

Caregiving Experiences and Families of Adults with ASD

A cry of anguish: A qualitative study of caregiving among parents of young adults with Autism Spectrum Disorder

Dr Rahul Ganguly
Senior Lecturer in Special Education-Mathematics School
of Linguistics, Adult and Specialist Education Faculty of
Business, Education, Law and Arts University of
Southern Queensland | Toowoomba, Queensland 4350 |
Australia

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Introduction

Autism Spectrum Disorder is a lifelong complex neurodevelopmental condition that affects, among other things, the way an individual relates to his or her environment and their interaction with other people. For example, individuals with ASD are characterised, in varying degrees, by repetitive behaviours and difficulties in verbal and nonverbal communication and social interaction (American Psychiatric Association [APA], 2013). Further, many individuals with ASD might have additional functional impairments, co-occurring physical and mental health conditions, and challenging behaviour problems (e.g. aggression and self-injury; Fenton et al., 2003; Simonoff et al., 2008). Given the core symptoms of this condition, it is understandable that many parents have reported feeling strained by caregiving.

The prevalence of ASD is reportedly increasing in most nations, including India and Australia. In their recent work, Arora et al. (2018) reported that about 1 in 100 children in India under age 10 has autism, and nearly 1 in 8 has at least one neurodevelopmental condition, which was ten times higher than the 1.3 per cent reported in the India 2011 Census. Studies have indicated that caregivers of individuals with ASD are more likely than caregivers of individuals with other neurodevelopmental disabilities to report higher anxiety levels (Weiss, 2002) and depression (Greenberg, Seltzer, Krauss, Chou, & Hong, 2004). Furthermore, DeGrace, (2004) stated that many families of individuals with ASD had to reassess their life priorities, commitments, and relationships to meet caregiving demands. For example, Buescher et al. (2014) found that many family caregivers had to restructure their work hours while facing high out-of-pocket care costs. Similarly, Schaaf et al. (2011) found that many families chose not to participate in social activities because their child with ASD required ongoing care, further contributing to their sense of social isolation.

Despite these deficit themes, the experience of caring for a loved one with disabilities is not entirely negative. However, few studies have shown that caregivers have reported positive aspects of caregiving, such as finding meaning and joy in the experience (Butcher et al., 2001) and a closer relationship with the care recipient (Duggleby et al., 2009, Navab et al., 2012, Netto et al., 2009, Shim et al., 2012). Furthermore, Shim et al. (2012) reported that caregivers who reported more positive

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aspects tended to demonstrate greater empathy and compassion than those who mainly reported negative or apathetic views of caregiving. Other positive experiences reported by caregivers include a sense of satisfaction in knowing that their loved one is getting excellent care, personal growth and increased meaning and purpose in one's life (Bayat, 2007). Therefore, the experience of caring for individuals with disabilities, including those with ASD, is broad, dynamic, and more often personalised.

Previous studies that have addressed caregiving experience have focused on young children with ASD. With improved life expectancies of young adults with ASD, caregivers of adults with ASD are often 'career' caregivers with extensive experience providing support and adapting to the ups and downs related to extended caregiving. Much research is needed to understand caregiving's impact on families and how they manage the new challenges presented as their son/daughter with ASD grows older.

Significance and Purpose of the Study

Although the prevalence of autism is increasing worldwide, not enough research has been conducted on supporting caregivers of adults with ASD. The extant research has mainly operated from a deficit model examining the negative aspects of care, such as burden, poor physical health, depression, and other psychosocial problems in caregivers. Furthermore, limited research has examined strengths that may aid in long-term caregiving. No studies have been conducted on the relationship between family dynamics and personal strengths in this population—despite the research documenting the importance of family values.

The current study aimed to identify components of resilience theory, namely risk factors, protective factors, and overlapping factors, from the perspectives of caregivers of young adults with ASD. Identifying these factors can help practitioners tailor their interventions to target specific areas so that risk factors can be mitigated and protective factors can be enhanced. Strengthening the factors contributing to resilience will help caregivers maintain their physical and socio-emotional well-being to continue providing quality care to their adult son/daughter with ASD. Specifically, the following two questions guided the study:

1. What is it like to be a caregiver of a young adult with ASD for more than 15 years?

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2. How have they overcome the adverse challenges of caregiving an individual with ASD?

Methods

Design

This study used a qualitative phenomenological approach to gain insight into the experiences of families who have young adults with ASD.

Participants Recruitment

We used purposive sampling to recruit participants directly involved in caring for a young adult with ASD. Recruitment occurred in two ways; firstly, an invitation to participate in the study was sent to the Directors of 12 Vocational Training Centres in West Bengal. Secondly, due to the low response rate, the author contacted the Department of Inclusive Education, Government of West Bengal, to recruit participants. Finally, participants were recruited from a Vocational Training Center for Students with Autism and Intellectual Disabilities in regional West Bengal.

Instrument Development

A semi-structured interview schedule was used to elicit information on the caregiving experiences of participants having a young adult with ASD. The interview included questions that focused on different areas, such as demographic information, the initial reaction to the diagnosis of ASD, and experiences of caring for an adult with ASD. Other topics included: what formal support services were used and what was missing, caring for own physical health and emotional well-being, social support structures and recommendations for new caregivers.

Data Analysis

There qualitative data in the current study answered two research questions: “What is it like to be a caregiver of an adult with ASD for two decades?” and “How have they managed to overcome the adverse challenges associated with caregiving an individual with ASD for more than 20 years?” This study adopted a phenomenological framework, reporting the participants’ experiences, meanings, and realities. All audio recordings were transcribed verbatim by an experienced transcriber.

Results

Study Participants

The selected demographic characteristics of participants are presented in Table 1. A total of 15 participants participated in this study. Of those 15 participants, 14 were mothers of young adults with ASD. The remaining 1 participant was the father of a young adult with ASD.

Table 1. Participants Demographics

Caregiver Participant				Young Adult with ASD		
Participants (M)other F(ather)	Parental Age (M)other F(ather)	Religion	Marital Status	Gender	Age	Age at diagnosis
P1 - M	49	Hindu	Married	Male	23	6
P2-M	45	Hindu	Married	Male	16	5
P3-M	54	Hindu	Married	Male	18	4.5
P4-M	49	Hindu	Married	Male	21	3
P5-F	58	Hindu	Widowed	Female	19	6
P6-M	65	Hindu	Married	Male	42	8
P7-M	64	Hindu	Married	Male	36	4
P8-M	63	Hindu	Married	Male	24	7
P9-M	59	Hindu	Married	Male	22	8
P10-M	58	Hindu	Married	Male	20	2
P11-M	50	Hindu	Married	Male	18	5
P12-M	49	Hindu	Married	Male	17	4
P13-M	59	Hindu	Married	Male	16	6
P14-M	56	Hindu	Married	Male	18	4
P15-M	49	Hindu	Married	Male	19	3

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Thematic Analysis of Caregiving Experiences

Analysis of the interview data yielded five significant themes that best captured the experience of caregiving a young adult with ASD (see Table 2).

Table 2. Major Themes and Subthemes

Major Themes	Subthemes
Emotional Roller-Coaster	Depression and Sense of Hopelessness Exhaustion Fear of Future Relative Appreciation and Acceptance
Feeling Alone	Isolation Lack of support from the community and extended family
Ignoring one's health	Poor physical health
Coping with difficult situations	Spiritual beliefs and prayer Support from spouse
Discovering strengths	Acceptance Inner strength

Theme 1: Emotional Roller Coaster. When asked about the overall impact of caregiving their son/daughter on their lives, the theme of emotional impacts most frequently and strongly emerged. In caregiving, participants reported going through many emotions, such as guilt, resentment, anger, worry, loneliness, grief, and defensiveness. The intensity of these emotions varied across specific points in time, such as initial diagnosis and admission to school and post-school.

Depression and Sense of Hopelessness. The most intense emotions were observed when participants discussed the initial diagnosis of ASD. All the participants reacted to the initial diagnoses with anxiety, depression, hopelessness, and frustration. Ten participants shed tears when discussing their feelings on their initial diagnosis, daily struggles, and thoughts about their son/daughter's future.

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One mother described how she felt heartbroken and disassociated when she learned of her son's diagnosis.

"I gave birth to an able-bodied child; he was diagnosed at four. ... I was heartbroken when my son became disabled because he is our only child." P6

Exhaustion. During the early years of caregiving, participants reported a sense of exhaustion, fear, doubt, and powerlessness in managing day-to-day activities. Further, the caregiving tasks became complicated as the participants' parents stayed with them. As one of the participants remarked:

"I am doing all the activities I think I have no option I have to do all these things. Definitely to caring of Riki for such a long some changes occur within me. Now sometimes I become angry, sometimes I feel though I know such type of feeling shouldn't come. I feel my husband's elder brother does not take any responsibilities, but I have such a child. Still, my husband and I have to take all the responsibilities as my father-in-law and mother-in-law stay with us." P7

Fear of the future. All participants were fearful of a future for their young adults with ASD. All the participants felt uncertain about the quality of life of their young adults with

Relative Appreciation and Acceptance. During the later period of caregiving, 12 participants described feeling grateful, appreciative, and even 'lucky' about aspects of daily life that might typically be taken for granted. For example, participant 4 remarked

"...in the earlier days, it was hard to see the positives, but as time went on you could see, you can reflect and go 'oh wow'...he just went to the toilet and I did not have to stand there, that is great!"

Theme 2: Feeling Alone. Participants in this sample felt anguished as they had very little social support. Some described how they became isolated over time. A majority of the participants reported they had few remaining social ties since their child's diagnosis. The reasons for social isolation included a lack of time to spend socially, an inability to bring children to social gatherings due to behavioural concerns, and a fear of judgment or stigmatisation. Many participants' social networks included other parents of students with ASD.

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“A lot of the few close friends that I still have now are parents of other children.

Participants recalled family attitudes and actions towards their family that made them feel vulnerable and isolated. The following narratives by participant 6 and participant 8 illustrate the societal isolation experiences:

“Due to this child, I broke up with all my relations. I had a good relationship with paternal family, such as my Aunt, and uncle. However, after this child, they thought it could be their burden in the future.” P6

Theme 3: Ignoring one’s own health needs

Many participants had significant physical and mental health challenges in this study, including bone and joint conditions, depression, and anxiety. However, a critical finding was that participants often put the health of their young adult with a disability before their own and were examples of delaying hip replacement surgery (P2), unreported chest pain (P6, P8), high blood pressure (P1, P6, P7, P9, P13, P16), thyroid (P3, P5, P7) and mental health problems (P4, P7, P8, P2 and P6). As stated by participant 6 and participant 11, a critical reason for delaying health care needs was the unavailability of care when the participants needed medical intervention.

“I went to Vellore to consult a heart specialist, he told me that there is a mild blockage and told me to do angioplasty and get admitted for two days, but Riki’s father cannot solely take care of him for two days, so two years gone, now I take medicine of local doctor but cannot do the operation.” P6

Theme 4: Coping with difficulties of caregiving

Participants discussed the different methods of coping with caregiving challenges. These included referring to God as a source of strength, as participant 6 stated. Further, participants also spoke about “no options available” or “getting used to it” as a process through which they adjusted. Lastly, participants reported support from their spouses to help cope with challenging situations and provide meaning to their lives.

Prayer and strength from God. All the participants emphasised their spiritual beliefs’ role in coping with caregiving challenges. These beliefs made them interpret why this child was born in their family and prayed to God for strength. Participant 4 stated, *“I pray a lot and believe in God”*.

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Similarly, Participant 6 remarked that her spiritual beliefs gave her the strength to be a good mother.

Support from Spouse. For most participants, assistance from a spouse was a critical coping factor. Except for one participant, others considered spousal support as crucial for caregiving.

Participant 15 recounted how her husband volunteered to take their son with autism to school. *“And my husband also supported me a lot. He said that as many days as possible, he would take him to the school.”* However, participant 13 remarked, *“Husband cannot get any mark, because only my parent, especially my father, helped me a lot in his childhood. He was on his own and even spoiled my elder son. Because of this child, I broke up with all my relations.”*

Theme 5: Discovering Personal Strengths

In this study, participants indicated that they were developing resilience in their changing roles as advocates, educators, and therapists for their children or children with ASD. *“Initially, I did not know anything about autism. I have studied a diploma course, and now I help other parents who have children with autism.” P9.*

The increased sense of personal strength seemed to also translate to other areas of life, with many participants describing themselves as psychologically healthy and having a positive frame of mind.

Figure 1 summarises the challenges of long-term caregiving of adults with ASD, as reported by the participants.

Discussion

The study provides firsthand accounts of the overall impacts families experience while caring for a child with autism for over two decades. The caregivers, predominantly mothers, provided evidence of many emotional and family challenges associated with having a young adult with ASD. Similar to other studies, mothers of children with ASD, who are generally the primary caretaker, undertake an unequal share of the associated responsibility and burden of providing care for the child with ASD.

Figure 1: Experiences in Mid-life Caregiving among parents of young adults with ASD.



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