

Research Paper

Exploring the Impact of Social Support on Quality of Life of Parents of Adults with Intellectual Disabilities and Autism Spectrum Disorder

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ABSTRACT

Aim: Social support is a significant psychosocial resource that help an individual to cope with critical life events. The transition to adulthood introduces unique stressors for both caregivers and individuals with Intellectual and Developmental Disabilities (I/DD), encompassing challenges related to financial difficulties, declining psychological well-being and health, assuming sole caregiving responsibilities following the death of a partner, and uncertainties surrounding the future care of the adult child with I/DD. Given these challenges, the present study aims to explore the impact of perceived level social support on QOL of parents of adults with ID and ASD. **Method:** The participants for this study consisted exclusively of parents who were caregivers of an adult child with ID and ASD (Certified by Government of West Bengal), age ranged 18 years to 30 years. The parents consisted of individuals who were a minimum age of 40 years to 55 years and were caregivers of adult children with ID and ASD. The Interpersonal Support Evaluation List (ISEL) was administered to measure the parent's perceived social support and The World Health Organization Quality of Life- Brief version (WHOQOL-BREF) was administered to assess the parent's perceived QOL. **Results:** There is no significant variation of level of condition and types of condition on the perception of QOL of the parents of adult sons/daughters with ID and ASD. The findings further indicated that there is a significant effect of perceived social support on the overall quality of life and its dimensions viz. psychological. **Discussion:** Parents considered that social support has an impact on their subjective well-being. **Conclusion:** The findings can be used to develop research informed policy and practice for parents of adult children with intellectual disabilities and autism spectrum disorder.

Keywords: *Social Support, Quality of Life, Intellectual Disability, Autism Spectrum Disorder*

Throughout the journey of raising and parenting children, parents experience joy, satisfaction, and plethora of challenges. Consequently, they experience parental demands and stress. Parents modify and adjust their lifestyles to meet the needs and responsibilities of raising children. Parents of children with developmental disabilities throughout their lives, generally serve as caregivers and support for their children which

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may last over 7 decades and ending with their death. In countless studies parents have reported heightened stress in raising a child with intellectual disability (Crnic et al.1983; Kazak & Marvin 1984; Orr et al. 1993; Baker et al. 1997; Fidler et al. 2000). Across the literature, parents of children with Autism Spectrum Disorder frequently reported higher levels of anxiety (e.g., Falk et al., 2014; Kuusikko-Gauffin et al., 2013;), higher levels of depression (e.g., Stein et al., 2011; Hayes and Watson, 2013; Falk et al., 2014;), and more health-related problems (e.g., Stein et al., 2011; Dykens and Lambert, 2013; Giallo et al., 2013; Fairthorne et al., 2015). The life expectancy of individuals with intellectual and developmental disabilities (I/DD) is increasing and they are outliving their parents. Many of these individuals are more likely to be living with ageing parents who themselves may have additional support needs due to the issues of ageing. This transition to adulthood introduces unique stressors for both caregivers and individuals with I/DD, encompassing challenges related to financial difficulties, declining psychological well-being and health, assuming sole caregiving responsibilities following the death of a partner, and uncertainties surrounding the future care of the adult child with I/DD. The majority of research on Quality of Life (QOL) in the context of caregiving has indeed indicated that parents of children with intellectual disabilities encounter heightened challenges such as anxiety, concerns about physical safety, and persistent worries regarding their child's future. These difficulties may adversely impact the environmental aspects of quality of life for parents in this situation (Singh, Kumar, and Chakraborti 2016).

As individuals with I/DD age, the availability of supportive services may decline due to factors such as isolation or financial constraints associated with older age (Dillenburger & McKerr, 2010). This shift introduces unique stressors for both caregivers and their wards, encompassing challenges related to financial difficulties, declining health, assuming sole caregiving responsibilities following the death of a partner, and uncertainties surrounding the future care of the adult child with I/DD. Literature on well-being have emphasised the role of social support against the detrimental effects of distress (Compton and Hoffman, 2013). Social Support is defined as individuals or groups (e.g., family members, friends) who provide various degrees of instrumental, informational, and/or emotional resources or assistance to help individuals overcome the hurdles (Schilling, Gilchrist, & Schinke, 1984; Thoits, 1995). Perceived social support is the subjective experience of social, psychological and interpersonal assistance that sustains and elevates health and well-being (Gottlieb, 2009). Proponents of disability research suggested that social support is a protective factor in maintaining the resilience of the individual (Seltzer et al., 2004). Also, caregivers who have high social supports can manage better in difficult situations than who have lower social support (Raina et al., 2014). Peer and Hillman (2014) studied that parents raising children with disability reported that support from their network plays significant role in managing caregiving stress and promoting positive outcomes through the non-judgemental discussion of their concerns, receiving empathy from others, venting out negative emotions and seeking support (Dey and Amponsah, 2020).

There is a dearth of research in Indian context focusing on the role of social support on quality of life of parents of adults with intellectual disabilities and autism spectrum disorder. Therefore, the present study aimed to explore the effect of Social Support on the Quality of Life of Parents of Adults with Intellectual Disabilities and Autism Spectrum Disorder.

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METHOD

Objective of the study:

- To assess the nature of Quality of Life of the parents with variation of the types of conditions (Intellectual Disabilities and Autism Spectrum Disorder) and the levels of conditions (mild and moderate).
- To identify the nature of Quality of Life of the parents of adult sons/daughters with Intellectual Disabilities and Autism Spectrum Disorder as assessed by parents with respect to their perceived level of (high and low) Social Support.

Hypotheses:

- There is a significant difference of the perception of Quality of Life of the parents with variation of the types of conditions (Intellectual Disabilities and Autism Spectrum Disorder) and the levels of conditions (mild and moderate).
- There is a significant difference of the perceived level of Quality of Life of the parents of Adults with Intellectual Disabilities and Autism Spectrum Disorder with variation of Social Support (high and low).

Sample:

The sample of participants for this study consisted exclusively of parents who were caregivers of an adult child with intellectual disability and autism spectrum disorder (Certified by Government of West Bengal), age ranged 18 years to 30 years. The parents consisted of individuals who were a minimum age of 40 years to 55 years and were caregivers of adult children with intellectual disability and autism spectrum disorder. Keeping this in mind here researcher carried out multistage random sampling method.

Inclusion Criteria:

- Parents (mother) who are caregivers of adults (age 18years to 30years) with intellectual/developmental disabilities (I/DD) and autism spectrum disorder.
- Parents (mother) are of age 40 years to 55 years.
- Parents (mother) are residence of Kolkata.
- Graduation is the minimum qualification of the parents (mother).
- Nuclear family.
- Monthly household income between Rs.25,000- 45,000.
- Parents (mother) who give consent and successfully complete the set of questionnaires given.
- Parents (mother) who can speak and read both Bengali and English.

Exclusion Criteria:

- Parents who will not give consent.
- Parents who is already diagnosed with psychiatric illness.
- Parents who belong from West Bengal, but currently residing outside West Bengal will not be included in the sample.

Measures:

- **Demographic Information Schedule:** It was developed to get some basic demographic information about the participant and relevant information related to the control variables matching with inclusion and exclusion criteria. It contains

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information's like age, gender, family income, family type, educational qualification, marital status, type of disability, and physical and mental health.

- **The Interpersonal Support Evaluation List (ISEL-12):** The Interpersonal Support Evaluation List (ISEL) was developed by Cohen and his colleagues (Cohen, Mermelstein, Kamarck, & Hoberman, 1985). It has three dimensions viz, Appraisal support; Belonging support and Tangible support. The Cronbach's Alpha for the present study was 0.813.
- **World Health Organization Quality of Life-Brief version (WHOQOL-BREF):** The World Health Organization Quality of Life- Brief version (WHOQOL-BREF) was used to assess participants' perceived quality of life. It has four dimensions (1) physical health (2) psychological health (3) social relationships and (4) environment. The Cronbach's Alpha for the present study was 0.852.

Procedure

During the collection of data importance was given to follow the ethical guidelines. First, the rapport was established with each participant and proper instructions were given to them, and informed consent were taken from each participant for this study.

At first, demographic information related to control variables was taken. On the basis of the demographic information, the questionnaires were administered on selected participants.

Statistical Analysis

- Standardization – reliability and validity of the scales were done.
- Central Tendencies (Mean, Median), Standard Score, Dispersion (Standard Deviation, Skewness and Kurtosis) to identify the nature of sample and scored distribution of measured variables were done.
- Correlation, and Independent sample t-test and ANOVA were computed for verification of hypotheses and comparison of samples.

Table 1: The Consolidated Psychometric Profile of the Scales with Reliability and Validity Index for the Scales Used:

Scales	No. of Enquiry Areas	Range of Correlational Values/				Reliability		Norms
		Individual Enquiry Area- Individual item score	Individual Item score- Item Total Score	Enquiry Area- Total Score	Inter Enquiry Areas Correlation (d)	Cronbach's Alpha	Spearman Brown	
The Interpersonal Support Evaluation List	1	0.513-0.788	0.275-0.699	0.790-0.932	0.529-0.618	0.813	0.814	M=52.08 SD=14.973
World Health Organization Quality of Life-Brief version	2	0.460-0.828	0.394-0.657	0.584-0.809	0.40-0.541	0.852	0.726	M=114.28 SD=44.204

The Reliability and Validity of all the scales are in accepted range.

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To identify the nature of Quality of Life of parents of adult sons/daughters with Intellectual Disabilities and Autism Spectrum Disorder.

Table 2: Characteristics Features of Quality of Life and its Dimensions of parents for their adult sons/daughters with Intellectual Disabilities and Autism Spectrum Disorder (N=236)

Variables and Dimensions	Mean	Median	Standard Deviation	Skewness	Kurtosis	Value	
						Min	Max
Quality of Life	121.32	97.00	46.238	-.471	-1.519	60	206
Physical Health	25.05	26.00	3.742	-.037	.127	15	34
Psychological	21.80	22.00	3.323	-.602	-.082	12	30
Social Relationships	11.31	12.00	2.016	-1.373	2.381	3	15
Environment	28.94	29.00	3.577	-.799	.955	16	37

The values displayed in the above table is to characterize overall Quality of Life and its dimensions, namely, physical health, psychological, social relationships and environment. From table it is seen that the mean values of Quality of Life, Physical Health, Psychological, Social Relationships and Environment is 121.32, 25.05, 21.80, 11.31 and 28.94 respectively which indicates existence of moderate level of perception of quality of life of parents for their adult sons/daughters with Intellectual Disabilities and Autism Spectrum Disorder. The mean, median and Standard deviation of the scales scores indicate the nature of normal probability distribution with slightly negatively skewed and leptokurtic (<3) in nature.

Table 3: Characteristics Features of Enquiry Areas of Social Support and its Dimensions of parents for their adult sons/daughters with Intellectual Disabilities and Autism Spectrum Disorder (N=236)

Variables and Dimensions	Mean	Median	Skewness	Kurtosis
Social Support	53.71	53.00	-.136	-.810
Aspirational Support	11.78	12.00	-.610	.574
Belonging Support	11.31	11.00	-.410	-.126
Tangible Support	11.03	53.00	-.342	-.126

The values displayed in the above table to characterize Social Support and its dimensions, namely, aspirational support, belonging support and tangible support. From table it is seen that the mean values of social support, aspirational support, belonging support and tangible support is 53.71, 11.78, 11.31, and 11.03 respectively which indicates existence of moderate level of social support of parents for their adult sons/daughters with Intellectual Disabilities and Autism Spectrum Disorder. The mean, median and Standard deviation of the scales scores indicate the nature of normal probability distribution with slightly negatively skewed and leptokurtic (<3) in nature.

Verification and Interpretation of Research Hypotheses

Significant Difference of the perception of the Quality of Life of the parents with variation of types of conditions (Intellectual Disabilities and Autism Spectrum Disorder) and levels of conditions (mild and moderate) for Verification of Hypothesis H₁

The statistical treatment was also done and shown in **Table 4A and 4B**.

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The level (Mild and Moderate) of conditions - Intellectual Disabilities (ID) and Autism Spectrum Disorder (ASD) included in this study is mentioned on their Disability Certificates and the assessments are done by recognised Government hospitals, service centres and National Institutes in Kolkata.

Table 4A: Frequency of the level (Mild and Moderate) and types of the conditions (ID and ASD) under consideration.

Level of Conditions	Types of the conditions of the Adult Children		Total
	Intellectual Disabilities (ID)	Autism Spectrum Disorder-(ASD)	
Mild	59	53	112
Moderate	68	56	124
Total	127	109	236

Table 4B: Result of Two Way ANOVA with variation of types of conditions (Intellectual Disabilities and Autism Spectrum Disorder) and levels of conditions (Mild and Moderate)

Effect		Value	F	Hypothesis df	Error df	Sig.
Disability	Pillai's Trace	.026	3.169 ^b	2.000	236.000	.044
	Wilks' Lambda	.974	3.169^b	2.000	236.000	.064
	Hotelling's Trace	.027	3.169 ^b	2.000	236.000	.074
	Roy's Largest Root	.027	3.169 ^b	2.000	236.000	.044
Severity	Pillai's Trace	.006	.675 ^b	2.000	236.000	.510
	Wilks' Lambda	.994	.675^b	2.000	236.000	.510
	Hotelling's Trace	.006	.675 ^b	2.000	236.000	.510
	Roy's Largest Root	.006	.675 ^b	2.000	236.000	.510
Disability * Severity	Pillai's Trace	.002	.190 ^b	2.000	236.000	.827
	Wilks' Lambda	.998	.190^b	2.000	236.000	.827
	Hotelling's Trace	.002	.190 ^b	2.000	236.000	.827
	Roy's Largest Root	.002	.190 ^b	2.000	236.000	.827

a. Design: Disability + Severity + Disability * Severity

b. Exact statistic

*Level of significance at .05 level. **Level of significance at .01 level.

There is no significant variation of type of condition on the perception of Quality of Life of the parents adult sons/daughters with Intellectual Disabilities and Autism Spectrum Disorder.

There is no significant variation of level of condition on the perception of Quality of Life of the parents adult sons/daughters with Intellectual Disabilities and Autism Spectrum Disorder.

There is no significant variation of Quality of Life of the parents adult sons/daughters with variation of types of conditions (Intellectual Disabilities and Autism Spectrum Disorder) and levels of conditions (mild and moderate).

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Therefore **H₁**: There is a significant difference of the perception of Quality of Life of the parents with variation of types of conditions (Intellectual Disabilities and Autism Spectrum Disorder) and levels of conditions (mild and moderate) is rejected.

To identify the nature of Quality of Life of the parents with Intellectual Disabilities and Autism Spectrum Disorder as assessed by parents with respect to their perceived level of (high and low) Social Support.

(The high level is considered from median value and above)

Table 5A: Independent Sample T-Test Measure for Quality Of Life And Its Dimensions Due To Variation Of The Perception Of Social Support (High And Low) Of The Parents For Their Adult Sons/Daughters With Intellectual Disabilities And Autism Spectrum Disorder.

QoL and its Dimensions	Mean Score and Standard Score of Perception of Quality of Life with		't' Values for Mean difference Between High and Low group	Level of Significance
	High (N=119)	Low (N=117)		
Quality of Life	M= 144.01 SD=43.380	M= 98.05 SD= 36.611	8.896	.000
Physical	M= 25.32 SD=3.804	M=24.78 SD=3.673	1.117	.265
Psychological	M= 22.28 SD=2.876	M= 21.32 SD= 3.675	2.253	.025
Social Relationships	M= 11.29 SD= 1.896	M= 11.34 SD= 2.140	-.189	.850
Environment	M= 29.13 SD=2.971	M= 28.75 SD= 4.111	.828	.409

*Level of significance at .05 level. **Level of significance at .01 level.

There is a significant effect of Social Support for the overall Quality of Life and its dimension viz. Psychological.

To identify the dimensions of social support responsible for the level of perception (high and low) of quality of life of the parents of adult sons/daughters with Intellectual Disabilities and Autism Spectrum Disorder are shown in the following tables:

Table 5B: Independent Sample t-test Measure for Quality of Life and its Dimensions in Relation to the Dimension of Social support - Aspirational Support of the parents for their adult sons/daughters with Intellectual Disabilities and Autism Spectrum Disorder.

Quality of Life and Its Dimensions	't' Values	Level of Significance
Quality of Life	.221	.825
Physical	2.097	.037
Psychological	3.768	.000
Social Relationships	1.788	.075
Environment	5.793	.000

*Level of significance at .05 level. **Level of significance at .01 level.

There is a significant effect of aspirational support on the dimension of quality of life, viz. Physical, Psychological and Social Relationships.

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Table 5C: Independent Sample t-test Measure for Quality of Life and its Dimensions in Relation to the Dimension of Social support - Belonging Support of the parents for their adult sons/daughters with Intellectual Disabilities and Autism Spectrum Disorder.

Quality of Life and Its Dimensions	't' Values	Level of Significance
Quality of Life	-.464	.643
Physical	-1.678	.095
Psychological	2.565	.011
Social Relationships	-.633	.528
Environment	1.025	.307

*Level of significance at .05 level. **Level of significance at .01 level.

There is a significant effect of belonging support on the dimension of quality of life viz. Psychological.

Table 5D: Independent Sample t-test Measure for Quality of Life and its Dimensions in Relation to the Dimension of Social support - Tangible Support of the parents for their adult sons/daughters with Intellectual Disabilities and Autism Spectrum Disorder.

Quality of Life and Its Dimensions	't' Values	Level of Significance
Quality of Life	.460	.646
Physical	.296	.767
Psychological	.248	.804
Social Relationships	-2.920	.004
Environment	1.055	.293

*Level of significance at .05 level. **Level of significance at .01 level.

There is a significant effect of Tangible Support on the dimension of Quality of Life, viz. Social Relationships.

Table 5E: Independent Sample t-test Measure for Quality of Life and its Dimensions in Relation to Social support of the parents for their adult sons/daughters with Intellectual Disabilities and Autism Spectrum Disorder.

Quality of Life and Its Dimensions	't' Values	Level of Significance
Quality of Life	9.169	.000
Physical	1.536	.126
Psychological	2.691	.008
Social Relationships	-.169	.866
Environment	1.152	.250

*Level of significance at .05 level. **Level of significance at .01 level.

There is a significant effect of Social Support on the overall Quality of Life and its dimension, viz. Psychological.

Therefore, **H₂: There is a significant difference of the perceived level of Quality of Life of the parents with Intellectual Disabilities and Autism Spectrum Disorder with variation of Social Support (high and low) is accepted.**

DISCUSSION

The aim of the present study was to explore the effect of social support on the quality of life (QoL) of parents of adult children with intellectual disabilities (ID) and autism spectrum disorder (ASD). The study indicated that there is no significant variation of Quality of Life

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of the parents of adult sons/daughters with variation of types of conditions (Intellectual Disabilities and Autism Spectrum Disorder) and levels of conditions (mild and moderate).

The second hypothesis that there is a significant difference of the perceived level of Quality of Life of the parents of Adults with Intellectual Disabilities and Autism Spectrum Disorder with variation of Social Support (high and low) was accepted. The present study confirmed that social support has an impact on the quality of life of parents of adult children with ID and ASD, which means social support improves the quality of life (Pozo et al. 2014). The study further indicated a significant effect of social support on psychological dimension of quality of life, which means high level of social support is associated with high level of positive feelings and thinking about self and the future, and improves mental health (Raina et al. 2004). Consistent with the prior studies that social support facilitates plan for the future (Horton, 2020). The study further revealed that aspirational support has a significant effect on physical, psychological and environment dimensions of QoL. It means perceived availability of someone to share about one's problem helps to get suggestions to cope with the difficulties. Also, sharing the positive and negative experiences of caregiving provide them the sense of acceptance, respect, care, solidarity, safety and sense of self-worth, which enhance positive quality of life (Yoong and Koritsas, 2012). The study also found that belonging support, i.e. perceived availability of people one can do things with has an impact on psychological dimension with quality of life, which means doing things together provides the sense of concern, empathy, sense of being and acceptance that facilitates the well-being of parents of adult children with ID and ASD (Sharifian and Gruhn, 2018). Tangible support- perceived availability of material aid has a significant effect on social relationship dimension of quality of life. It indicates that tangible support provides the sense of being loved and supported during the time of crisis.

The present study supported the mechanism of the convoy model (Kahn & Antonucci, 1980) which was consistent with the findings that perceived social support improves the subjective well-being of mothers of children with ASD (Benson, 2012).

The findings of the study can be used to develop research informed policy and practices for parents of adult sons/daughters with intellectual disabilities and autism spectrum disorder. Also, Supportive and Collaborative approaches can be created to support Parents of adult sons/daughters with intellectual disabilities and autism spectrum disorder.

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Conflict of Interest

The author(s) declared no conflict of interest.

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