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Exploring the factors affecting psychological well-being among parents of children with autism spectrum disorder

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Abstract

Background: Given the constant stress that parents with kids on the spectrum feel, there appears to be a pressing need for helping these families deal with the hardships and restore their psychological equilibrium.

Objectives: The study aims to explore the correlates and predictors of psychological well-being (PWB) among parents of children with autism spectrum disorder.

Methods: Seventy five parents of children with autism were selected for assessing their PWB, coping mechanisms and perceived levels of social support. Standardised tests were used to assessed these variables. Pearson correlation and stepwise multiple regression analysis were used to unveil the correlates and predictors of PWB.

Results: 96% of respondents were mothers and only 4% were fathers. Pearson correlation analysis revealed that PWB was significantly and positively related to coping strategies of self-distraction, use of emotional support, use of instrumental support, positive reframing, acceptance and religion, as well as with social support from significant other, family and friends. A significantly negative relationship was found with behavioral disengagement and self-blame. Regression analysis further indicated that psychological well-being was most significantly predicted by positive reframing, support from significant other and self-blame among parents.

Conclusion: The present study has implications for health care professionals to view parents of children on the spectrum as beings who also need help with their emotional and psychological well-being, so as to become capable of fulfilling the needs of their impaired child, demands of their family, in addition to being compassionate towards their own self.

Keywords: Autism, psychological well-being, coping, social support

Introduction

The complex neurodevelopmental disorder known as autism has been recognized as a combination of rigid, repetitious behaviors and challenges with language, communication acquisition as well as interactions with others. Because the condition impacts individuals with an array of symptomatology, capabilities and severity of impairment, autism is known as a "spectrum disorder".

The arrival of a child creates a hedonistic environment that affects all members of the family, especially the parents and can lead to a number of modifications in the organization and functioning of the family unit. But as time passes and their child struggles to meet developmental standards, parents who had hoped for a child in good health and happiness experience a period of bereavement and might feel that one of their most significant life objectives has not been achieved.

Children on the spectrum need greater parental involvement, attention, and support owing to their limitations. In India, caregivers are frequently taken for granted because it is customary to expect family members to care for individuals who are intellectually impaired, regardless of the compromises that could be potentially needed ^[1]. After tending to their children, parent's own emotional, physical, and psychological needs are often disregarded ^[2, 3]. Occasionally families retreat because of concerns regarding their child's inappropriate social conduct, humiliation over certain behaviours, or the extreme tiredness that most parents of autistic children feel ^[4].

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Often, as both parents come to terms with having this child in their family, they go through distinct phases of grief. Parents usually agonise over what may happen to their child when they pass away or are unable to take care of them. Parents face numerous challenges, including an extended care burden, a poor prognosis for autism spectrum disorder, its detrimental effect on family members, declining mental and physical wellness among parents, increasing financial difficulties, a dearth of autonomy, judgements and discrimination from the general public towards them along with their children due to the condition's misinterpreted nature, and a severely inadequate amount of interpersonal support received by parents [5-8].

Although there is a wealth of academic research exploring the various aspects of psychological well-being among parents of children with impairments, homogeneous studies involving carers of children with autism spectrum disorder tend to be scarce, with only a few studies uncovered for the Tricity (Chandigarh, Mohali, and Panchkula) region. Given the constant stress faced by parents of children on the spectrum, as well as the adaptations they make, there appears to be an urgent need to aid such families in coping with adversity and preserving their psychological well-being.

In light of the difficulties and problems pertaining to the care and welfare of children with autism, it is imperative that parents of such children navigate their distinct psychological challenges in an efficient manner that upholds their full potential for the good of the entire family.

Hypotheses

In light of prevailing literature, following hypotheses were framed:

H₁: It was expected that PWB and its sub scales will have a significant and positive relationship with coping dimensions of active coping, use of emotional support, use of instrumental support, positive reframing, planning, humor, acceptance and religion, as well as with perceived social support from significant other, family and friends.

H₂: It was expected that PWB and its sub scales will have a significant and negative relationship with coping dimensions of self-distraction, denial, substance use, behavioral disengagement, venting and self-blame.

H₃: It was expected that coping (self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion and self-blame) and perceived social support (support from significant other, support from family and support from friends) would emerge as salient predictors of psychological well-being.

Materials and Methods

The data was collected from 75 parents of children in the age range of 3 to 12 years diagnosed with Autism Spectrum Disorder. The participants were selected from a list of special education schools, hospitals, mental health diagnostic clinics, private service providers located in Tricity region (Chandigarh, Mohali and Panchkula).

Prior permission was taken from the heads of all institutes/clinics approached for the research. Each participant was explained the research objective and thereafter signed an informed consent form indicating their willingness to

make contribution to the research. The participants received assurances that all information pertaining to them or their child would be kept completely confidential. The study participants were approached for data collection at their convenient hours either at their residence or therapy centres. Details concerning their socioeconomic status and demographics was obtained through a precise, closed-ended instrument. The research employed purposive and snowball sampling method. The inclusion criteria entailed parents who were currently not employed and whose children had received the autism spectrum diagnosis for at least an year and also utilising therapeutic interventions from the service centres/ institutes in the Tricity region.

Responses were obtained using standardised scales namely Psychological Well-being Scale [9], Multidimensional Scale of Perceived Social Support [10], and Brief COPE Inventory [11].

Parental well-being was evaluated with the help of 18 item short version of Psychological well-being scale developed by Ryff & Keyes (1995). The items are rated on a seven point scale encompassing six facets of psychological well-being namely self-acceptance, positive relations with others, autonomy, purpose in life, environmental mastery and personal growth. A high score indicates a person's expertise in that particular facet of life

The parents perception of social support was assessed using the Multidimensional Scale of Perceived Social Support (MSPSS). It is a 12 item seven point Likert scale ranging from 1 (Very strongly disagree) to 7 (Very strongly agree). The scale measures support from three sources- social support from significant other, support from family and support from friends. Higher the score, higher the perceived social support experienced by the parent.

The Brief COPE Inventory measures different ways in which people typically react to stressful situations. It comprises of 28 item scale with 2 items in each of the 14 subscales which are active coping, planning, positive reframing, acceptance, humor, religion, use of emotional support, use of instrumental support, self-distraction, denial, venting, substance use, behavioral disengagement and self-blame. It is based on a 4 point Likert scale ranging from 1 (I haven't been doing this at all) to 4 (I have been doing this a lot).

Statistical Analysis

Data was entered and analysed using software Statistical Package for the Social Sciences (SPSS) version 29.0.1.0 (171). Pearson's correlation analyses was used to explore the relationship of psychological well-being with coping and perceived social support with a significance level at $P < 0.05$, $P < 0.01$. On the other hand, stepwise multiple regression analysis were employed to unveil the predictors of psychological well-being among parents.

Results

A total of 75 respondents gave consent to participate in the research study out of which 72 (96%) were mothers and only 3 (4%) were fathers, majority of whom lied in the age range of 30-35 years. The mean age of parents was 35.21 years. Children with autism mean age at the time of diagnosis was found to be 2.94 years. Table 1 shows the demographic characteristics of participants.

Table 1: Demographic characteristics of the participants

Characteristic	N (%)
Gender of the child	
Male	57(76%)
Female	18(24%)
Primary Caregiver	
Mother	72(96%)
Father	3(4%)
Child's current age	
3-6 y	50(66.7%)
6-9 y	16(21.3%)
9-12 y	9(12%)
Child's age at diagnosis	
< 2 y	7(9.3%)
2-2.5 y	15(20%)
2.5-3 y	17(22.7%)
3-3.5 y	16(21.3%)
>3.5 y	20(26.7%)
Parent's age	
25-30 y	4(5.3%)
30-35 y	29(38.7%)
35-40 y	27(36%)
40-45 y	15(20%)
Type of family	
Nuclear	45(60%)
Joint	30(40%)

Correlates of Psychological well-being

Table 2 and table 3 shows the correlates of psychological well-being as well as its subscales.

Psychological well-being has been found to have a significant and positive correlation with self-distraction, use

of emotional support, use of instrumental support, positive reframing, acceptance and religion. Whereas, it had a negative relationship with behavioral disengagement and self-blame. Psychological well-being has been found to have a significantly positive correlation with support from significant other, support from family as well as support from friends

Autonomy had a significant positive relationship with acceptance, support from significant other.

Environmental mastery was found to have a significant positive relationship with positive reframing, acceptance, support from significant other, support from family.

Personal growth had a significant positive relationship with self-distraction, active coping, positive reframing, humor, acceptance, religion, support from significant other. Whereas, it had a significantly inverse relationship with behavioral disengagement.

Positive relations with others had a significant and positive relationship with use of emotional support, use of instrumental support, positive reframing, support from significant other, support from family, support from friends. Whereas, it had a significant negative relationship with behavioral disengagement and self-blame.

Purpose in life was significantly and positively related to active coping, use of emotional support and planning.

Self-acceptance had a significant and positive relationship with positive reframing, support from significant other, support from family, support from friends. On the other hand, self-acceptance was found to have a significant negative relationship with self-blame.

Table 2: Correlation between psychological well-being and its six sub scales with coping.

	Psychological Well-being	Autonomy	Environmental Mastery	Personal Growth	Positive relations with others	Purpose in Life	Self-Acceptance
Self-distraction	0.302**	0.113	0.120	0.258*	0.223	0.134	0.192
Active Coping	0.223	0.178	0.004	0.286*	0.001	0.328**	0.077
Denial	-0.200	-0.098	-0.126	-0.205	-0.064	-0.028	-0.187
Substance Use	-0.023	-0.086	-0.087	-0.105	-0.188	-0.027	-0.098
Use of ES	0.350**	0.125	0.118	0.186	0.350**	0.241*	0.169
Use of IS	0.327**	0.216	0.225	0.175	0.370**	-0.027	0.136
Behavioral Disengagement	-0.251*	-0.205	-0.217	-0.247*	-0.237*	0.155	-0.107
Venting	-0.030	0.022	-0.119	-0.170	-0.106	0.158	-0.145
Positive Reframing	0.528**	0.192	0.360**	0.375**	0.279*	0.132	0.480**
Planning	-0.048	0.031	-0.143	0.060	-0.178	0.289*	-0.125
Humor	0.138	0.090	0.054	0.273*	0.094	-0.034	0.022
Acceptance	0.334**	0.250*	0.244*	0.392**	0.219	0.033	0.069
Religion	0.256*	0.101	0.206	0.230*	0.134	0.207	0.054
Self-blame	-0.296**	-0.128	-0.205	-0.035	-0.356**	-0.083	-0.290*

Correlation is significant at the **0.01 level, *0.05 level. ES: Emotional Support, IS: Instrumental Support

Table 3: Correlation between psychological well-being and its six sub scales with perceived social support.

	Psychological Well-being	Autonomy	Environmental Mastery	Personal Growth	Positive relations with others	Purpose in Life	Self-Acceptance
Support from Significant other	0.482**	0.254*	0.291*	0.249*	0.444**	0.145	0.258*
Support from Family	0.391**	0.047	0.371**	0.053	0.479**	-0.095	0.359**
Support from Friends	0.295*	0.153	0.222	-0.026	0.317**	0.046	0.248*

Correlation is significant at the **0.01 level, *0.05 level

Predictors of Psychological well-being

The regression analysis revealed that positive reframing ($\beta = 0.528$), support from significant other ($\beta = 0.369$) and self-

blame ($\beta = -0.233$) emerged as the most salient predictors of psychological well-being contributing a total of 46% variance in psychological well-being, as shown in Table 4.

Table 4: Stepwise multiple regression equation for criterion variable psychological well-being and all sub-variables of coping and perceived social support as predictors

Independent Variable	Regression Coefficient	β	t	p	Multiple R Square	F	DF	p	R square change	F change	Sig. F change
Positive Reframing	4.316	0.528	5.314	0.001	0.279	28.241	73	0.001	0.279	28.241	0.001
Support from Significant other	0.840	0.369	3.929	0.001	0.406	24.630	72	0.001	0.127	15.435	0.001
Self-blame	-1.516	-0.233	-2.653	0.010	0.460	20.144	71	0.001	0.054	7.039	0.010

Multiple $R^2 = 0.460$, F value = 20.144, DF = (3,71), $p \leq 0.001$

Discussion

Compared to neurotypical children of the same age, autistic children often require extensive care and depend more on caregivers for almost everything. The results clearly show that hypotheses H_1 , H_2 and H_3 have been partially accepted. Studies have indicated that the sacrifices to a parent's life that come with having a kid with autism begin immediately after the child is diagnosed and can include daily difficulties in caring for the child, annoyance with the child's behavior, and even animosity against the child.

Seymour *et al.* (2013) indicated that the intensity of behavior problems faced by caregivers of children with autism spectrum disorder had a substantial impact on both parental weariness and inadequate coping skills [12].

Carer stress has also been linked to unhealthy coping strategies [13], and research has indicated that it is the primary predictor of mental wellness and overall quality of life for parents of autistic children [14].

In India, the evolution from joint to nuclear families, where the parents are mostly in charge of child care, is becoming more and more common. A study by Mohammed *et al.* (2020) found positive relationship of psychological well-being with use of emotional and instrumental support along with acceptance as coping strategies. On the other hand, it had an inverse relationship with self-blame and behavioral disengagement among parents of children with Down syndrome [15]. These results were also consistent with a study done by Barakat and Mohamed (2019) which also indicated that mothers tend to use lesser coping techniques, have enormous stress levels and poor psychological well-being [16].

A positive relationship was also seen between maternal well-being and perceived social support [17, 18], wherein perceived social support and perceived stress contributed 55% variance in well-being of mothers of children with cerebral palsy [19].

Support from significant other plays a pivotal role for parents of children with autism as evident from our regression analysis results. Not only does it enhance psychological well-being of parents but also mitigates child's intensity of behavioral problems and parenting stress [20]. Additionally, it helps in increasing positive affect, optimism and satisfaction with life [21].

In a study by Choudhury and Chandel (2022) mothers expressed their genuine wish for their spouses to lend compassionate ears and provide them with emotional support and recognition [22]. Additionally, perceived social support has been seen to increase parental competence to cope and tolerance for failures and setbacks alongside enhancing their openness to new experiences [23].

Above all, social support tends to help parents reinterpret their situation and their child's diagnosis in a positive light that in turn promotes their overall well-being and growth in the aftermath of a traumatic incident [24]. Positive reframing of the situation aids in regulating emotional repercussions

among parents, being non-judgmental and empathetic, thereby restoring their sense of control and getting away with adverse coping strategies like self-blame which adversely impacts parental psychological well-being.

Implications

This study could serve as a catalyst for enabling parents of children with autism spectrum disorder by employing a holistic parent-professional framework while offering parents with expertise and methods, acknowledging them as experts in the field on their child's behaviour and urging them to assume an active role in the course of their therapy.

By accepting and respecting their pain and grief, allowing families to make the finest use of their recovery time, and bolstering them with the necessary knowledge about autism and associated limitations, assisting professionals can help families of autistic children on their path to adaption.

The study emphasizes how vital it is to normalize support groups' functioning and significance in the society at large. Families with autistic children greatly benefit from the emotional aid and cathartic relief that support groups offer.

This study also underscores the importance of advocating for personal psychotherapy as a crucial element of autism support and care. It offers individuals a supportive and secure setting to explore and control their emotions, learn effective coping mechanisms, and develop resilience.

These implications serve as a road map for health care professionals, policy makers, organisations, and communities seeking to improve the well-being of these families.

Limitations and future suggestions

Future studies can take into account a larger sample size along with comparative analyses on participants belonging to different socio economic strata. Longitudinal studies can be conducted to see changes in use of coping strategies and perceived levels of social support among parents over time. Studies can also explore differences in perceived social support between maternal family and in-laws family. Furthermore, comparisons can be made between mothers and fathers' psychological well-being.

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