

## Research Article

### Family Burdens of Caring for a Child with an Autism Spectrum Disorder

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#### Abstract

Autism Spectrum Disorder (ASD) is a group of complex disorders that affect neurodevelopment, behaviors, and physical health. Caring for individuals with ASD could be emotionally and physically taxing. While understanding of ASD as a disorder and its impact on individuals with ASD has gained momentum, the awareness of the burden on families who care for these individuals is less established. This study evaluates these burdens based on a validated questionnaire. Sixteen parents or caregivers were interviewed on their day-to-day physical, emotional, social, cognitive functioning, communication, worry, and daily activity problems. Data on the child's age, race, gender, level of functioning, comorbidities, family's socioeconomic status, parental marital status, and secondary family members' involvement and support were also collected. This case serial study demonstrated high family burdens in all aspects of functioning in the majority of families participated, especially in those with low levels of functioning, medical or behavioral comorbidity, and familial discourse. Sources of burden were discussed. The investigators hope to provide a basis for further extended studies on family burdens in ASD and other developmental disorders.

**Keywords:** Autism; Emotional Burnout; Family Burden; Social Isolation

#### Introduction

Autism Spectrum Disorders (ASD) are neurodevelopmental disorders with a prevalence of 1 in 59 [1]. In addition to their core symptoms of impairments in social interaction, language and communication, repetitive behaviors and restricted interests, individuals with ASD may also suffer from many medical and psychiatric comorbidities [2]. While the effects of ASD on individuals have been extensively studied, the impact which the disorder has on caretakers of these individuals in day-to-day life has not been systematically investigated. Although support systems are usually available for individuals with ASD, such as early intervention programs, special needs programs in schools, and community-wide organizations such as Autism Speaks, resources for parental or caregiver relief are less ready. One study found consistent stress profiles in mothers of children with autism [3]. The

study used a questionnaire to examine mothers of autistic children of different ages and different functioning levels, and mothers were consistently stressed regarding dependency, cognitive impairment, limits on family opportunity, and life-span care. It is generally acknowledged that having a child with developmental disorders presents unique challenges to the family's well-being.

This study aims to explore the effects of ASD on family dynamics, physical and mental health, and social functioning. This study used parental interviews with questions from the PedsQL™ Family Impact Module [4] questionnaire. The questions pertain to problems with physical, emotional, social, or cognitive functioning, communication, worry, daily activities, and family relationships. It is a validated instrument for measuring parent self-reported health-related quality of life and family functioning [4]. We also assessed the impact of other factors such as the child's age, child's physical health, health insurance status, ethnicity, socioeconomic status, medical history of child, additional treatment expenses that are not reimbursable by health insurances, parental job status,

current marital status, and number of caregivers to the child. These questions were modeled from a prior study of family burdens in ADHD [5]. If trends can be discovered among the quality of life of parents of children with ASD, perhaps stress can be reduced with treatment programs. Additionally, this information may lead to more research on the impact of parental stress on the clinical management and care of children with ASD.

## Subjects and Methods

The subjects of this study are caregivers of children with a known diagnosis of ASD according to DSM-V. All of the children with ASD were established patients of the pediatric neurology practice and recruited during their clinic visits between June 1 through July 31, 2019. The study was offered to caregivers of ASD during this time period, and 16 sets of caregivers agreed with the interview. The caregivers were interviewed by a trained research assistant (BW or MY), supervised by the principal investigator (XM). Demographic data including age, gender, ethnicity, health insurance, level of functioning, ASD diagnosis, and comorbidities were collected from electronic health records. Primary caregivers are the person(s) who care for the child on a day-to-day basis,

including mother, grandmother, father, grandfather, or other family members. Four of the sixteen families had two caregivers present at the time of interview and both were interviewed; there was little disagreement in answers among two caregivers in all four sets of caregivers. The examples of the questions are as follows:

In terms of caring for your child with ASD, “Which of the following do you have problems with: being frustrated, anxious, sad, helpless, or hopeless?” “Do you feel isolated from others, have trouble getting support from others, hard to find time for social activities, or do not have enough energy for social activities?” “Do you feel that others do not understand your family’s situation?” “Is it hard for you to talk about your child’s health with others?” “Do you worry about how others will react to your child’s condition?” “Do you have difficulty making decisions together as a family?” “Is there stress or tension between family members?” “Do you spend out of pocket expenses for medical treatment for your child?” “What would you have done differently in hindsight?” “How has autism impact you as a person?” The answers were collated and input into a spreadsheet anonymously, the data were synthesized and shown in (Table 1). This study was approved by the Institutional Review Board of our university.

Subjects	Child's Age (Yrs)	Child's Gender Race, SES <sup>1</sup>	ASD Dx	Level of Functioning <sup>2</sup>	Comorbidity <sup>3</sup>	# of 1 <sup>st</sup> caregivers and employment <sup>4</sup>	2 <sup>nd</sup> caregivers <sup>5</sup>	Emotional Burnout <sup>6</sup>	Familial Discourse <sup>7</sup>	Social Isolation <sup>8</sup>	Additional Medical Expenses <sup>9</sup>
1	10	M, W, 1	Autistic	Low, nonverbal, fully dependent	SZ, insomnia, AI	2, PI (Mom) U (grandma)	yes	severe	Yes	Severe	Yes
2	8	M, B, 1	Autistic	High, mainstream class with support	AI, ADHD	1, PI, Single mom	No	Mild	No	Mild	No
3	20	F, B, 1	Autistic	High	SZ, Bipolar, AI	1, U, Single mom	No	Severe	Yes	Moderate	No
4	7	M, H, 1	Autistic	Low	SZ, AI, hearing impairment	2, F (dad), U (mom), married	No	Severe	No	Moderate	No
5	9	M, H, 1	Autistic	High	None	1, P, (Single mother)	Yes	Mild	Yes	Mild	No
6	12	M, B, 1	Asperger	High	ADHD	2, U, (grandparents), married	No	Mild	No	Mild	Yes
7	19	F, B, 2	Autistic	Low	Epilepsy, Insomnia, AI	1, F (mom), Divorced	Yes	Severe	Yes	Severe	Yes
8	9	M, H, 1	Autistic	High	OCD	2, F (dad), U (mom), married	No	Mild	No	Mild	No
9	20	M, H, 1	Autistic	Low	AI	1, U (mom), divorced	No	Moderate	Yes	Severe	No
10	4	M, W, 2	Autistic	Low	Insomnia, ADHD	2, F (both parents)	Yes	Moderate	No	Moderate	No

11	2	M, H, 1	Autistic	Low	AI	2, F (dad), U (mom), married	Yes	Mild	No	Mild	No
12	19	M, H, 1	Autistic	Low	Epilepsy, AI, OCD	2, U (dad), F (mom)	Yes	Moderate	No	Mild	No
13	4	M, O, 2	Asperger	High	ADHD	1, P (mom), divorced	No	Moderate	Yes	Moderate	Yes
14	9	M, B, 2	Autistic	Low	GI, AI, ADHD, Insomnia	2, F (mom and dad), married	No	Severe	No	Severe	Yes
15	18	M, B, 2	Autistic	Low	None	2, F (mom and dad), parents divorced	Yes	Mild	Yes	No	Yes
16	9	F, B, 1	Autistic	Low	Epilepsy, AI	1, P (mom and dad), parents separated	No	Severe	Yes	Severe	No

**Table legend:**

1. Gender: Male (M), Race: White (W), Black (B), Hispanic (H), Other (O): Asian, Arabic etc. Social economic status as measured by whether the family is qualified for a Medicaid insurance. 1: Medicaid qualified or charity; 2: Commercial insurance
2. Level of functioning: high functioning is operationally defined as verbal, able to self-care of activity of daily life, within two grades of age appropriate academic achievements; low functioning is defined of those do not fulfill the criteria for high functioning.
3. Comorbid disorders: in addition to core diagnosis of ASD, the child has a medical or psychiatric comorbidity. SZ: epilepsy or a seizure disorder; Insomnia: sleep onset or maintenance disorder; GI: chronic constipation or dysmotility, or other GI dysfunction; AI: aggression and irritability; ADHD: attention deficit hyperactivity disorders; OCD: obsessive compulsive disorder.
4. Number # of primary caregivers: primary caregivers are defined as providers who care for the child on daily basis. Primary care-givers employment status: Full time (F), Part time (P), Part time intermittent: (PI), Unemployed: (U).
5. Secondary caregivers: family members or friends who cared for the child when 1<sup>st</sup> caregivers are not available or in need of respites.
6. Emotional burnout that arises from caring of the child: Severe: a caregiver reports hopeless, helpless, or feeling depressed; Moderate: a caregiver reports angry, frustrated or sad; Mild: a caregiver reports anxious
7. Familial Discourse: affirmative if a parent departed or parents separated in association with caring for the child
8. Social Isolation: Severe: caregivers do not socialize with others outside family or work due to child's behaviors, diagnosis, lack of time; Moderate: caregivers are reluctant to socialize, having received little support from others; Mild: caregivers limit social activities only to major activities such as church and holidays
9. Additional Medical Expenses: additional expenses associated with medical care of a child with ASD that are not reimbursable by health insurance.

**Table 1:** Cases of ASD and their family burdens.

## Results and Discussion

We interviewed caregivers of children with ASD aged 2 to 20 years, of whom 13 were boys, and 3 were girls. Gender skew is reflective of this male dominant disorder. One child the father was the only one being interviewed, four families had both caregivers present and were interviewed; the rest of the families were either the single mother or only the mother was available for interview. More than two-thirds of the families qualified for Medicaid, and there was a mix of different ethnicities, representatives of the local community. A majority of the families cared for a low functioning ASD child as shown on (Table 1).

The following observations were made.

1. Emotional burnouts were more likely reported in families with low functioning ASD and comorbidities.
2. Social isolation tended to coexist with families that reported significant emotional burnouts.
3. Families with more than one caregiver experienced less emotional burnout and social isolation.

4. Families who had higher Socioeconomic Status (SES) tended to spend more money on medical treatments that were not inclusive in health insurance policy.
5. There was no pattern regarding the age of the child on emotional burnout, social isolation, or familial discourse.
6. Families with an aggressive and irritable child tended to experience more social isolation and emotional burnout.
7. Comorbid medical and/or behavioral disorders were common in these 16 individuals with ASD.

Most families reported burdens, and about half of them reported familial discourse associated with caring for their child. Nine of the 16 families reported being ridiculed, misjudged for child abuse, or inappropriately submissive by the general public, thus limiting their child from attending to social events or places such as churches, supermarkets, restaurants, or public transportation, suggesting the inclusiveness of families with ASD in the general public remains to be improved.

The following example excerpts were abstracted for specific illustrations.

“My son had a meltdown at the restaurant, and a fellow customer was angry and told me that ‘he needs a good butt whipping’”; “A passerby called 911 to report child abuse when I tried to restrain my son from darting into traffics”; “I switched jobs around because of my frequent absences due to caring for him.” There were also positive messages offered by many of the families. “Our love grew stronger over time because of our love and care for him together”; “I am a better person, more understanding and patient with people in general”; “Autism has made us appreciate life more”; “My son inspires me to move on and forward”; “I think of the needs of others more than mine, since God gave me a child with autism.”

Some families have messages for families caring for a child with autism. “Acknowledge your child’s diagnosis and start treatment without delay”; “Setbacks are not the reason to give up”.

The data presented provide insight into the significant impact of raising a child with ASD has on families. This may be helpful in the medical setting for doctors to provide support to their patients’ parents and for the general public to be more accepting of families with ASD. In addition, the findings can be used to advocate for better resources for individuals and families with ASD to improve the quality of life of these parents and families. Furthermore, the findings may lead to new research strategies to minimize the burdens that contribute to family and parental stress. An extended research comparing family burdens of ASD, attention deficit hyperactivity disorder, and controls will be planned.

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