



Prevalence of Anxiety and Stress in Mothers of Children with Autism Spectrum Disorder (ASD): A Review of Literature

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Abstract

Objective: Mothers of children with autism spectrum disorder (ASD) are likely to develop and experience stress and anxiety due to the overwhelming amount of new information, research on their child's needs, and coping with everyday hardships. **Method:** This systematic review analyzed seven recent research articles related to the anxiety and stress in mothers raising children with ASD. Studies were limited to a focus on maternal mental health experiences raising a child with ASD. **Findings:** All studies examined show a sample of mothers that have anxiety while raising children with ASD. Researchers employed different methodologies in measuring these mothers' anxiety at either one or two points in time. Strengths and weaknesses of each study were reviewed. Some studies even reported a direct effect concerning the way mothers interact with others and their children as a result of their mental health state. Limitations in most of the studies reviewed showed a smaller sample size than originally intended. **Conclusion:** While there are many studies that focus on children with ASD, there is a lack of research on the mental health state of their parents, specifically mothers. These parents take on the role of being a provider, advocate, and channel between their children and a world that is rarely accessible to them. Research in this area can greatly benefit new mothers experiencing this, and all parents that may have an unhealthy mental state when dealing with the responsibility and work it takes raising a child with a disability.

Keywords: Anxiety; Autism; Disabled child; Maternal mental health.

1. Introduction

1.1. Introduction into Autism

It is common, now more than ever, to have come across an individual that shows a different way of communication or exhibits difficulty receiving sensory stimuli. Society tends to find these individuals *different* and *atypical*, when in all actuality these individuals are trying to navigate a world accustomed to one way of thinking. Lai *et al.* (2015) uses the American Psychiatric Association (2013) definition of autism as, "Autism spectrum disorder (ASD) is a neurodevelopmental disorder defined by deficits in communication and social interaction, and the engagement in restricted and repetitive patterns of behaviors" (p. 258).

1.2. What This Can Mean for Mothers of Children with Autism

When raising a child who has been diagnosed with ASD, many mothers do not know how to handle the situation and are bombarded by newfound child-rearing questions. What does this mean for my child? Will he/she need therapy for the rest of their life? What does this mean for schooling, interaction, and quality of life? It is not surprising to see the levels of anxiety and stress rise in mothers raising children with ASD. While no mother and child combination are the same, very often these mothers share the same experiences of feeling lost and confused as to where to begin. If there is such a prevalence in autism diagnoses, where is the aid available for their primary caretakers? These questions can lead a mother into overwhelming stress and anxiety that can ultimately transfer over into the way they interact with others.

This review will cover the prevalence of anxiety and stress of mothers raising children with ASD. By analyzing the following reviews, more attention can be brought to the number of mothers in need of proper mental health assistance.

1.3. Terms and Definitions

As Galvan and Galvan (2017), suggested, defining variables allow readers to understand terms that may have multiple or broad definitions throughout selected articles. Common terms used throughout this article are defined in Table 1. Lai *et al.* (2015), were the only authors, in these selections, to define the term, *autism*. The author derived

his definition from the American Psychiatric Association (2013) Diagnostic and Statistical Manual of Mental Disorders and states clearly what autism is and the characteristics people with autism can demonstrate. The DSM-IV-TR is a common term throughout these selections as it is a standardized tool that many psychologists and clinicians use to diagnose autism. Iida *et al.* (2018) uses DSM-IV-TR when explaining validity of diagnoses for the children involved in his study. The terms anxiety, applied behavior analysis, and coping are defined clearly in their respective references and citations. Each definition is included for the purpose of clarifying variables that are talked about throughout the review.

Table-1. Terms and Definitions Related to Autism and Anxiety

Term	Definitions
anxiety	“Anxiety, characterized by fearful emotion, worried thoughts and physiological symptoms such as muscle tension” (Neil <i>et al.</i> , 2019).
applied behavior analysis	“An application of behavioral principles to help children with ASD learn new skills (e.g., language, joint attention, play skills) and reduce disruptive behaviors” (Agazzi <i>et al.</i> , 2017).
autism	“Autism spectrum disorder (ASD) is a neurodevelopmental disorder defined by deficits in communication and social interaction, and the engagement in restricted and repetitive patterns of behaviors (American Psychiatric Association, 2013)” (Lai <i>et al.</i> , 2015).
coping	“A process an individual engages in to cope with a negative event” (Ekas <i>et al.</i> , 2019).
DSM-IV-TR	“The Diagnostic and Statistical Manual of Mental Disorders” (Iida <i>et al.</i> , 2018).

2. Methodology

When searching for articles, major descriptors included anxiety, mothers, autism, and stress. All chosen articles for review had the requirement of these four aspects. The database that was used in locating these articles, WorldCat, had the filters “last 5 years,” “peer-reviewed,” “TAMIU Killam Library access,” and “article format” to narrow down thousands of possible results. Boolean operators, such as NOT and AND, also allowed for a narrower search as it excluded topics of articles that were not relevant to literature being discovered. Descriptors such as *mental health resources* and *United States* helped in the search of relevant articles but did not make the final cut into a requirement for these articles. In order to find an article on more narrative based results, the author added the descriptor “qualitative” to search terms, successfully finding 4 articles to be considered for review. This search included the search term “disability” along with expanding the time frame search to include “last ten years”, to further expand search results. For the purpose of this review, articles containing both parent’s (mother and father) experiences were excluded to solely focus on the maternal point of view. A strict requirement for relevant articles was the focus on mothers with children, excluding mothers of teenagers or adults. Children require more attention and guidance than older people usually do. Relevant studies included those that entailed a closer look at the measurement of anxiety and stress in mothers raising a child with autism. Articles that spoke on anxiety and stress that may have caused autism in a child were also excluded. Galvan and Galvan (2017) state, “include explicit references to the specific aspects of a study that relate to your topic” (p. 61). It was through these guidelines that articles were chosen as documented in the search results in Table 2.

Table-2. Audit Trail of Database Searches

Database	Dates Reviewed	Search Terms	Sources Located	Relevant Sources
WorldCat	January 2016- January 2020	“autism” AND “mothers” AND “anxiety” AND “United States” NOT “parents”	59	1
WorldCat	January 2016- January 2020	“autism” AND “mothers” AND “anxiety” AND “quantitative”	150	0
WorldCat	January 2016- January 2020	“autism” AND “mothers” AND “mental health resources” AND “anxiety”	145	3
WorldCat	January 2016- January 2020	“anxiety” AND “autism” AND “mothers” AND “stress” NOT “parents”	90	2
WorldCat	January 2016- January 2020	“mental health resources” AND “autism” AND	125	5

		“mothers” AND “United States”		
WorldCat	January 2010- January 2015	“qualitative” AND “disability” AND “mothers” AND “mental health” NOT “parents”	125	7

3. Analysis

3.1. Overview of Analysis

Methodology details of each article including participants, methods, and findings are listed in Table 3 and 4. It is important to note that five out of the seven articles discussed are based on quantitative studies. Results for a qualitative study along with a mixed method study are detailed in Table 4. Other information such as measurements of depression, or findings related to other goals in these studies, were not included as the focus is on the measurement of stress and anxiety present in these mothers.

Bourke-Taylor *et al.* (2010) and Bourke-Taylor *et al.* (2012) both used a mixed methodology. Bourke-Taylor *et al.* (2010) used a qualitative method for obtaining results that consisted of in-depth interviews and narratives. Major points include the smaller participation pool, the methods of recording narrative data, and findings included in direct quotes. A detailed table listing these points, including a direct quote from one participant, is found in Table 4.

Bourke-Taylor *et al.* (2012) is a comprehensive study that briefly covered what is already known on the topic of the mental health of mothers of children with a disability and highlights what the study at hand would add. This study consisted of a mixed methodology report involving interviews along with a scored self-screening survey of mental health completed by participants.

Table-3. Detailed Methodology and Findings for Quantitative Literature Reviewed

Authors and Publication Year	Participants	Detailed Methodology	Findings
Agazzi <i>et al.</i> (2017)	3 parent-child dyads. Children: Ages 3-7, one female and 2 males, required autism diagnoses. Parents: Mothers required to be English speaking, have transportation, and have insurance/funds for treatment.	“Single-case design, each dyad completed 2 baseline assessments, followed by weekly 1-hour PCIT treatment sessions” (p. 288). “Generalized Anxiety Disorder 7-item (GAD-7; Spitzer, Kroenke, Williams, & Lowe, 2006): The GAD-7 is a 7-item brief measure of anxiety symptoms. It assesses how often respondents were bothered by each symptom (e.g., feeling nervous, trouble relaxing) during the last 2 weeks” (p. 291). This research took place to find how treating disruptive behavior in children with autism could affect their mother’s anxiety, depression, and stress.	“Two of the three mothers reported reductions in anxiety (Participant A did not endorse anxiety at baseline)” (p. 298).
Ekas <i>et al.</i> (2019)	73 mothers “of a child with ASD under the age of 18 and self-identifying as Christian in an initial screening” (p. 4549).	“The State Anxiety subscale of the State-Trait Anxiety Inventory for Adults (STAI) which consists of 20 items, was completed by participants to evaluate current anxiety symptoms (Spielberger et al., 1970)” (p. 4551).	“Mothers with more positive perceptions also reported lower levels of anxiety symptoms” (p. 4552). “Higher levels of spirituality were associated with mothers’ reporting more positive contributions of their child with ASD which were, in turn, associated with lower levels of anxiety symptoms” (p. 4554).
Iida <i>et al.</i> (2018)	30 mothers of children with ASD (4-7 years old).	The State-Trait Anxiety Inventory (STAI) “purports to measure one’s conscious	Parent Training showed a decrease in mothers’ trait anxiety.

		awareness at two extreme states of anxiety affect: labeled state anxiety (A-state) and trait anxiety (A-trait)” (p. 3358). Researchers distributed this test before the parental training and after. Results were used to show relationship and change in score between pre- and post-parental training program.	
Lai <i>et al.</i> (2015)	136 parents (80.9% mothers); 54% had child with ASD, 46% had child with no ASD diagnoses.	Depression Anxiety Stress Scales (DASS-21; Lovibond & Lovibond, 1995) “The DASS-21 is a self-report screening tool, which measures frequency of behaviors or intensity of feelings based on three subscales of anxiety (DASS-A), depression (DASS-D) and stress (DASS-S)” (p. 2584). Researchers used this tool “to measure the status of psychological well-being of parents in the current study” (p. 2584).	“Parent-reported anxiety symptoms are insufficiently salient at this point in time to observe significant differences between parent comparison groups” (p. 2590).
Neil <i>et al.</i> (2019)	Subsample: 17 mothers of autistic children, 15 mothers of typical children.	Beck Anxiety Inventory (BAI; Beck et al.,1988): Parent Self-Report. “In their session, parents were administered the parent-report and self-report versions of the Ambiguous Scenarios Interview” (p. 1040).	“Strong association between mothers’ own anxiety and their reports of children’s anxiety and coping in the autistic group” (p. 1043). “The association between mothers’ anxiety and their accounts of their children’s ‘traditional’ anxiety might be moderated by the severity of children’s autistic symptoms, or children’s qualitatively different anxiety symptom” (p. 1043).

Table-4. Detailed Methodology and Findings for Qualitative in Mixed-Methods Literature Reviewed

Authors and Publication Year	Participants	Detailed Methodology	Findings
Bourke-Taylor <i>et al.</i> (2010)	“The intensity sample consisted of [8] Australian mothers of school-aged children with a disability, who were willing to share their stories” (p. 128).	Qualitative Report “Following informed consent, individual interviews were conducted lasting 1–2 hours using in-depth interviewing” (p. 129). Researchers transcribed interviews via unnamed professional service and were also sent back to participants before analyzing to ensure accuracy.	“Mothers offered firsthand accounts of their mental health concerns, such as depression and anxiety (see next section), and other accounts of excessive emotional distress” (p. 131). “Maternal anxiety was described as immobilising, creating an overwhelmed household that could ‘exacerbate behaviour problems’ exhibited by children” (p. 133). “The family had to accommodate Peter [the child with a disability], saying ‘Peter’s needs impact on everything that we do everyday.’ Phillipa [the mother] felt overwhelmed

			and distressed by David’s unhappiness” (p. 133).
Bourke-Taylor <i>et al.</i> (2012)	Sample consisted of 152 mothers of school-aged children with developmental disabilities. “The majority of mothers lived with the child’s father (84%); had more than a secondary school qualification (56%); and had been diagnosed with a mental health condition that required ongoing medical management” (p. 155).	Mixed Methodology “An initial qualitative study (Study 1) involved interviews and design of instruments. A quantitative study (Study 2) used a mail-out survey to measure the situation of a larger group of mothers and evaluate instruments” (p. 154). Researchers used SF-36v2 that measures eight domain scores including physical functioning, role physical body pain, vitality, general health, social function, role emotional and mental health.	“Significantly higher subjective stress has also been reported by mothers of children with other conditions such as ASD” (p. 154). “A brief scale that measures a mother’s report of challenging behaviours exhibited by her child that are associated with compromised mental health and care giving ability was also developed during this research” (pp. 155, 157). “Although depression has been identified as a risk factor for care givers in general, few studies have investigated the actual rates or the causes” (p. 154).

3.2. Strengths and Weaknesses

With every point an author does make, there is most likely an area they neglected to study, or a part of a population they could not include. Strengths and weaknesses of each study are listed in Table 5. According to Galvan and Galvan (2017), it is essential for a reviewer to bring forth strengths they have found in the article to increase validity, and weaknesses to show studies’ limitations and areas that need further research. These two categories were based on the methodology and results of each article to analyze the procedures taken and parts of literature that lacked either clarity or required more explanation.

Table-5. Strengths and Weaknesses within Literature

Authors and Publication Year	Strengths	Weaknesses
Agazzi <i>et al.</i> (2017)	By distributing tests that are specific to each variable being considered (i.e. stress and anxiety), it formed a very detailed analysis to better inform their reader and add onto findings. Researchers also used a very extensive screening process to ensure eligible participants and valid conclusions.	The participants were “in a small sample of White, middle-class children and their mothers who were referred for treatment and had private health insurance to cover the costs of treatment” (p. 299). Definition and elaboration for major terms such as <i>anxiety</i> and its traits would be beneficial to readers.
Bourke-Taylor <i>et al.</i> (2010)	Categorized interview responses into common themes. Themes, such as “Issues for Mothers” and “Effects Autism diagnoses had on mothers” guide the readers through an overview of how each interview is connected.	Also, for a qualitative study, the researchers failed to describe the team analysis and collaboration to discuss results/interview findings. Discussion on how team members each contributed to analysis would be beneficial to readers.
Bourke-Taylor <i>et al.</i> (2012)	Clearly identified what this field of study lacks and highlighted the importance of mental health in a caregiver. Mixed methodology promotes mothers investigating their own mental health as a caregiver and allows researchers to gain perspective.	Study failed to incorporate direct quotes from interviews held. Selection of participants was made on a self-selection basis and a “recruit a friend” (p. 154) recruitment process which may have opened the possibility of bias. In future studies, a different method of recruitment along with verification of mental health diagnosis for each participant would be beneficial.
Ekas <i>et al.</i> (2019)	Included an extensive look into past-related studies that give some sort of contribution into their current study. This	Study limited to Christian denominations. Expanding sample size to other religions would give results

	allows readers to gain background knowledge on the subject to better understand the study and its purpose. Researchers provided a detailed demographics table and outlined results of each tested variable score. This shows important and notable information that will eventually contribute into conclusion and discussion.	more diversity.
Iida et al. (2018)	Provided a detailed description of each psychological test that was distributed to participants and why it will directly benefit the results after study is over. Researchers also provided a schedule of when exactly each part of their procedure would take place.	“Because there was no control group, it was impossible to determine whether the observed changes between pre- and post-PT [Parent Training] were specific to PT effectiveness” (p. 3361).
Lai et al. (2015)	Comprehensive demographic information was combined into a table that would later provide readers with a correlation to each variable. Variables which included gender, ethnicity, occupation, and so on are accounted and used later to show correlation in results.	Sample was limited to parents of children with ASD that sought out help from NBC Autism Services at IMH Singapore. The authors could benefit from a nation-wide sample to evaluate a widespread sample.
Neil et al. (2019)	Terms clearly defined. Researchers assigned quantitative scores to measurements that used qualitative evaluation. This is done to better summarize findings later in the article.	“Cross-sectional data did not allow researchers to find what is driving the association between parental anxiety and their children’s anxiety” (p. 1043).

4. Findings/Discussion

4.1. Summary of Findings

Studies show a prevalence of anxiety in almost all qualified participants. Anxiety measurements were recorded either once or twice within these studies to show presence or change in levels. Higher anxiety levels were shown in mothers who have children with ASD compared to mothers who have typically developing children. While 3 of the 5 quantitative studies reviewed focused on the measurement of anxiety in mothers without any type of added experiment, [Iida et al. \(2018\)](#) and [Agazzi et al. \(2017\)](#), measured their participants’ stress level at two points in time. This was before and after an experiment or application of service was applied to participants. For example, [Iida et al. \(2018\)](#) reported a significant decrease in anxiety once their participants underwent parent training.

In the qualitative study, [Bourke-Taylor et al. \(2010\)](#) collected narrative data on mothers’ experiences in raising a child with ASD. According to [Galvan and Galvan \(2017\)](#), it is important for researchers to provide demographics and sufficient detail to allow readers to make inferences on the adequacy of the sample. [Bourke-Taylor et al. \(2010\)](#) included details such as mothers’ work type and status, and professionals’ years of experience and vocation (p. 129). By listing out details on each participant according to name or label, readers received a more comprehensive description about which one they were reading.

[Bourke-Taylor et al. \(2012\)](#) reported that mothers found their mental health being a barrier to providing adequate care to their children. According to data collected, mothers of a child with a disability, such as autism, had poorer mental health. Bourke-Taylor writes, “Carers who have additional mental health needs require additional supports and services if they are to continue to adequately meet the requirements of their role as a primary carer to their child with a disability and care for themselves” (p. 158).

5. Implications/Conclusions

5.1. Suggestions

Future studies can benefit from expanding participant pools across a broader range of people. This can include expanding to mothers nationwide or using less restrictive qualifications for participation. For example, because [Lai et al. \(2015\)](#) included a sample that was not selected at random and had a low number of participants, differences that were shared were not as significant and may have only been relevant to the participants that attended the health clinic where they were initially contacted.

Studies that clearly listed and defined key terms, methodologies, and findings throughout the article were easier to comprehend and read than those that did not. Clarity is important as readers must be able to fully comprehend each section being discussed. For example, [Bourke-Taylor et al. \(2010\)](#) did fail to grant readers a more in-depth investigation into the analysis of data collected. While interviews were discussed in detail, there was a lack of professional explanation as to how data would be then transcribed and analyzed within the next part of the larger quantitative study.

5.2. Concluding Statements

Raising a child is not an easy task, especially when that child is diagnosed with a disability that requires more attentiveness, planning, and education. Countless new responsibilities are taken on by the child's caregiver. Often, it is the maternal figure in the family who takes on the new and difficult stress that comes with uncertainty. There is a presence of anxiety and the difficulty of having a constant barrier between yourself and the world. With today's technology, more and more children are being diagnosed with intellectual, developmental, and learning disabilities. Parents of these children are in need of more resources to fully cope, manage, and care for their children along with the emotional stressors that they will inevitably experience. Educators, health care professionals, and advocates can all help in this effort by educating themselves on the multitude of responsibilities and aspects of raising a child with autism.

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