

Stress, Psychological Wellbeing, and Coping Styles among Parents of Younger Children and Adolescents with Autism Spectrum Disorder

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ABSTRACT

Comparative studies analyzing the experiences of stress, wellbeing, and coping styles in parents of children with autism across their age group are minimal. The present study aimed at comparing stress, psychological wellbeing, and coping styles in parents of children (3-10 years old) and adolescents (11-18 years old) with autism spectrum disorder (ASD). The study included 49 parents of children with ASD from West Bengal, India. Mixed method was used to fulfill the objectives of the study. Findings revealed that parents of younger children and adolescents did not differ in their experience of stress, however, parents of younger children with autism reported higher stress in their child's core social disability compared to adolescents. Also, parents of adolescents had better psychological wellbeing and used more coping strategies compared to the parents of younger children with autism. Qualitative results showed that child's future concern, however, was the common stressor for parents of both age groups.

Keywords: *Autism, Stress, Coping, Psychological Wellbeing*

Autism Spectrum Disorder (ASD) is primarily characterized by social, communicational, and behavioural impairments (American Psychiatric Association (APA), 2013; Esbensen, Sellzer, Lam, & Bodfish, 2009), including the symptoms of avoiding eye contact, difficulty understanding non-verbal cues, and restricted and repetitive behaviour (APA, 2000; APA, 2013). In the recent past, there has been an increase in the rate of prevalence of autism. It is estimated that 16.9% of the population suffers from autism globally (Elsabbagh et al., 2012) and over 2 million people in India are diagnosed with at least one form of the spectrum (Krishnamurthy, 2008).

Autism does not only affect the child but also the parents raising these children. Previous studies have reported that parents of children with ASD are more vulnerable to stress and have low psychological wellbeing than the parents of typically developing children or parents of children with other developmental disabilities (Costa, Steffgen, & Ferring, 2017;

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Mcstay, Dissanayake, Scheeren, Koot, & Begeer, 2013; Ogston, 2010; Pisula, 2011; Zablotsky, Bradshaw, & Stuart, 2013), which may further increase risk of dysfunctional parenting behavior that might affect both parent and child (Duarte, Bordin, Yazigi, & Monney, 2005). The primary stressors experienced by the families of ASD are identified as, lack of awareness of the disorder, financial pressure to meet the treatment needs, family disharmony, child's behavioural problems, failure to procure social and professional support, social isolation, and child's future concerns.

Pathappillil (2011) studied Indian mothers settled in the United States on their perception of autism. The author reported that mothers were not aware of autism and its symptoms until their children were diagnosed with it. Due to high stigmatization in Indian society, families, especially mothers of children with any form of disability face many social and emotional strains. Further, the mothers added that their child's diagnosis also affected their psychological wellbeing. Other researchers reported similar findings (Bashir, Khurshid, & Qadri, 2014; Velsamy, 2016; Tehee, Honan, & Hevey, 2009).

Perumal, Veeraraghavan, and Lekhra (2014) found that parents of children with autism spectrum disorder show significant impairment in all the four domains of wellbeing i.e., physical, psychological, social, and environmental when compared to the parents of children with a physical disability or typically growing children. It is reported that parents of children with ASD are more prone to anxiety, depression, and other mental health problems, compared to the parents of children with other developmental disabilities (Bashir et al., 2014; Cappe, Wolff, Bobet, & Adrien, 2011; Johnson, Frenn, Feetham, & Simpson, 2011; Neff, & Faso, 2013; Predescu, & Sipos, 2013; Pushpalatha, & Shivakumara, 2016; Zablotsky et al., 2013).

Though parents face many challenges in raising a child with ASD, however, studies have documented that coping strategies play an important role in dealing with these challenges (Benson, 2010; Grey, 2006; Predescu, & Sipos, 2013; Smith, Seltzer, Tager-Flusberg, Greenberg, & Carter, 2008; Zablotsky et al., 2013). Smith and colleagues (2008) have found coping styles helped reduce stress in parents regardless of the child's developmental stage. In the initial stage, the parents may try to enhance their knowledge about the disorder from varied sources such as seeking professional help, browsing the internet, seeking support from family and friends, reaching out to autism support groups, and talking to other parents with a similar situation, and taking structured parenting classes (Mancil, Boyd, & Bedesem, 2009; Sharma, & Sharma, 2016). Others have identified 'me time', 'planning', 'sharing the load', 'knowledge is power', 'lifting the restraints of labels', 'recognizing the joys', and faith in God, as their coping styles (Kuhaneck, Burroughs, Wright, Lemanczyk, & Darragh 2010; Storm, 2012). Studies indicate that parents who reach out for social support, practice emotional regulation, make use of different coping skills, and indulge themselves in more positive thinking reported having a positive daily mood, less stress, and decreased levels of depression. Whereas, parents who adopt blaming, worrying, and withdrawal as coping strategies reported having a negative outlook towards every situation, having higher levels of daily stress, and increased feelings of depression and sadness (Sharma & Sharma, 2016; Tehee et al., 2009).

In sum, past research highlights stress, wellbeing, and coping in parents of individuals with ASD. Unfortunately, the majority of research was conducted with the parents of young children and neglected the experiences of parents of adolescents, especially in the Indian

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context. Therefore, the present study aimed to examine the differences in parental stress, wellbeing, and coping styles among parents of younger children and adolescents with ASD.

METHOD

Sample

The sample consisted of 49 parents (including mother and father) of ASD from West Bengal, India. The study included parents of 25 children with ASD between the age group of 3-10 years and parents of 24 adolescents with ASD between 11-18 years.

Tools

To fulfill the objectives of the study, the following psychological tools were used:

- **Autism Parenting Stress Index (APSI):** APSI is developed by Silva and Schalock (2012) and has three dimensions, i.e., the core social disability (child's ability to communicate, relation with peers and siblings), difficult-to-manage behaviour (temper tantrums, self-injurious behaviours), and physical issues (bowel problems, sleep problem, diet issues). In the present study, the reliability of APSI was 0.70 (Cronbach Alpha).
- **Ways of Coping Questionnaire (WCQ):** WCQ was developed by Lazarus and Folkman (1984) to identify the various coping styles used by an individual in a stressful situation. The Ways of Coping (Revised) is a 66-item and has eight subscales, namely, confrontative coping, distancing, self-controlling, seeking social support, accepting responsibility, escape-avoidance, planful problem-solving, and positive reappraisal. The reliability of WCQ in the present study was 0.70 (Cronbach Alpha).
- **The Ryff Scale of Psychological Well-Being:** To measure wellbeing, the Ryff's scale of psychological wellbeing consisting of 18 questions (short form) developed by Carol Ryff (1995) was used. The questionnaire consisted of a series of statements reflecting the six areas of psychological well-being namely, autonomy, environmental mastery, personal growth, positive relations with others, purpose in life, and self-acceptance. In the present study, Cronbach's alpha was .90.

Qualitative data

A semi-structured interview schedule was constructed to collect data from the parents. The focus was to identify the challenges faced by the parents in raising children with autism, various ways of coping, and their psychological wellbeing. For this purpose, 8 mothers and 4 fathers, from both groups i.e., four mothers and two fathers from childhood, and four mothers and two fathers from adolescence, were interviewed. Questions for the interview were based on the review of related literature. Each interview lasted for about 30-40 minutes and was tape-recorded with their consent.

Inclusion and exclusion criteria

Parents of children with autism falling under the age group of 3-18 years were included but parents of children with ASD along with other comorbid disorders (ADHD or ID) or any other physical disorders were excluded from the study.

Procedure for data collection

Parents of children with ASD were approached through special schools, clinics, and hospitals. The parents were requested to produce their child's disability certificate to verify that the children were diagnosed by the professionals. After receiving the consent, the

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participants were briefed on the intent of the study. The parents filled out the questionnaires along with the demographic details (i.e., gender, age, education, income, language).

Data Analysis

t-test was computed to examine the difference in stress, coping styles, and psychological well-being between parents of younger children and adolescents with ASD using the statistical package for social studies (SPSS) version 23. Qualitative data were analyzed thematically.

RESULTS

Sample Profile

Out of 49 participants, 25 (51.0%) parents of children (3-10 years old) with ASD and 24 (49.0%) parents of adolescents (11-18 years old) with ASD were included.

Stress, Coping Style, and Psychological Wellbeing in Parents of Young Children and Adolescents with ASD

To compare the stress, coping styles, and psychological well-being among parents of young children with ASD and parents of adolescents with ASD, t-test was computed.

Table 1 Mean, SD, and t-test for Stress in Parents of Children with ASD and Adolescents with ASD

Variables	Mean	SD	t-value
<i>Stress</i>			
Young Children	19.60	6.67	1.12ns
Adolescence	17.41	6.85	
<i>Core Social Disability</i>			
Young Children	10.76	3.87	2.21*
Adolescence	8.37	3.65	
<i>Difficult to manage behaviours</i>			
Young Children	4.96	3.65	.71ns
Adolescence	5.70	3.62	
<i>Physical Issues</i>			
Young Children	3.88	2.61	.78ns
Adolescence	3.33	2.21	

*p<.05; **p<.01; ns=not significant

Table 1 showed that there was no significant difference in stress between parents of younger children with ASD and parents of adolescents with ASD ($t=1.12$, $p>.05$). However, the result showed that there was a significant difference in the 'core social disability' dimension of stress scale in parents of younger children and adolescents with ASD ($t=2.21$, $p<.05$). No significant difference was found on the other two dimensions of stress, i.e. difficult to manage behaviours ($t=.71$, $p>.05$) and physical issues ($t=.78$, $p>.05$).

Table 2 Mean, SD, and t-test for Psychological Wellbeing in Parents of Children with ASD and Parents of Adolescents with ASD

Parents of ASD (childhood and adolescence) significantly differed in their psychological wellbeing ($t=2.39$, $p<.05$). In other words, the psychological wellbeing of parents of adolescents with ASD ($M=85.08$, $SD=9.34$) was higher than the parents raising younger children with ASD ($M=79.08$, $SD=8.21$).

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Variables	Mean	SD	t-value
<i>Psychological Wellbeing</i>			
Childhood	79.08	8.21	2.39*
Adolescence	85.08	9.34	
<i>Positive Relations with Others</i>			
Childhood	12.44	3.26	.82ns
Adolescence	13.20	3.27	
<i>Self-Acceptance</i>			
Childhood	12.20	2.12	.42ns
Adolescence	12.45	2.16	
<i>Autonomy</i>			
Childhood	13.72	2.38	2.09*
Adolescence	15.00	1.84	
<i>Self-Growth</i>			
Childhood	13.56	2.59	2.48*
Adolescence	15.41	2.63	
<i>Environmental Mastery</i>			
Childhood	13.32	1.70	2.04*
Adolescence	14.62	2.68	
<i>Purpose in Life</i>			
Childhood	13.84	1.99	.87ns
Adolescence	14.37	2.26	

*p<.05; **p<.01; ns=not significant

Table 2 showed that the parents of children with ASD and parents of adolescents with ASD did not differ significantly on positive relations with others ($t=.82$, $p>.05$), self-acceptance ($t=-.42$, $p>.05$), and purpose in life ($t=-.87$, $p>.05$) dimensions of psychological wellbeing. Whereas it was found that parents of adolescents with ASD had better psychological wellbeing in the areas of autonomy (Mean=15.00, SD=1.84), self-growth (Mean=15.41, SD=2.59) and mastery over the environment (Mean=14.37, SD=2.68) compared to the parents of younger children with ASD (Mean=13.72, SD=2.38, Mean=13.56, SD=2.59 and Mean=13.32, SD=1.70, respectively).

Table 3 Mean, SD, and t-test for Coping Style in Parents of Children with ASD and Parents of Adolescents with ASD

The result showed that the parents of younger children with ASD and parents of adolescents with ASD significantly differed in coping styles. In other words, parents of adolescents with ASD used a greater number of coping styles compared to the parents of children with ASD.

Variables	Mean	SD	t-value
<i>Coping Style</i>			
Children	88.28	16.24	2.88**
Adolescence	95.22	18.10	
<i>Confrontive</i>			
Childhood	8.68	2.82	4.09**
Adolescence	11.95	2.77	
<i>Distancing</i>			
Childhood	7.60	2.64	2.56*
Adolescence	9.37	2.16	

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<i>Self-controlling</i>			
Childhood	11.72	2.37	1.48ns
Adolescence	12.83	2.85	
<i>Seeking social support</i>			
Childhood	10.16	3.42	1.50ns
Adolescence	11.70	3.77	
<i>Accepting Responsibility</i>			
Childhood	4.24	1.61	2.20*
Adolescence	5.25	1.59	
<i>Escape-avoidance</i>			
Childhood	15.24	4.04	1.21ns
Adolescence	16.75	4.64	
<i>Planful Problem Solving</i>			
Childhood	14.92	3.34	2.57*
Adolescence	17.75	4.31	
<i>Positive Reappraisal</i>			
Childhood	15.72	3.82	.97ns
Adolescence	16.830	4.14	

*p<.05; **p<.01; ns=not significant

From the table above, it is understood that parents of children with ASD and parents of adolescents with ASD significantly differed in confrontive coping ($t=4.09$, $p<.01$), distancing ($t=2.56$, $p<.05$), accepting responsibility ($t= 2.20$, $p<.05$) and planful problem solving ($t=2.57$, $p<.05$). In other words, the parents raising adolescents with ASD used more confrontative coping, distancing, accepting responsibility, and planful problem solving compared to parents of younger children with ASD. However, the dimensions self-controlling, ($t= 1.48$, $p>.05$), seeking social support ($t= 1.50$, $p>.05$), escape-avoidance ($t= 1.21$, $p>.05$) and positive reappraisal ($t= .97$, $p>.05$) did not show any significant difference.

Qualitative Analysis

The purpose of collecting data from the interview was to understand in-depth the stressors experienced by the parents of younger children and adolescents with autism in their daily lives and the different coping styles used by these parents to deal with the same. Semi-structured interview schedule allowed parents to express their insight on various issues related to parenting a child with autism. Interview transcripts were coded and then organized into various themes. Direct quotes and narrative descriptions have been used for interpretation of the results. The section is divided into two categories. The first section deals with the stress, wellbeing, and coping in parents of younger children with ASD and the second section discusses the stress, wellbeing, and coping in parents of adolescents with ASD.

The common stressors experienced by the parents of both groups were the child's early symptoms of atypical development, lack of understanding of the disorder, social life, and the child's future concerns. These stressors indicated the low level of psychological wellbeing of parents. However, social support provided by the neighbors, relatives, and special schools were the major coping strategies in dealing with challenges faced by the parents of adolescents with ASD.

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Parents of Younger Children with ASD

Some of the parents reported that they noticed atypical symptoms in their children from the early age of seven months. One of the most common symptoms visible in the early years was the child's inability to communicate (verbal and non-verbal). Parents of both age groups reported that initially, their child developed like any other typically growing. They spoke words such as *mama*, *daddy*, *didi*, but soon it was replaced by complete muteness. Parents further reported that the child would sing, and respond to the sound of the vehicle and TV ads, but would fail to respond when called by their names.

A parent reported:

Initially, my child would sing, but when called by his name, he would not respond. When there is his favorite ad or song on TV, he comes running from the other room but if we ask him anything he does not even look at our face. It seems like he does not hear...

Parents reported that many times they failed to understand the needs and problems faced by the child because of the impairment in communication. The child may simply throw tantrums or engage in self-stimulating behaviours for reasons not apprehended by the parents. A father stated:

Sometimes it happened that he would cry all day... we keep guessing and asking if his stomach was hurting or his tooth was hurting or if he was upset with something, we have to go on making guesses. At times his mother makes the right guess and we can help him and at other times both of us (child and parents) have to bear with it throughout the day and night.

It was found from the interviews that the parents had almost no knowledge about autism until their child was diagnosed with it. Other than a couple of participants, the rest all reported,

I had not heard the term 'autism' before.

Another parent said,

Initially, I could not even pronounce the term correctly. It was so new to us.

Initially, the parents lacked awareness about the disorder and the resources and support system available to them. Parents also reported that because of their child's disorder they could not attend family and social gatherings.

We are experiencing a change in every field. Physical and mental, both kinds of changes. We don't even socialize much. Yes, that's true. And that's the fact! We do not go much outside. Once we went to a relative's house and my son was playing with the other children. And the father of the other kid called my son 'mad'... 'yeh Pagal'. How would we, as parents feel about it?

Another parental stress was related to the child's future. There was a constant fear of what will happen to the child after the parent's death.

A father said,

What will happen to the child when we are not there in this world is my biggest concern. And I am sure it is a concern for all the parents who have special children... Another mother narrated with much sadness and worry, I have no idea... I don't know what to think...I am not keeping well. I get regular headaches, back pain, and stomach pain. If suddenly anything happens to me, what will happen to her? All these things worry me, so before I go, I want to put her somewhere.

Some parents said that they were looking for a place where they can put their child and where the child can learn, grow and also be safe. A mother expressing her concern for her growing autistic girl child reported,

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When she is grown up she cannot come to school. She will be at home and she is completely dependent on me. I have to go to work, who is going to take care of her? I cannot trust anyone, especially when the world is getting worse. Every day we hear about some incident. That's why I look for a place where my daughter will be safe.

The constant fear of a child's future after the parents were reported to be one of the biggest stressors in the life of the parents of children with ASD. It was noted that a parent's fear and concern depended on the child's degree of disorder and their level of dependency. Some of the parents also reported that they were saving some amount which they plan to give to the person who promises to take care of their child after them.

The Internet, on the other hand, seemed to be another important source of information, a coping style that was easily accessible to the parents. Thus, it was a new and most feasible coping method identified in the study. Results showed that the internet was one of the important sources of information that helped in understanding the disorder.

A mother of a four-year-old mentioned,
Doctors told me that he has autism and nothing more. Then I searched on the internet and got to know more about it... I often browse the internet. It helps me know my child better...
The parents of children with ASD were more vulnerable to stress compared to parents of adolescents with ASD. After the recent diagnosis of the child's disorder, the parents were in a state of trauma, and denial and some even blamed themselves for the child's condition. The parents described the long tiring journey of diagnosis and their disappointment to know that there was no proper medication to cure the disorder. It was also observed that parents of younger children with ASD were reluctant to share their situation and were preoccupied with the thoughts of a child's disorder.

Parents of Adolescents with ASD

The parents of adolescents reported both positive and negative responses from their relatives and neighbours. However, for some parents, the societal reaction became the main source of parental stress. There are certain social situations where the parents felt that their child will never be accepted by society.

A mother reported,
Society will not accept, that's a known fact. If we go somewhere alone society will be very accepting, but at the same place if we go with our children, there we get to know the truth. If the child is just sitting, people ask why he is sitting, if he runs, they will comment why is he running around so much. Which school does he go to, which subject does he study, and which class is he studying? So we have to face all these questions...
In the same line, a mother narrated,
Relatives normally say, do this, do that...feed this to the cow, feed that to something... so they don't understand. We have been taking care of him for so long...did we not pray to God before diagnosis? So when most of the relatives do not understand it's very frustrating and I get angry (she paused and reflected).
Thus, at times the standards laid by them added and also exaggerated the stress experienced by the parents of children with ASD.

The poor infrastructural facility was another issue reported by the parents. Giving an example, a mother of an 11-year-old child with autism explains,

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...when we go to malls or any other public places, we face a serious problem with toilet facilities. This is a primary need. It has not happened to me but it just came to my mind that now my child is young and my guard accompanies him to the toilet... when he is in his teens or his adolescence it will not be possible for me to take him to the female toilet nor can I accompany him to the male toilet. There is much talk about inclusion but is society ready to include our children?

She narrated an incident,

Once I faced an issue in Big bazaar. My son is very fond of cold drinks. He saw the Pepsi stall, grabbed a bottle, and moved around...And there I was standing in a long queue. And my child was very restless at that time. Finally, I reached the counter and then something happened to the computer there and then I had to wait for some more time. I was getting furious...there should be a special counter for elderly people as well as for people with special children. Then how can we take our children out when there is no proper support system?

The poor infrastructural setup in most places makes it inconvenient for parents with special children to visit the social forum. This, in turn, makes the child and also the family less social. The inadequacy of the social setting could be the main reason why the special children are not seen in the outside world much, though their population is increasing rapidly. This limitation to the world of children with ASD and also the parents could be a significant stressor in their daily life. These challenges faced by the parents, in turn, affect their psychological wellbeing.

It was found that the child's future was a major concern for the parents of both groups.

A parent responded,

Yes, we are very much worried about his future. We are looking for different workshops...here infrastructure isn't good enough, It's a parental organization where parents take up the initiative and parents themselves are volunteers, but what after this? This is the concern for most of the parents here.

Though the reactions received from society were the main stressor, for some, the family members, relatives, and neighbours were supportive and accepted the child's condition. A mother reported how her neighbours had always supported her,

...Neighbours are very supportive. They all are doctors, and officers so you know they have a different mindsets. my son ran into my senior's house. I felt a little embarrassed, but they were happy and told me that the child was so confident to come inside by himself. They are very supportive. Once my son went missing...normally they do not come out of their apartments but that day they came and searched for him all over the place.

The support from the neighbours boosts the morale of the parents and encourages them to accept their child's condition. Another mother described the support received from the special school,

I got a great deal of help from the school which also helped me deal with my stress. There was a time when my son was 4- 5 years old and somebody called him mad (paagal)... and he went around singing the same. Hearing this I felt shattered. I would cry. Then I would discuss things with the founder of the autism society and she would console me and guide me as to what I should do to help my child. Yes, the school has been helpful in many ways.

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Parents whose children went to special schools reported that they received constant and selfless support from the school. Parents further reported that the school and the parents of other children with special needs were their extended families. They could share the worry, and progress of their child with each other. The parents reported that the bond they shared with the school was stronger than the bond shared with their family members. Further, the school trained and provided them with enough information on the child's condition that helped them deal efficiently with their child.

DISCUSSION

The results indicated that stress did not differ significantly for parents of children and adolescents with ASD. In the study conducted by Lai (2013), the results of an independent sample t-test showed no significant differences in parental stress between the two groups (childhood and adolescents). However, studies have found that there is a decrease in the severity of ASD symptoms as the child grows older (Esbensen et al., 2009; Shattuck et al., 2007), which led to lesser stress and better psychological wellbeing in parents of adolescents compared to the parents of younger children with ASD (Barker, Seltzer, & Greenberg, 2011; Gray, 2002; Smith et al., 2008; Tehee et al., 2009). Some of the themes identified in the present study that caused stress to the parents of children with autism were the child's atypical development, initial and prolonged diagnosis, and social, emotional, and behavioural impairment. Parents reported having experienced greater stress in dealing with younger children with ASD compared to dealing with adolescents with ASD. These qualitative findings were in line with the previous research (DePape, & Lindsay, 2014; Bashir et al., 2014).

Results also showed that parents of younger children with ASD and parents of adolescents with ASD significantly differed on the 'core social disability' dimension of APSI. In other words, parents of children with ASD showed higher stress concerning the child's communication skills and their relationship with siblings and others in comparison to parents of adolescents with ASD. Studies have found that parents' most common concerns are related to communication, followed by concerns over the child's social skills (Chawarska et al., 2007; Dabrowska, & Pisula, 2010; Hess, & Landa, 2012). The above finding is supported by the qualitative results, which state that parents faced a lot of difficulty because of the child's social disability. As reported by the parents, most of the children lacked social orientation, like failure to respond to their names, whereas they would effectively respond to the ads on the television or the sound of the vehicles. Research conducted on infants who were later diagnosed with autism revealed a similar understanding of the symptoms observed at an early age (Osterling, & Dawson, 1994; Osterling, Dawson, & Munson, 2002). Most of the time the parents fail to understand the need and requirements of the child because of their communication impairment. On the other hand, the parents of adolescents reported that their children could follow instructions and communicate their needs which helped in improved communication skills. Empirical evidence has shown that adolescents have significantly fewer impairments in non-verbal communication and social reciprocity in comparison to toddlers (Seltzer, Shattuck, Abbeduto, & Greenberg, 2000; Shattuck et al., 2007; Smith et al., 2008).

The result further indicated that parents had high psychological well-being in personal growth, autonomy, and environmental mastery. Empirical evidence shows that parenting a child with a disability may not always be linked with poor family functioning (Dyson, 1997) or lower levels of physical and psychological well-being (Seltzer et al., 2000). Research

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suggests that parenting a child with a disability may bring several positive psychological changes in the lives of parents (Behr, Murphy, & Summers, 1992; Pakenham, Sofronoff, & Samios, 2004; Scorgie, & Sobsey 2000). According to Naseef (1997), parents may experience several advantages of parenting a child with a disability such as developing an increased capacity for compassion and empathy and learning how to both give and receive help in relationships. Moreover, increased levels of personal growth, improved relations with others, and changes in philosophical or spiritual values are three areas where parents may experience significant positive changes while raising a child with a disability (Scorgie, & Sobsey, 2000). The result is in line with the qualitative findings. As reported by the parents, though the parents went through a lot of challenges in their daily life, they also felt a positive change in themselves. Some parents reported having experienced a positive change in their life in the form of patience and empathy, as they now can understand the feelings of other parents. Rearing a child with a disability has further helped the parents in the overall development of a humane personality with the positive qualities of hope and faith.

However, the result showed that the parents' psychological well-being was low in the areas of self-acceptance, positive relationships with others, and purpose in life. Higgins, Bailey, and Pearce (2005) reported that parents may find themselves inadequate in dealing with the behaviours commonly exhibited by children with ASD (i.e., repetitive behaviour, withdrawal behaviour, and/or misbehaviour) that make social outings for families difficult. The study further described that families with children with ASD had a restricted level of contact with the community because family, friends, and the community did not understand the behavioural characteristics of children with ASD. Sivberg (2002) reported that parents of children with ASD scored higher on coping behaviours of distancing and escape, a behaviour aimed at withdrawal from a stressful situation. The result is supported by the qualitative findings. The parents reported that one of their major concerns was the reaction from society. Parents have mentioned that society will not accept their children. This, in turn, affected the parents' relationship with others. However, the parents reported having received support and acceptance from the neighbours who were educated and had some knowledge of the disorder.

Results showed that parents of adolescents with ASD had better psychological well-being compared to the parents of children with ASD. Additionally, it was found that psychological well-being for parents of adolescents with ASD was high in personal growth and autonomy in comparison to the parents of children with ASD. Longitudinal studies have shown that parental perception of the condition improves as their children with disabilities grow (Bayat, 2007; Trute, Hiebert-Murphy, & Levine, 2007). Kausar, Jevne, and Sobsey (2003) argued that the initial experience of frustration evolves into personal growth and a new meaning in the life of parents. Furthermore, with time and experience, there is an improvement in the parents' coping resources and adaptation skills which, therefore, improve their sense of well-being (Ha, Hong, Seltzer, & Greenberg, 2008). Parental maturation can also have a positive effect on the sense of well-being (Charles, & Piazza, 2009; Jorm et al. 2005). In the present study, the parents of adolescents with ASD reported that the child's condition had improved a lot compared to what it was when the child was first diagnosed with ASD. In the study conducted by Grey (2006) parents reported having lesser emotional disturbances when their child was in the adolescent stage compared to the phase when their child was young. In general, studies have identified that efficient coping strategies help in the better functioning of parents of children with ASD (Gour, & Pandey, 2016; MacMullin, Tint, & Weiss, 2011; Tehee et al., 2009).

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It is found that there is a shift from a problem-focused coping style to an emotion-focused coping style with the development of the child. In particular, it is found that there is a general tendency for young adults to use more problem-focused coping strategies and middle-aged adults to use emotion-focused coping strategies (Grey, 2006; Lazarus, 1996). Vidyasagar and Koshy (2010) found that mothers of children with ASD used more emotion-focused coping compared to the parents of typically growing children. The researchers further added that the mothers raising children with ASD put an effort to add positive meaning to the situation and are more focused on personal growth and religious beliefs (Grey, 2006; Vidyasagar, & Koshy, 2010). However, the results from the present study reported that the most frequently used coping strategies were problem-solving, positive reappraisal, and escape avoidance in both the groups. Meaning that the parents of children and parents of adolescents with ASD have used both coping strategies (problem-focused and emotion-focused) in the process of dealing with their stress. The finding is in line with previous studies (Dardas, 2014; Hastings, & Taunt, 2002; Mancil et al., 2009). It was further found that parents of adolescents with ASD used more coping strategies compared to the parents of younger children with ASD. Previous studies have found that child age has a relation to the usage of coping styles by the parents of children with ASD (Gray, 2006; Hastings et al., 2005; Mandell, & Salzer, 2007; Smith et al., 2008).

ASD as a disorder can be diagnosed at an early age of one to two years. During the initial diagnosis, the parents are mostly in a state of shock and denial. However, with time and situational demands, the parents become aware and also reach out to various support systems. Parents of children with ASD report better psychological wellbeing, mental health, and lesser parenting burden in the later phase of their life and it has often been credited to the development of effective coping strategies (Fitzgerald, Birkbeck, & Matthews, 2002; Gray, 2002; Smith et al., 2008). Hence, the above discussion highlights the possibility for the parents of older children to use greater coping styles and have better psychological wellbeing compared to the parents of younger children with ASD.

Further, from the qualitative investigation, it was found that it was troublesome to take the child to social settings moreover when the infrastructure is not efficient enough to accommodate the child. Such results are found in earlier studies too (Mancil et al., 2009). The child's future concern was one of the major stressors for the parents of children with ASD (DePape, & Lindsay, 2014; Ogston, 2010). Though all the parents have consistent worry about their child's future, the parents of children with moderate autism and parents with girl autistic children seemed to have a greater fear of their child being abused or neglected. The above finding is in line with the research conducted by Gupta and colleagues (2012). Further, it was found in the present study that parents of children with ASD got a lot more information on the disorder from the internet. This finding seemed to be noble and a competent coping strategy that helped the parents feel equipped and well-oriented about their child's disorder.

Limitations and future recommendations

It is worth noting that one of the limitations of this study is the inability of the present data to determine which of these factors – parental stress or coping strategies – is the most important in affecting the changes in parental wellbeing. Research using larger samples would be necessary to ascertain which factor, stress, and coping strategies had the most significant effect on parental wellbeing over time, especially in the Indian context.

CONCLUSION

In conclusion, the results of this study highlight that parental stress, psychological wellbeing, and coping styles vary greatly depending on the developmental level of the child. Parents of younger children with ASD face a greater amount of stress in 'core social disability' in comparison to parents of adolescents with ASD. In addition, the qualitative studies have highlighted stressors like child's initial diagnosis, lack of social support, and, child's future concern which adds to parental stress. Findings show that parents of adolescents with ASD have better psychological wellbeing, especially in areas of autonomy, personal growth, and mastery over the environment than the parents of younger children with ASD. Also, coping strategies specifically positive reappraisal, planful problem-solving, and escape avoidance were used frequently by both groups. These coping strategies enabled the parents to overcome the stressful experiences of raising their child with ASD.

The findings of the study, thus, suggest that providing parents with information and training programmes on access and utilization of available resources may help parents to overcome challenges, improving their ability to cope and effectively reduce stress. Results also show that parents' needs and concerns may be subject to change as their children enter different stages of development. Taking this into consideration, programmes and services should be designed in a user-friendly and parents' appraisal of the efficacy and availability of resources when planning for service provision. Further research specific to the needs of parents of different child age groups would be useful in advising service providers.

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