

## Social Support and General Well-being of Caregivers of Children with Neurodevelopmental Disorder

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### ABSTRACT

The present study investigated the relationship between perceived social support and general well-being among caregivers of children with neurodevelopmental disorders, and examined the differences between the gender of the parent (mother or father) on general well-being and perceived social support. The participants (from Mumbai, Delhi, and Bangalore) responded to the scale of general well-being (PGI General Well-being Measure) and perceived social support (Multidimensional Scale of Perceived Social Support) (N=34). The findings suggested that the caregivers perceive high social support from family and significant other than friends. A moderate positive relationship exists between perceived social support and general well-being among caregivers ( $r = .489, p < .005$ ). There is no significant difference found in mother's and father's score on perceived social support and general well-being.

**Keywords:** *Neurodevelopmental Disorders, Caregivers, Perceived Social Support, General Well-being*

*"Life doesn't make any sense without interdependence. We need each other, and the sooner we learn that the better for us all." –Erik Erikson.*

We, humans, need one another and it's common to see people underestimating the benefits and needs of support. Dr. Joseph Pratt, pioneer in group therapy, in his work with patients with tuberculosis showed strong evidence of how powerful and beneficial social support can be on an individual's physical and mental health. Social support (SS), in general, refers to the various ways that people help one another. It is frequently defined as a group of people who one can rely on for emotional or material support in order to manage stress. Perceived social support (PSS) is individual's perception about the availability and adequacy of support they are receiving. It includes both the availability and satisfaction with the support individual have (Sarason, Sarason, & Pierce, 1990). People's perceptions of their social support impact how they see themselves and the world around them. Research suggests that a network of meaningful relationships predicts mortality more accurately than other lifestyle factors like smoking or exercise (Holt-Lunstad et al., 2010). Perceived support is the cognitive component of social support. In contrast,

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received social support can be viewed as the behavioral component of social support, as it requires activation in particular interpersonal transactions (Dunkel-Schetter, 1990).

Literature has shown that both mental and physical health is positively correlated with PSS and social connections. PSS is a valuable protective mechanism that can enhance psychological well-being by maintaining positive emotional feelings and reducing stress. A positive relationship exists between PSS and psychological well-being. Different aspects of PSS can predict various aspects of hedonic well-being, including life satisfaction and positive and negative affects (Cobo-Rendón et al., 2020). Wellbeing is a concept studied in positive psychology. Wellbeing can be physical, economic, social, developmental and active, emotional, psychological, life satisfaction, domain-specific satisfaction, and engaging in activities and work (*Well-Being Concepts*, 2019). It is defined as “a state of happiness and contentment, with low levels of distress, overall good physical and mental health and outlook, or good quality of life” (APA Dictionary of Psychology, 2014).

The focus of this study is narrowed down to General well-being (GWB). Recently, GWB has been defined as "the experience of life going well." (Huppert & So, 2011). It can also be described as the subjective experience of fulfilment, joy, satisfaction with life's experiences and one's place in the workplace, a sense of accomplishment, usefulness, and belongingness, as well as the absence of distress, dissatisfaction, or worry, among other things. GWB have a positive correlation with the quality of life, job satisfaction, the general level of satisfaction, sense of achievement, and so on, and a negative correlation with neuroticism, psychotism, and other such variables. The concept of GWB relates to the harmonious operation of a person's physical and psychological aspects of their personality, resulting in both personal fulfillment and societal benefits. GWB also includes people's cognitive and affective evaluation of their lives (Karatzias, et al., 2006). In the past, resilience has been shown to have a significant positive impact on general wellbeing (Gao et al., 2017). People with high levels of resilience can keep happy, continue to go through difficulties, and achieve success, making life enjoyable and fulfilling. (Ryan & Deci, 2001).

### *Need and Significance*

This study aims to understand PSS, and GWB amongst the parents/caregivers of children with neurodevelopmental disorders (NDD). According to data collected from 4000 families in 6 regions of India, 10–18% of children between the ages of 2-9 had one or more NDD (Sachidananda Kamath, 2015). Based on the Global Burden of Disease study, more than 11 million Indian children under the age of five may have developmental disabilities (Ansari, 2021). NDD are a group of conditions with onset in the developmental period, characterized by deficits that produce impairment of personal, social, academic, or occupational functioning (American Psychiatric Association, 2013). Due to these deficiencies, the child finds themselves in situations where they require ongoing care and attention from family members, institutions of higher learning, and society at large. Both cross-sectional and longitudinal studies have found that the behavioral and emotional issues that children with NDD display are significant stressors for family members (Halstead et al., 2017). Compared to parents of children without specific disabilities, parents of children with special needs face more caregiving challenges, such as more health issues, more feelings of restriction, and higher levels of stress or depression (Heiman, 2002). Most interventions for special needs children focus and evaluate only in terms of child outcomes, and tend to ignore parental and family factors that have an influence on both the immediate and long-term effects of therapy. Even significant improvements in the diagnosed child cannot be assumed

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to increase the already existing parent and family distress, especially given that the time and cost of intervention may cause additional family disruption.

The present study aims to find the relationship between PSS and GWB of caregivers of children with NDD. From the broad number of NDD, study focuses on- Intellectual disability (ID), Autism Spectrum Disorder (ASD), Attention-deficit/hyperactivity disorder (ADHD), and Specific Learning Disability (SLD).

### ***Statement of the problem***

The present study is undertaken to evaluate the relationship between PSS and GWB among caregivers of children who have NDD. In addition, the study sought to identify differences in GWB and PSS in the gender of the parent (mother or father).

### ***Objectives***

- To evaluate perceived social support among caregivers of children with neurodevelopmental disorders.
- To evaluate general well-being among caregivers of children with neurodevelopmental disorders.
- To evaluate if a relationship exists between perceived social support and the general well-being of caregivers of children with neurodevelopmental disorders.
- To determine if there is any difference in social support based on the gender of the parent.
- To determine if there is any difference in general well-being based on the gender of parents.

### ***Hypothesis***

- H<sub>01</sub>: There is no significant relationship between perceived social support and the general well-being of caregivers of children with neurodevelopmental disorders.
- H<sub>02</sub>: There is no significant difference in perceived social support based on the gender of the parent.
- H<sub>03</sub>: There is no significant difference in general well-being based on the gender of the parent.

### ***Sample***

The sample of the present study was collected through purposive sampling. The sample consists of 34 parents/caregivers of children between the ages of 3 to 18 years with NDD. For the quantitative data, responses were collected from the urban cities of India- Mumbai, Delhi, and Bangalore. Caregivers were approached through special schools in these three cities. Data was collected via the pen-paper form for people who were in physical proximity and for those who were distant; an e-form was circulated. The content in both forms were the same.

### ***Tools***

- 1. Multidimensional Scale of Perceived Social Support (MSPSS):** Zimet, Dahlem, Zimet, and Parley (1988) developed the Multidimensional Scale of Perceived Social Support (MSPSS) a self-report measure that subjectively assesses social support adequacy. It consists of 12 items on a 7-point Likert scale, where (1) if Very Strongly Disagree, (2) if Strongly Disagree, (3) if Mildly Disagree, (4) if Neutral, (5)

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if Mildly Agree, (6) if Strongly Agree, and (7) if Very Strongly Agree. The measure also provides scores on three subscales, each subscale comprising four items- family social support subscale, friends' support, and lastly significant other's support. Scores for each of these scales range from 1 to 28, where a higher score expresses higher social support.

- 2. PGI General Well-being Measure:** Santosh K. Verma and Amita Verma (1989) developed the 20 item scale-P.G.I General Well-being scale. It is the Hindi version of the original General Well- being Schedule by Dr. H Dupuy (1970). The subjects are instructed to tick the items that are applicable to them- how they felt in the past one month. The number of ticks is counted and constitute scores are the well-being score of the individual. A score of 0-3 is interpreted as 'poor well being', a score of 4-7 as 'below average well being', a score of 8-12 as 'average well being', a score of 13-16 as 'good well being' and a score of 17-20 as 'very good well being'. It takes around 5-6 minutes to administer and score the scale. The scale has been found to be independent of socioeconomic status and education but has a significant correlation with age.

### *Procedure*

The data for the study was collected from caregivers of children (ages 3-18) with NDD. Responses were collected from the urban cities of India- Mumbai, Delhi, and Bangalore. Caregivers were approached through special schools in these three cities. Data was collected via the pen-paper form for people who were in physical proximity and for those who are distant, an e-form was circulated. The content in both forms is the same. Participants are asked for informed consent, with demographic details along, and responses on MSPSS and PGI GWBM were taken.

The present study investigated the relationship between PSS and GWB among caregivers of children with NDD. The study also examined the differences between the gender of the parent (mother or father) on GWB and PSS. The results include an analysis of responses by 34 parents of children with NDD on the scale of GWB and PSS, which is the Multidimensional Scale of Perceived Social Support (MSPSS), and PGI General Well-being Measure respectively. Participants were from the urban cities of India- Mumbai, Delhi, and Bangalore.

## **ANALYSIS AND INTERPRETATION**

*Table 1 Socio-demographic data of the participants*

Demographic Data	N	%
Gender of the child		
Male	24	70.58
Female	10	29.41
Parents		
Father	16	47.05
Mother	18	52.94
Nature of schooling		
Special school	28	82.35
Not attending	6	17.64

Table 1 shows the demographic data of the participants regarding the gender of the participant, the child, and nature of schooling. The table shows N (total no. of participants)

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and % (percentage) of participants. Participants included parents of children with NDD amongst which, the number of male children was 24 (70.58%), and the number of females was 10(29.41%). The number of fathers participated was 16(47.05%), and mother participant were 18(52.94%). Amongst the children, 28(82.35%) were attending a special school, and 6 (17.64%) were currently not attending but were enrolled in school.

**Table 2 Mean and Standard Deviation of General well-being and Perceived social support**

Variable	N	M	SD	Interpretation
General Well-being	34	13.059	4.741	Above Average
Perceived Social Support	34	55.441	16.969	Average
Significant other subscales	34	19.324	7.301	High
Family subscale	34	19.324	7.586	High
Friends subscale	34	17.100	6.402	Low

Table 2 shows the mean (M) and standard deviation (SD) of GWB and PSS. For GWB, the M is 13.059, interpreted as above average, and the SD of 4.741. For PSS, M is 55.441, which is interpreted as average, and SD of 16.969. The M and SD of the subscale of significant other, family, and friends in PSS are 19.324 and 7.301, 19.324 and 7.586, 17.100 and 6.402 respectively. The findings suggest that the caregivers show above-average GWB, and average PSS. Caregivers received the most support from family and significant other, whereas the least support from their friends. Parents find it difficult to maintain friendships and tend to engage more with their children and family. Similar results were found in the study by Bailey and colleagues (1999), family support was rated highest along with formal support. In contrary, Drogomyretska et al. (2020) found PSS from friends as most significant factor in reducing stress whereas support from significant others and family members seems to have less of an impact on parents of children with ASD. The present studies finding is different from this study, perhaps due to the cultural differences. In India, family is given importance over friends. There is also more support provided by family members and even extended family. In many cases, grandparents are the primary caretaker to the children. In such case, support from family and significant other is valued more by the parents.

According to the normalcy test of Shapiro-Wilk, it was found that the data was not distributed normally. Due to this, nonparametric tests were used for the data analysis.

**Table 3 Relationship between perceived social support and general well-being among caregivers of children who have neurodevelopmental disorders**

Variables	M	SD	1	2
Perceived social support	55.441	16.969	-	.489
General well-being	13.059	4.741	.489	-

\* $p < .05$

Table 3 displays the relationship between PSS and GWB caregivers of children with NDD. The relationship is found to be moderately positive and statistically significant ( $r = .489$ ,  $p < .005$ ). Hence, Hypothesis 1 which says that “There is no significant relationship between perceived social support and the general well-being of caregivers of children with neurodevelopmental disorders” is rejected. In other words, there is a positive relationship between PSS and GWB among caregivers. However, this relationship is found to be

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moderate, perhaps due to the small sample size. This finding is in line with the existing literature. Parents, who appraise the support they receive, score low on the scales of depression, anxiety, and anger (Gray & Holden, 1992). Better quality of life is observed when parents perceive a high level of social support (Kuru & Piyal, 2018). A study by Cantwell et.al (2014) identified stress and mastery as significant predictors of poor physical health in parents who care for children with developmental disabilities, but not social support. They found social support, acting as a moderator of the relationship between stress and physical health, with parents who reported feeling less stressed and had higher levels of social support reporting better physical health. Social support is a multidimensional concept and can be quantitatively best measured through how an individual perceives social support rather than the social support they receive. Also, because it is very difficult to quantify received social support and an important aspect is- how an individual recognizes the support rather than what they get. Parents' perception of support is strongly related to their well-being. Low levels of anxiety and depression may suggest the presence of resilience (Bitsika et al., 2013). Resilience helps in recovering from difficult or stressful situations. Additional to well-being, social support also serves as a protective factor, affecting the link between maternal depression, life satisfaction, positive affect, and child behavioral and emotional problems. A study on parents of children with Tourette's disorder found that parental stress and the severity of the child's symptoms are partially mediated by PSS (Schoeder & Remer, 2007). All these findings make up the understanding that an increase in the perception of social support in parents can bring positive changes in the general well-being, quality of life, mood, anxiety, and stress of parents and can also improve the symptoms of the child consequently.

**Table 4 Difference in perceived social support based on the gender of the parent.**

Gender of the parent	Mother (N=18)		Father (N=16)		Z	U	p
	M	SD	M	SD			
Perceived social support	51.556	16.335	59.813	17.104	-1.021	114.50	.104

\*p<.05

Table 4 shows the results of the Mann-Whitney Test to assess if there is any difference in PSS between mother and father of the child. The mean value and standard deviation of PSS for mothers are 51.55, and 16.33, and for fathers are 59.81, and 17.10 respectively. The "Z" value obtained between the two groups for PSS is -1.021, "U" value of 114.50, which corresponds to the "p" value of .104. The test results show a significance of .104 which is more than .05, we accept Hypothesis 2 which says that "There is no significant difference in perceived social support based on the gender of the parent". Hence, there are no differences in how mothers and fathers of children with NDD perceive the social support they receive.

**Table 5 Difference in General well-being based on the gender of the parent.**

Gender of the parent	Mother (N =18)		Father (N=16)		Z	U	p
	M	SD	M	SD			
General well-being	12.278	5.027	13.938	4.388	-1.019	97.00	.307

\*p<.05

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Table 5 shows the results of the Mann-Whitney Test to assess if there is any difference in GWB of fathers and mothers. The mean value and standard deviation of PSS for mothers are 12.27, and 5.02, and for fathers are 13.93, and 4.38 respectively. The “Z” value obtained between the two groups for GWB is -1.019, “U” value of 97.00, which corresponds to the “p” value of .307. The test results show a significance of .307 which is more than .05, we accept Hypothesis 3 which says that “There is no significant difference in general well-being based on the gender of the parent”. Hence, there are no differences in the GWB of mothers and fathers of children with NDD.

### **Implications**

The study spotted the light on the caregivers and their burden. The findings are essential to increase awareness among caregivers regarding the importance of social support. The study showed a positive relationship between social support and well-being, this understanding can be beneficial for working professionals in planning multidimensional interventions and can be utilized for improving parents’ mental and physical health. The findings are in addition to the existing literature and can be considered in policy-making, or utilized by organizations that deal with special needs.

### **Limitations**

The population of the study was difficult to find, as a result, the sample size is small. Findings cannot be generalized due to the small sample size. Self-report scales were used that have possibility of unreliable data.

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### **Conflict of Interest**

The author(s) declared no conflict of interest.

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