RESEARCH PAPER

Quality of Life Among Care Givers of Children with Intellectual Development Disorder- A Cross Sectional Study

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ABSTRACT
Raising a child with a disability is unique challenges; it includes the mental stress and physical exhaustion of family care giving. When caring for a child with a disability, it is difficult to balance work, home, and care giving responsibilities of the disabled child. Quality of life has been expressed as the extent to which an individual feels about their living standard, health status, life achievements, personal relationships, safety, community connectedness and security into the future. The study aims to assess the quality of life among caregivers of children with intellectual development disorder at selected special school. The objectives of the study includes assessing the quality of life among caregivers of children with intellectual development disorder and to find out the association between the level of quality of life among caregivers of children with intellectual development disorder with their selected demographic variables. Hence quantitative research approach with descriptive research design was adopted for this study. 30 caregivers were selected using a non-probability purposive sampling technique, in a selected special school. Standardized WHO-BREF scale was used to assess the quality of life of the caregivers. The study findings revealed that 13(43%) of the caregivers experienced poor quality of life, 9(30%) experienced moderate quality of life, 6(20%) reported good quality of life and 2(7%) reported very good quality of life.

Keywords: Intellectual development disorder, caregiver, quality of life, special school

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INTRODUCTION

Caring a child with an intellectual disability (ID) gives rise to unique challenges that significantly disturb the daily lives and well-being of their caregivers. Intellectual disability, characterized by limitations in intellectual functioning and adaptive behaviour, requires continuous attention, supervision, and support, making care giving a full-time and often lifelong responsibility of their caregivers. In many cultural settings, significantly mothers are traditionally the primary caregivers, bearing the major responsibility of care giving the disabled children. This extended care giving role leads to high levels of care burden that includes physical, emotional, financial, and social strain. Over time, this burden worsens the quality of life (QoL) of the care givers, and provides negative impact on physical health, emotional well-being, social functioning, and even spiritual fulfilment.

Intellectual Developmental Disorder (IDD) is marked by impairments in intellectual abilities and adaptive behaviour, which influence conceptual, social, and practical skills. It usually becomes apparent before the age of 18. According to the WHO, IDD refers to a condition that affects an individual's capacity to learn, reason, and perform effectively in everyday life. Every parent worries about their children and how to provide the best for them in life. But when the child has a disability, these fears are often magnified. Raising a child with a disability can be extremely challenging.

Quality of life has been expressed as the extent to which an individual feels about their living standard, health status, life achievements, personal relationships, safety, community connectedness and security into the future (Avdagic et al. 2021).

Although there is literature reporting that a child with intellectual disabilities has many benefits for the family, such as stronger familial bonds, developing of patience and empathy **(Aksamit and Wehmeyer 2022)** there are also many reports that caring for such a child places an increase in parental and family stress **(Staunton, Kehoe, and Sharkey 2023).**Caregivers of children with intellectual disabilities often experience reduced Quality

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of Life due to stress, anxiety, stigma, economic hardship, and a lack of social support systems (**Raina et al., 2005).**

Nowadays, research on quality of life has primarily focused on healthy individuals and, thereafter, on the quality of life of children with disabilities **(Molavi, Nojoomi, & Anbari, 2008. Felce and Perry (1995)** define quality of life as overall well-being, including both objective and subjective measures of one's physical, material, social, and emotional well-being, as well as activities that are linked to goal-oriented and personal growth-oriented.

In developing countries the burden is intensified by limited access to rehabilitation services, poor awareness, social isolation, and cultural beliefs associated with disability. This further aggravates the psychological and emotional toll on caregivers. Studies have shown that the psychological burden can be as debilitating as the physical workload, leading to increased risk of depression, burnout, and reduced overall life satisfaction **(Gupta & Singhal, 2004).**

Statement of the Problem:
A Study to assess the quality of life among caregivers of children with intellectual development disorder at selected special school.

The Objectives of the study are

1. To assess the quality of life among caregivers of children with intellectual development disorder.
2. To find out the association between the level of quality of life among caregivers of children with intellectual development disorder with their selected demographic variables.

METHODS AND MATERIALS

The present study adopted a quantitative research approach with descriptive research design to assess Quality of life among caregivers of children with Intellectual Development Disorder (IDD) at a selected special school, Tamil Nadu.

The study population consisted of caregivers of children diagnosed with IDD who were attending the special school. A total of 30 caregivers were selected using a non-probability purposive sampling technique based on inclusion criteria, which included caregivers who were willing to participate, able to read and write the language Tamil, and whose who caring the children diagnosis of IDD at least for the period of one year. Caregivers of children with any psychiatric disorder, and those who are unwilling to participate were excluded from the study.

The data collection tool consisted of three parts: Section A included demographic variables such as age, education, occupation, income, number of children, age of the child with IDD, and type of family. Section B used a standardized WHO-BREF scale.

The content validity of the tool was established with expert review, and reliability was tested using the test-retest method, yielding a reliability coefficient of 0.84, indicating strong reliability. Ethical clearance was obtained from the Institutional Ethical Committee and permission was granted by the school authorities. Oral consent was obtained from all participants, ensuring confidentiality, anonymity, and informed their right to withdraw from the study at any time.

Data collection was conducted over a period of two weeks. The mothers were briefed about the study objectives and guided through the questionnaire by the investigator. The collected data were coded, entered, and analyzed using descriptive statistics such as frequency, percentage, mean, and standard deviation to describe the demographic profile and Quality of life. Inferential statistics, including the chi-square test, were used to identify the association between the Quality of life and their selected demographic variables.

RESULT:

Table 1: Distribution of demographic variables of caregivers of children with intellectual development disorder.

S. No	Demographic Variable	Frequency (f)	Percentage (%)
1	**Age of the Caregiver**		
	a)Below 25 years	4	14
	b)26–35 years	10	33
	c)36–45 years	9	30
	d)Above 45 years	7	23
2	**Gender**		
	a)Male	11	37
	b)Female	19	63
3	**Relationship with the Child**		
	a)Mother	13	43
	b)Father	8	27
	c)Grandparent	6	20
	d)Other	3	10
4	**Educational Qualification**		
	a)No formal education	5	17
	b)Primary	7	23

	c)Secondary	10	33
	d)Graduate and above	8	27
5	**Occupation**		
	a)Homemaker	13	43
	b)Daily wage earner	4	14
	c)Private employee	7	23
	d)Government employee	3	10
	e)Self-employed	3	10
6	**Monthly Family Income (₹)**		
	a)Less than ₹10,000	10	33
	b)₹10,001–₹20,000	10	33
	c)₹20,001–₹30,000	6	20
	d)Above ₹30,000	4	14
7	**Type of Family**		
	a)Nuclear	17	57
	b)Joint	10	33
	c)Extended	3	10
8	**Residence**		
	a)Urban	11	37
	b)Semi-urban	8	26
	c)Rural	11	37
9	**Number of Children**		
	a)One	16	53
	b)Two	10	33
	c)More than two	4	14
10	**Duration of Caregiving (years)**		
	a)1-2 year	4	14
	b)2–3 years	10	33
	c)3–4 years	12	40
	d)>4 years	4	14
11	**Type of Intellectual Disorder**		
	a)Mild	18	60
	b)Moderate	12	40
12	**Any Previous Counselling Taken**		
	a)Yes	12	40
	b)No	18	60

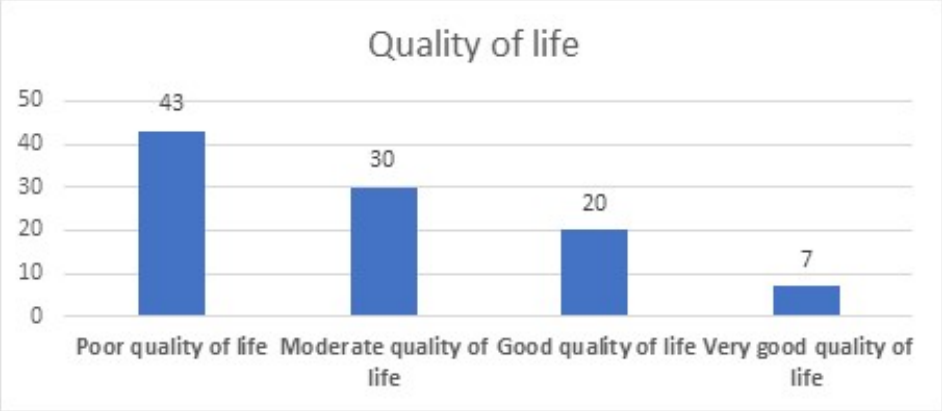

Figure 1: Frequency and percentage distribution of stress among mothers of children with Intellectual development disorder.

The study findings revealed that 13 (43%) of the caregivers experienced poor quality of life, 9(30%) experienced moderate quality of life, 6(20%) reported good quality of life and 2(7%) reported very good quality of life. Among the demographic variables, no variables showed a statistically significant association with quality of life ($p< 0.05$) level, suggesting that no variables are influencing the quality of life among caregivers.

Table 2: Association between the quality of life among caregivers of children with intellectual development disorder

S. No	Demographic Variable	Level of quality of life				Chi-Square	Tab. value	Sign
		Poor quality	Moderate quality	Good quality	Very good quality			
1	**Age of the Caregiver**							
	a)Below 25 years	1	1	1	1	7.572	16.919 DF=9	NS
	b)26–35 years	3	4	2	1			
	c)36–45 years	4	3	2	0			
	d)Above 45 years	5	1	1	0			
2	**Gender**							
	a)Male	3	4	3	1	1.82	7.815 DF=3	NS
	b)Female	10	5	3	1			
3	**Relationship with the Child**							
	a)Mother	8	3	2	0	12.64	16.919 DF=9	NS
	b)Father	3	1	3	1			
	c)Grandparent	1	4	1	0			
	d)Other	1	1	0	1			
4	**Educational Qualification**							
	a)No formal education	1	3	1	0	9.449	16.9.19 DF=9	NS
	b)Primary	3	2	2	0			
	c)Secondary	6	2	2	0			
	d)Graduate and above	3	2	1	2			
5	**Occupation**							
	a)Homemaker	5	3	3	2	6.064	21.026 DF=12	NS
	b)Daily wage earner	2	2	0	0			
	c)Private employee	3	2	2	0			
	d)Government employee	1	1	1	0			
	e)Self-employed	2	1	0	0			
6	**Monthly Family Income (₹)**							
	a)Less than ₹10,000	5	3	2	0	4.86	16.919 DF=9	NS
	b)₹10,001–₹20,000	5	2	2	1			
	c)₹20,001–₹30,000	3	2	1	0			
	d)Above ₹30,000	0	2	1	1			
7	**Type of Family**							
	a)Nuclear	8	5	3	1	0.741	12.592 DF-=6	NS
	b)Joint	4	3	2	1			
	c)Extended	1	1	1	0			
8	**Residence**							
	a)Urban	3	4	3	1	3.91	12.592 DF=6	NS
	b)Semi-urban	4	2	1	1			
	c)Rural	6	3	2	0			
9	**Number of Children**							
	a)One	6	5	4	1	1.798	12.592 DF=6	NS
	b)Two	5	3	1	1			
	c)More than two	2	1	1	0			
10	**Duration of Caregiving**							
	a)1-2 years	2	1	1	0	1.097	16.919 DF=9	NS
	b)2-3years	4	3	2	1			
	c)3– years	5	4	2	1			
	d)>4 years	2	1	1	0			
11	**Type of Intellectual Disorder**							
	a)Mild	8	6	2	2	3.272	7.825 DF=3	NS
	b)Moderate	5	3	4	0			

12	**Any Previous Counselling Taken**							
	a)Yes	3	5	2	2	5.55	7.815	NS
	b)No	10	4	4	0		DF=3	

CONCLUSION:

The present study was conducted to assess the quality of life among the caregivers of children with Intellectual Development Disorder at selected Special School, Tamil Nadu. The study concluded that caregivers of children with Intellectual Development Disorder predominantly experienced poor quality of life indicating a need for supportive interventions to enhance their quality of life.

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