Findings

The study focused on the quality of life (QOL) of parents with children who have intellectual disabilities, aiming to evaluate the impact of education level and gender on QOL. Findings indicate that these parents report a significantly lower QOL compared to parents of typically developing children. This aligns with previous research; for instance, Memisevic (2017) found that parents of children with intellectual disabilities experience lower QOL across various domains.

However, some studies present nuanced findings. Leung and Li-Tsang (2003) observed that while parents of children with disabilities had lower QOL in physical and mental health domains, they reported higher QOL in social relationships and environmental support. Additionally, Gallagher et al. (2008) noted that these parents experience higher levels of anxiety and depression, contributing to a diminished QOL.

It's important to note that variations in research methodologies can make direct comparisons challenging, yet the overall trend indicates a disparity in QOL. Social support has been identified as a crucial factor in enhancing QOL, emphasizing the importance of maintaining positive family relationships (Meral et al., 2013).

The study also corroborated previous findings regarding the influence of parental education level and gender. Parents with lower education levels and mothers of children with intellectual disabilities reported lower QOL than their counterparts. Kazmi et al. (2014) found that mothers of disabled children experienced reduced QOL and were more prone to depression compared to fathers. Similarly, Romeo et al. (2010) discovered that mothers of children with cerebral palsy had a lower QOL than fathers. Dervishaliaj (2013) noted that parents of disabled children often experience feelings of inadequacy and powerlessness, particularly among mothers.

Educational attainment appears to correlate with QOL, with higher education levels associated with better socioeconomic status (SES), leading to improved QOL and reduced exposure to stress (Ross & Van Willigen, 1997).

These findings have practical implications. Enhanced social support has been shown to improve QOL, suggesting the need for comprehensive support services for parents of children with disabilities. Implementing support programs can help parents develop coping strategies, advocate for their children's rights, and improve overall family well-being. Prioritizing support for mothers, who are often more adversely affected, is essential. Societal recognition of the efforts made by these parents can contribute to better outcomes for both parents and children. A higher QOL for parents is likely to result in a higher QOL for their children with disabilities.

Limitations of this study

Due to the small sample size, care must be taken to generalize these results to all Croatian parents, then only the total scores of her QOL scales were used as the outcome variable. Assessing QOL profiles across the five QOL scale domains is useful and informative. Quality of life should be the focus of research on the quality of support programs for both persons with disabilities and their families.

Data Availability Statement (DAS):

"The data generated and analyzed in this study are not publicly available due to ethical and privacy restrictions. However, summary statistics or de-identified data may be available from the corresponding author upon reasonable request."

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