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Parents’ Immediate Reaction and Responses to their Child’s ASD Diagnosis: A Synthesis Review

Réaction et réponses immédiates des parents suite au diagnostic de TSA chez leur enfant : une revue de synthèse

Author Information

Abdinasir Ali*,[1]
Marghalara Rashid*,[2]
Andrea Davila-Cervantes [3]
Liz Dennett [4]
Sandra Thompson-Hodgetts [5]
Helly Goez [6]

** These authors contributed equally to this work*

[1]Faculty of Science, University of Alberta, Edmonton, AB, Canada
[2]Department of Paediatrics, University of Alberta, Edmonton, AB, Canada
[3]Office of Lifelong Learning, Faculty of Medicine & Dentistry, University of Alberta, Edmonton, AB, Canada
[4]Scott Health Sciences Library, University of Alberta, Canada
[5]Faculty of Rehabilitation Medicine, University of Alberta, Edmonton, Alberta, Canada
[6]Department of Pediatrics, University of Ottawa, Canada

Correspondence:

marghala@ualberta.ca

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Abstract

The number of children diagnosed with autism spectrum disorder (ASD) has been increasing. The majority of literature is focused on treatments and interventions to assist children and families. There has been no knowledge of parents' immediate responses to diagnoses of autism. The aim of the review was to explore what existing research suggests about parental reaction and response during the diagnostic process and immediate coping approaches after the diagnosis of autism. A search was conducted in eight electronic databases and a total of 60 studies met inclusion criteria.

Four main themes and six sub-themes were constructed through a rigorous and reflexive process of analysis. The main themes were:

1) Parental emotional reaction and response towards child's ASD diagnosis,

2) Subjective experience of parents in the process of obtaining a diagnosis,

3) Importance of support immediately post diagnosis, and

4) Stigma associated with the diagnosis of autism.

Résumé

Le nombre d'enfants recevant un diagnostic de trouble du spectre de l’autisme (TSA) est en augmentation. La majorité des écrits scientifiques se concentrent sur les traitements et les interventions pour soutenir les enfants et les familles. Il n'y a pas eu de regard sur les réactions immédiates des parents à la suite du diagnostic d'autisme. L'objectif de cette revue des écrits était d'explorer ce que la recherche existante suggère à propos de la réaction et des réponses des parents pendant le processus diagnostique ainsi que les stratégies d'adaptation suivant immédiatement un diagnostic d'autisme. La recherche a été effectuée dans huit bases de données électroniques. Au total, 60 études répondaient aux critères d'inclusion. Quatre thèmes principaux et six sous-thèmes ont été identifiés par un processus d'analyse rigoureux et réflexif. Les thèmes principaux étaient :

1) Réaction émotionnelle parentale et réponse au diagnostic de TSA de l'enfant,

2) Expérience subjective des parents au cours du processus d'obtention d'un diagnostic,

3) Importance du soutien immédiatement après le diagnostic, et

4) Stigmatisation du diagnostic d'autisme.

Mots-clés : Autisme, revue de synthèse, réactions, parents, réponses

Introduction

Autism spectrum disorder (ASD; hereafter autism) is a lifelong, neurodevelopmental condition, which is diagnosed based on persistent and pervasive deficits in social communication and social interaction (APA, 2013). The estimated prevalence of autism[1] in children has been steadily increasing in recent decades and is currently estimated at 1 in 50 in Canada and 1 in 44 in the US (Maenner et al., 2021). There is great variability in the autistic clinical phenotype (Toal et al., 2010). This variability may partially be explained by a wide range of genes that contribute to its susceptibility. Common co-occurring conditions include attention problems, impulsivity, sensory and behavioural dysregulation, mental disorders, feeding and sleeping difficulties, intellectual impairment, and epilepsy among other health conditions (Faras et al., 2010; Taylor et al., 2013). Autism occurs across all racial, ethnic, and socioeconomic groups (CDC, 2019). The increasing prevalence of autism over time and the heterogeneity of adaptive behaviour can create significant challenges for parents and families.

Parents of autistic children may face challenges that impact their family and overall quality of life, and they may be required to make adjustments to daily life (Neupane, 2020). Existing literature shows that parents' reactions to their child's diagnosis may include emotions such as anger, guilt, relief and/or denial (Patrick-Ott & Ladd, 2010). Parenting an autistic child is often associated with higher parental stress compared to parenting a child without any known disability, or another disability (Hayes & Watson, 2013). Parents of autistic children may feel lost and unprepared initially (DesChamps et al., 2020) However, receiving an autism diagnosis can lead to positive outcomes such as decreased parent guilt and self-blame especially when health providers promote positive reactions of caregivers and prevent confusion by increasing warmth, respect, and clarity (Anderberg & South, 2021).

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[1] We use identity first language to align with the preferences of the autistic and autism communities (Kenny et al., 2016)

Research has shown a clear positive impact of early interventions on the reduction of stress in families with autistic children (Schertz et al., 2018). Further, studies have shown that health professionals' perceptions of parental reactions will influence the advice and recommendations they provide to the parents (Anderberg & South, 2021). The purpose of this knowledge synthesis is to compile and summarize existing knowledge about parents' immediate responses to their child's autism diagnosis. More specifically, we explore what exists in the current literature about parental reactions and responses, as well as their approaches to coping, immediately after they receive their child's autism diagnosis.

Methods

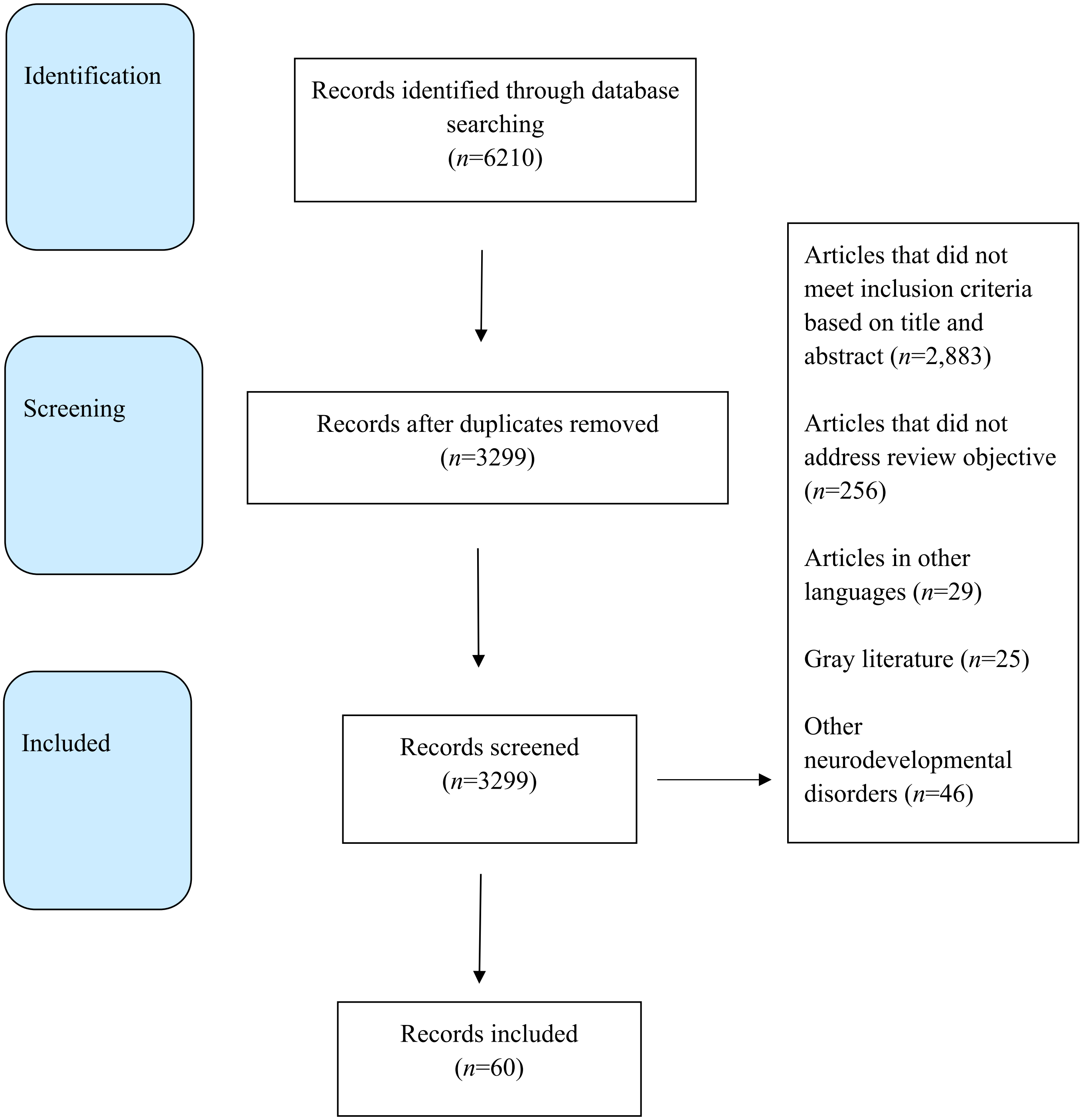
Search Strategy

A health sciences librarian conducted searches in Medline (Includes In-Process & Other Non-Indexed Citations as well as Medline Daily), Embase (Ovid interface), PsycINFO (Ovid interface), Scopus, CINAHL Plus with Full Text (Ebscohost interface), ERIC (Ebscohost interface), Child Development & Adolescent Studies (BSCOhost interface) and SocINDEX (Ebscohost interface) on March 29, 2019. We updated our search on May 12, 2021, for the years 2019-2021. The new search in 2021 resulted in 600 new articles of which 100 were duplicates and only five articles met our inclusion criteria (Figure 1). Our search was restricted to the English language; no date or publication type limits were applied. At its core, the search combined four concepts: 1) parents, 2) experiences related to parenting their child, 3) diagnosed with, and 4) a developmental disability. (We initially searched for all developmental disabilities and later decided to synthesize the articles related to autism in a separate review). The search was challenging because all four concepts were present in many articles that explored both parent and child experiences throughout their journey with autism, but we were interested in only the time immediately after diagnosis. To be as specific to our topic as possible while still being appropriately sensitive, the following strategies were used.

In Medline, we used three different methods to combine the first three concepts to be both sensitive and specific.

1. Parent keywords in close proximity to both experiential keywords and diagnosis keywords in the title/abstract/keywords.
2. Parent keywords in close proximity to experiential keywords AND any developmental disability subject heading with the di (diagnosis) subheading attached.
3. (Only used for studies with no abstracts) Parent subject headings with px (psychology) attached AND any developmental disability subject heading with the di (diagnosis) subheading attached.

Figure1. PRISMA 2009 Flow Diagram



From: Moher D, Liberati A, Tetzlaff J, Altman DG, The PRISMA Group (2009). *P*referred *R*eporting *I*tems for *S*ystematic Reviews and *M*eta-*A*nalyses: The PRISMA Statement. PLoS Med 6(6): e1000097. doi:10.1371/journal.pmed1000097

For more information, visit www.prisma-statement.org

We then combined each of these strategies with a list of keywords and subject headings for developmental disabilities as well as a "relevancy forcing" title line to ensure that one of the following words was in the title: diagnos* or caregiver* or guardian* or parent* or mother* or father* or moms or dads or maternal or paternal or family or families or familial or "my child" or "your child" or "our child". Over 200 excluded articles were reviewed to ensure we were not missing anything useful with our "relevancy forcer". The search was translated to the other databases and was modified to be optimized for each database. Databases without appropriate indexing (Scopus, ERIC, Child Development & Adolescent Studies, and SocINDEX only used method #1 to combine the first three concepts. The complete search strategy is available as per the author's request.

Inclusion/exclusion of studies

This review focused on parents' immediate reactions or responses to their child's autism diagnosis. We included all studies that met the following inclusion criteria: (1) a focus on parental and caregivers' reactions and/or responses to their child's autism diagnosis, (2) publications in English, (3) peer-reviewed literature, and (4) no restriction on the study design. Exclusion criteria were: (1) the primary language was not English, (2) grey literature, including personal websites and blogs, (3) diagnosis of other developmental disabilities (DD) that are not autism; and (4) studies that focused on autistic adults. Two reviewers screened articles retrieved from the search. The articles were screened by both reviewers based on the title and abstract, and any screening discrepancies were addressed at this stage. In the second stage of our extraction, the full texts of all the potentially relevant articles were retrieved for review for further screening. Articles were grouped into three categories: include, exclude, or unsure. Both reviewers met to review the full texts for the 'unsure articles' with a unanimous final decision to either include or exclude each article.

Data extraction and analysis

Data were extracted from all the included articles. We extracted information related to the study's publication (e.g., year of publication, country), general study characteristics, participant characteristics, study methods and findings. Two reviewers extracted data and checked the entries to make sure that the content was accurate. Extraction discrepancies were resolved by consensus upon review of the original articles. In the case of unclear or unreported information in the original studies, primary authors were contacted. A qualitative thematic analysis was done by three team members based on Braun and Clarke's (2006) six phases of data interpretation, which are cyclical in nature: (1) familiarizing oneself with the data, (2) generating initial codes of the included literature, (3) searching for themes, (4) reviewing themes as a team, (5) defining and naming themes as a group, and (6) producing the report. Themes were conceptualized as patterns of shared meaning with a central organizing concept (Braun & Clarke, 2019). The thematic analysis required us to conduct multiple levels of reading of each paper to better understand the content of the included papers. Initial coding was done from which redundant outcomes and patterns were generated and synthesised into themes over four meetings. After the initial coding stage, we met as a team to discuss themes (Cook, 2012).

Results

Characteristics of the included studies

The online electronic database search generated a total of three thousand two hundred ninety-nine articles after removing the duplicates, two thousand eight hundred eighty-three of which did not meet our inclusion criteria based on the title and abstract. Four hundred sixteen articles were selected for a full review with sixty studies meeting our inclusion criteria (Figure 1). As shown in Table 1, the majority of the studies were conducted in the United States (*n*=24) and the United Kingdom (*n*=11). However, we have included studies from various countries such as Canada, Israel, Ireland, Switzerland, Japan, Malaysia, Taiwan, Australia, South Africa, Sweden, China, Korea, and Iran. Most of the studies were qualitative and mixed methods in design. The included studies were published between 1998 and 2021.

Four main themes and six sub-themes were constructed through a rigorous and reflexive process of analysis.

Theme 1: Parental emotional reaction and response about their child's autism diagnosis

This theme focused on parental negative and positive emotions and reactions following their child's autism diagnosis. Obtaining an autism diagnosis can be an emotionally overwhelming experience for parents.

Sub-theme 1 – Negative emotions and reactions associated with an autism diagnosis

The shock was a common first parental reaction to the diagnosis, documented in more than one-third of the included studies (Abbott et al., 2013; Alvarado-Heredia, 2017; Braiden et al., 2010; Craig, 2015; Fleischmann, 2004; Fowler & Karen, 2021; Huang et al., 2012; Hutton et al., 2005; McCabe, 2008; McConkey & Kelly, 2012; McCutcheon, 2019; Mulligan et al., 2012; Navot et al., 2016; Rabba et al., 2019; Rabbitte et al., 2017; Russell et al., 2012; Roberts et al., 2017; Samadi et al., 2012; Tait et al., 2015; Wayment & Brookshire, 2017, Wong et al., 2016). In 17 of the publications, it was reported that parents experienced a brief period of denial immediately following brief period of denial upon learning of the autism diagnosis as they struggled with acceptance of the diagnosis (Russell & Norwich, 2012; Alvarado-Heredia, 2017; Chamak et al., 2013; Frye et al., 2015; Heiman, 2000; Huang et al., 2012; Ilias et al., 2019; Klein et al., 2011; McCabe, 2008; McCutcheon, 2019; Midence et al., 1999; Potter et al., 2016; Rabba et al., 2019; Roberts et al., 2017; Rossi, 2012; Ryan et al., 1989; Wachtel, 2006). However, parents eventually came to terms with the diagnosis, and the denial phase was followed by a stage of acceptance as reported in 12 studies (Tait et al., 2015; Avdi et al., 2020; Chao et al., 2018; Daniels et al., 2017; Frye et al., 2015; Lopez et al., 2018; Midence et al., 1999; Navot et al., 2016; Poslawsky et al., 2013; Rabba et al., 2019; Ryan et al., 1989; Tomiyama et al., 2018). Following the above-mentioned stages, parents experienced a state of grief, which was reported as one of the most emotionally distressing reactions to their child's diagnosis (Evans, 2010; Frye et al., 2015; Hutton et al., 2005; Mulligan et al., 2012; Russell et al., 2012; Wayment et al., 2017). This stage was associated with parental feelings varying from "helpless[ness]" to feelings of sadness and some parents reported being depressed as a result (Wachtel & Carter, 2008).

Another reaction was the feeling of guilt and self-blame (Chaturvedi, 2011; Dale et al., 2006; Kent, 2012; Kim et al., 2011; McCutcheon, 2019; Midence & O'Neill, 1999; Mitchel et al., 2014; Navot et al., 2016; Ryan et al., 1989; Samadi et al., 2020; Slator, 2012; Wachtel et al., 2008; Wayment et al., 2017). Following their child's diagnosis of autism, many parents felt lost, and confused, and did not understand what their child was experiencing or how they should deal with their child's diagnosis (Russell et al. 2012).

Sub-theme 2- Positive emotions and reactions associated with an autism diagnosis

Many studies also reported positive elements associated with their child's autism diagnosis. For example, some parents felt grateful that their child was not diagnosed with something they perceived as more critical (Rossi, 2012; Tait et al., 2016; Hutton & Caron, 2005; Samadi et al., 2012). Other parents also felt relieved as the diagnosis confirmed their suspicions that something was atypical about their child's development (Mansell & Morris, 2004). As a result of the diagnosis, some parents reported giving more attention to their children and mentioned that the diagnosis strengthened their family relationships (Ilias, Cornish, Park, Toran & Golden, 2019). Additionally, Ilias (2019) found that 77.3% of parents in their study reported that they felt more hopeful about their child's accomplishments following the diagnosis.

Theme 2: Subjective experience of parents related to the process of obtaining a diagnosis

One of the most challenging aspects for parents obtaining their child's autism diagnosis is the diagnostic process itself, which reportedly caused parental frustration and anger for some families (Klein et al. 2011). Twelve studies described two major parental concerns: the delay in determining the final diagnosis and the lack of adequate communication between physicians and parents related to their child's diagnosis (Abbott et al., 2013; Andersson et al., 2014; Crane et al., 2012; Fleischmann, 2004; Frye et al., 2015; Heiman, 2000; Hidalgo, 2018; Hodge, 2006; Mitchell et al., 2014; Potter et al., 2016; Rabba et al., 2019).

Sub-theme 1- Delay in determining the final diagnosis

Existing research identified a delay in determining a diagnosis as one of the main challenges for parents. For example, a study conducted in Taiwan in 2018 showed that the average time for parents to receive an autism diagnosis for their child was 3.19 years after their first encounter with a healthcare professional (Chao et al., 2018). Another study conducted by researchers in the UK showed that it took an average of 3.5 years for parents to receive an official autism diagnosis for their child after their first appointment with the specialist (Crane et al., 2012). Twenty-six percent of parents involved in a research study conducted by Andersson and colleagues (2012) expressed that the diagnostic process for suspected autism for their child was perceived to take too long and they were not satisfied with this delay in the system. Research indicates that such a delay in the diagnostic process tends to magnify the emotional reaction experienced by parents, resulting in increased depression, emotional distress, and anxiety (Reed et al., 2019; Wong et al., 2016). Parents preferred a more structured and efficient diagnostic process that allowed them to get an accurate diagnosis within a short amount of time (Hannon & Hannon, 2017).

Sub-theme 2- Lack of adequate communication between physicians and parents

Some parents experienced communication barriers with health professionals (Alvarado-Heredia, 2017; Zuckerman et al., 2014), which often hindered their overall perception of the diagnostic experience. Chamak and Bonniau (2013) reported that healthcare professionals misdiagnosed autism and instead told parents that their child was lazy. Wong (2016) found that 40% of parent participants reported that they were not satisfied with the medical staff who provided care during the diagnostic process, due to inadequate communication with them (Wong et al., 2016).

Theme 3: Importance of support immediately post diagnosis.

Eleven studies reported that receiving the diagnosis of autism can be very difficult for parents, and the lack of proper support post-diagnosis might result in parents being left in a state of isolation (Avdi et al., 2000; Banach et al., 2010; Braiden et al., 2010; Chamak et al., 2013; Fleischmann, 2004; Hodge, 2006; Banach et al., 2020; Hennel et al., 2015; Kent, 2012; Rabba et al., 2019; Samadi et al., 2012; McCutcheon, 2019). Furthermore, 59.1% of parents in one study reported feeling isolated from their family members and friends. This feeling was attributed to a fear of embarrassment due to social stigma (Avdi et al.,2000). A study by Potter (2016) reported a lack of support immediately after the diagnosis, stating that parents felt there was absolutely no advice on where to go to get help or support. Parents often do not know how to access resources, and the professional support and resources that are available may not be perceived to be adequate to support parents who are struggling emotionally and psychologically with their child's new diagnosis (Tait et al., 2016). However, other research indicated that healthcare providers often try to do their best in providing resources to these families and direct them to appropriate support, such as social workers (Hidalgo, 2018; Banach et al., 2010; Alvarado-Heredia, 2017; McCutcheon, 2019).

Sub-theme 1- Support from other parents

Having a strong support system was viewed as vital for parents and families who have an autistic child, especially during an overwhelming and stressful time post-diagnosis (Navot et al., 2016). Existing research shows that parents sought out support and advice from other parents who were in the same situation as them (Banach et al., 2010). Furthermore, eight studies showed that parents benefit from a solid and helpful support system that makes them feel less overwhelmed and vulnerable (Midence et al., 1999; Rabba et al., 2019; Banach et al., 2010; Braiden et al., 2010; Fowler & Karen, 2021; McCutcheon, 2019; Wachtel, 2006; Wachtel et al., 2008). Parents found that seeking help from other parent groups was the most appropriate and helpful support system post diagnosis (Rabbitte et al., 2017). A study conducted by Tomiyama et al. (2018) indicated that social support interventions such as networking and being part of parent support groups yielded a lot of positive outcomes for parents mainly in reducing parents' stress, depression, and anxiety levels.

Sub-theme 2- Support from immediate and extended families

Parents viewed the support from their immediate and extended families as being valuable and key to having a better quality of life (Hutton et al. 2005). Ilias et al (2019) showed that 50% of mothers believed that maintaining clear communication with their immediate family members, including their spouses, was extremely important during this sensitive phase of their life. This helped maintain their emotional stability while navigating the healthcare system in an attempt to find the best services for their children (Good et al., 2012). Overall, general community support was considered an asset for these families post diagnosis (Roberts et al., 2017).

Theme 4: Stigma associated with an autism diagnosis

Although significant efforts have been made to increase knowledge about autism, there is still a stigma about autism as a sensitive subject (Mazumder & Thompson-Hodgetts, 2019; Nissenbaum et al., 2002). The stigma surrounding autism "occurs in circumstances when people are less open in accepting a child's challenging behaviour may be due to their ASD diagnosis" (Hornstein, 2012, p.4). Often people attribute a child's behaviour to 'bad parenting', label the child as a 'bad mannered child' or a 'lazy student'. Existing literature indicates that it is still common that such a negative narrative is imposed on parents and children rather than attributing them to the underlying autism diagnosis (Zuckerman et al., 2014). To avoid the stigma associated with their child's diagnosis parents tend to connect and seek help from other parents who have an autistic child (Hornstein, 2012). Stigmatizing attitudes resulted in families isolating themselves from friends, and their own families, and overall avoiding social interactions and networking (Kent, 2021; Mazumder & Thompson-Hodgetts, 2019; Slator, 2012). In more than 27% of the included studies, norms and beliefs around autism appear to be linked to preconceived attitudes and negative stereotyping of these families (Abbott et al., 2013; Alvarado-Heredia, 2017; Avdi et al., 2000; Censor et al., 2017; Chamak et al., 2013; Chao et al., 2018; Craig, 2015; Evans, 2010; Hannon et al., 2017; Hidalgo, 2018; Hodge, 2006; Hornstein, 2012; Huang et al., 2011; Ilias et al., 2019; Lopez et al., 2018; McCabe, 2008; Nissenbaum et al., 2002; Russell et al., 2012; Rossi, 2012; Samadi et al., 2011; Slator, 2012; Zuckerman et al., 2014). For instance, 45.5% of the parents who participated in a study by Ilias et al. (2019) reported that social stigma had an impact on their lives, making it more difficult to cope with their child's diagnosis. High levels of discrimination toward families who have autistic children are attributed to a lack of knowledge and education about autism in some countries (Tait et al., 2016; Zuckerman et al., 2014; Chamak et al., 2013). Further, autistic children were labelled "spoiled" resulting in familial isolation and avoidance of social encounters with neighbours and friends (Chamak et al., 2013; McCabe et al., 2008; Ilias et al., 2019; Hannon et al., 2017). The stigma associated with a child's autism diagnosis made some parents fearful of seeking medical care (Daniels et al., 2017; Alvarado-Heredia, 2017; Zuckerman et al., 2014). Parents who have an autistic child stated that misinterpretations about autism need to be addressed so their children can have a better quality of life and become productive members of society despite their diagnostic label (Rabbitte et al., 2017).

Table1. Study Findings

Author, Location	**Aim**	**Sample**	**Methodology**	**Main findings (Immediate Parental reactions)**
Abbott et al. (2013); United Kingdom	To assess the communication of the diagnosis of autism between parents and health care professionals as apart of Child and Adolescent Mental Health Practice	*N*=9 parents	Qualitative study	Parents portrayed feelings of nervousness, hopelessness, shock, uncertain of what to do next, lost, guilt, relief, and despair
Alvarado-Heredia (2017); United States	To educate and understand the cultural influences that may impact families with children diagnosed with ASD	*N*= 15 parents	Qualitative study	A majority of parents reacted to the initial diagnosis of their children with self-blame, denial, shock, depression, sadness, and embarrassment. It was also shown that some parents had more of a positive response, including a stronger connection to religion, and focusing more on the well beings of themselves and others close to them.
Andersson et al. (2014); Sweden	To assess the parent's response of the diagnostic processes of ASD for their children by screening their children's preschool experience	*N*=34 parents/teacher	Quantitative study	For the majority, 42% of parents that participated in the study stated they had been "positively affected" by the information introduced after the diagnosis. However, some parents and teachers stated that there was little effect if no effect at all.
Avdi et al. (2000); United Kingdom	To study reactions involved in diagnosing a learning disability for a family and to ensure that there is a normal developmental pathway post diagnosis	*N*= 3 sets of families	Qualitative study	Guardians of the children reported feelings of acceptance, uncertainty, relief, and guilt.
Banach et al. (2010); United States	To determine if support groups and community resources for parents with children with ASD are effective to meet their needs.	*N*= 11 Parents	Quantitative study (Pilot study)	Parents who receive a diagnosis of ASD face a lot of feelings and are overwhelmed with information.

Braiden et al. (2010); Ireland	To provide information on the parental experience of the diagnostic process of their children being diagnosed with ASD	*N*=11 mothers	Qualitative study	Parents that were in the study reported having feelings of bewilderment, concernment, shock, overwhelming, as well as satisfaction of the structure of the diagnostic process
Chao et al. (2018); Taiwan	To examine the experiences of children diagnosed with ASD in Taiwan	*N*=15 parents	Qualitative study (Phenomenology)	Parents had feelings of bewilderment, uncertainty, anxiety, lost, self-blame, angry, and sometimes optimistic. Parents reported their feelings shifted towards hopefulness and acceptance after accepting the diagnosis.
Censor et al. (2017); Israel	To decipher Arab-Israeli parent's (specifically mothers) psychological and emotional responses with respect to their child's diagnosis of ASD	*N*= 46 mothers	Mixed methods	After coming to terms with the diagnosis, the mother described having feelings of sadness, worriedness, and increased stress.
Chamak et al. (2013); United States	To decipher the parental experience of the diagnostic process of autism in France	*N*=248 parents	Mixed methods	As a result of the diagnosis, parents began to acquire feelings of guilt, denial,
Chaturvedi (2011); United States	To explore the relationship between parents and their non-ASD children as well as to explore the impact of ASD on the family as a whole.	*N*=8 parents	Qualitative study (Interpretive Phenomenology)	Some participants had feelings of self-blame and recrimination when given the diagnosis
Craig (2015); United Kingdom	To explore teenagers and mothers experience to diagnosis and everyday life with ASD	*N*=4 young people with ASC and *N*=4 mothers	Qualitative study (Phenomenology)	Participants had diverse reactions to diagnosis, some mothers had a sense of relief, others unaware of the possibility had strong feelings of shock and guilt. Some teenagers had feelings of hatred and shame. Not all participants had emotional reactions to diagnosis.
Crane et al. (2016); United Kingdom	To provide an outline of the experience a parent has in the United Kingdom when getting a diagnosis of ASD for their child	*N*=1047 parents	Quantitative study	It was noted that 82% of the parents who had to undergo the diagnostic process felt stressed out. Also, parents described having feelings of fear of the future for their child.

Dale et al. (2006); United Kingdom	To explore and examine the effect of a parent's beliefs of their child's ASD diagnosis on their emotional response	*N*=16 parents	Mixed methods	Parent's reported feelings of self-blame, shame, guilt, depression, helplessness, incompetence, and scaredness.
Daniels et al. (2017); United States	To interpret and understand the process of the diagnosis of autism within families	*N*= 758 caregivers	Quantitative study	Caregivers experienced feelings of helplessness, acceptance and overall parental stress
Ducey (2009); United States	To explore the experiences of parents prior to and during the process of receiving the diagnosis of autism	*N*=4 mothers	Qualitative study (Phenomenology)	The participants described the initial realization of the diagnosis as traumatic and being profoundly sad.
Evans (2010); United States	To explore parents' responses to the diagnosis of ASD	*N*=15 parents	Qualitative study	Some parents experienced negative emotions such as sadness, despair, bewilderment, sorrow and grief. Other parents experienced relief and reassurance that the parenting had not been inadequate.
Fleischmann (2004); Israel	To examine the coping mechanisms of parents with children with autism by examining self-published material on the internet	*N*=20 parents	Qualitative study	Narratives included feelings of shock, guilt and anger mixed with relief to finally have a diagnosis.
Fowler & Karen (2021); Ireland	To decipher the reaction and experience of mothers of the children diagnosed with ASD	*N*=19 mothers	Qualitative study (Thematic Analysis)	A few of the mothers described their reaction as not being surprised. However, a large majority reported feelings of shock, with a few also reporting feeling overwhelmed. Additionally, some of the mothers also reported feelings of relief from the guilt they were previously feeling.
Frye et al. (2015); United States	To interpret and understand a father's experience when receiving a diagnosis of ASD for their children	*N*=10 fathers	Qualitative study (Phenomenology)	Feelings of the father included grief, denial, anger, depression, separation, helplessness, guilt, and eventual acceptance

Hannon et al. (2017); United States	To investigate the process of father's first discovering about their child's diagnosis of autism	*N*= 16 fathers	Qualitative Study (Grounded Theory)	The prognosis caused increased stress levels for the father, as well as other emotional distress
Heiman (2000); Israel	To examine how resilience emerges in families with a child with a disability.	*N*=32 parents	Mixed methods	Parents had negative emotional reactions to the diagnosis (84%) that included feelings of depression, anger, denial, fear, guilt, confusion, hostility.
Hennel et al. (2015); Australia	To examine the experiences of parents with a doctor's report and the process by which there is a delivery of the diagnosis	*N*=57 parents	Quantitative study	After getting the diagnosis, parents report feelings of satisfaction (87%) after having an individual that supports them through the process. Also, some parents felt uninformed of the actual prognosis of their child.
Hidalgo (2018); United States	To acquire information about psychological reactions of parents after the diagnosis	*N*=31 parents	Qualitative study (Phenomenology)	Many parents report having experienced a long delay before receiving the diagnosis. They also had feelings of isolation, confusion, and frustration
Hodge (2006); England	To explain the experience of the parents who have children that undergo the diagnostic process of ASD	*N*= 3 sets of parents	Qualitative study	As a result of the diagnosis, parents felt feelings of frustration, helplessness, sadness, uncertainty, and anger. Some parents also reported feeling that they had failed their responsibility as a parent and believe that the reason the illness occurred was their fault.
Hornstein (2011); United States	To investigate experiences of mothers receiving an autism diagnosis through three decades	*N*=7 mothers o	Qualitative study	Mothers' reactions to the autism diagnosis ranged from devastating and stunned to relief.
Huang et al. (2012); Taiwan	To investigate the experiences of fathers with a Chinese cultural background that have children diagnosed with a developmental disorder	*N*=16 fathers	Qualitative study (Hermeneutic Phenomenology)	Fathers began to lose hope in the future as a result of the diagnosis of their children. Also, feelings of shock, sadness, denial, guilt and increased stress were accompanying symptoms as a result of the diagnosis as well.

Hutton et al. (2005); United States	To examine coping strategies and adaptation of families of a child with autism	N=21 parents	Qualitative study	Most common reaction to the diagnosis was relief, followed by grief and loss, shock and self-blaming.
Ilias et al. (2019); Malaysia	To examine the effect of protective experiences on a parent's state of mind	N= 22 parents,	Qualitative study	Parents of the children diagnosed with ASD felt strong feelings of denial, emotional distortion and resilience.
Kent (2012); United States	To inquire upon the relationship between children's siblings with ASD and parents in order to determine the effect that the disorder had on their family	N=8l parents	Qualitative study (Phenomenology)	One of the major impacts experienced by parents post diagnosis is the feeling of uncertainty for their child's future, guilt, relief due to their pre-established support network,
Kim et al. (2020); United States	To investigate the efffect on child ASD diagnosis on Korean American families	N=5 mothers	Qualitative study	Korean American mothers expressed considerable negative reactions to the diagnosis including feeling guilty
Klein et al. (2011); Canada	To increase application of family care in tertiary diagnostic assessment clinics	N=9 parents	Qualitative study	Mothers of the children experienced depression, self-reproach, anxiety, as well as denial.
Lopez et al. (2018); United States	To explore reactions of Latino and White parents to the diagnosis of ASD and how family and culture impact the process of acceptance	n=44 Latino mothers and n=52 white mothers o	Qualitative study	Latino mothers were surprised by the diagnosis which provided a sense of guilt for not having information or seeking the diagnosis beforehand.
McCabe (2008); Switzerland	To explore the experiences of families of children with ASD in China.	N=78 parents	Mixed methods .	Parents expressed being shocked, devastated, denial and lack of understanding when the diagnosis was given

McCutcheon (2019); United States	To discover and explain the experience of the caregivers pre-prognosis, during and post prognosis in order to reduce the negative experiences of caregivers following ASD diagnosis	*N*=7 parents	Qualitative study (Phenomenology)	Caregivers reported feelings of overwhelment, denial, shock, devastation, despair, fear, as well as guilt.
Midence et al. (1999); United Kingdom	To investigate and experience how a diagnosis of autism happens	*N*=5 families	Qualitative study (Grounded Theory)	The main feelings that accompanied parents were feelings of acceptance, denial, confusion, and guilt.
Mitchell et al. (2014); South Africa	To observe the experiences of South African parent with children diagnosed with ASD	*N*= 8 parents	Qualitative study	The children's mothers describe strong feelings of anger, guilt, frustration/confusion, depression, stress, and anxiety.
Mulligan J et al. (2012); Canada	To explore the diagnostic experience of parents receiving a diagnosis of ASD for their child.	*N*=10 parents	Qualitative study (Phenomenology)	Parents reported diverse feelings related to the diagnosis, some felt grief and shock the vast majority felt relief accompanied by a sense of loss and validation.
Navot et al. (2016); United States	To investigate the process of family planning with mothers of children diagnosed with ASD both before and post diagnosis	*N*= 22 mothers	Qualitative study (Grounded Theory)	Mothers stated that they had feelings of guilt, self-blame, fear, confusion, separation, acceptance and indulged more focus in the current moment.
Nissenbaum et al. (2002); United States	To interpret the perspectives of the parents and their relationship to the doctors who diagnosed their children	*N*= 17 parents	Qualitative study	The study described the parents having feelings of despair, uncertainty, and anxiousness
Poslawsky et al. (2013); United States	To examine the reactions of parents after their children are diagnosed with ASD	*N*=77 parents	Quantitative study	There was an increase in parental stress, feelings of depression, and eventual acceptance of the diagnosis of their child

Potter et al. (2016); United Kingdom	To determine a father's emotional response to the diagnosis	*N*=306 fathers	Mixed methods	Father stated feelings of anger, dismay, fearful, sadness, denial, frustration, panic, depression, anxiety and eventual relief.
Rabba et al. (2019); Australia	To investigate the parents' experiences and level of support needed following ASD to further implement appropriate interventions following the diagnosis.	*N*=10 mothers and 3 fathers	Qualitative study (Thematic Analysis)	These parents reported a spectrum of reactions including feelings of devastation, uncertainty, acceptance, shock, denial, anger, sadness, but a significant majority (66%) reported feelings of being overwhelmed.
Rabbitte et al. (2017); Ireland	To underline the process of getting an autism diagnosis for parents with daughters that have ASD in Ireland	*N*=6 families	Qualitative study (Phenomenology)	Parents reported feelings of initial shock as a result of the diagnosis, which then later shifts towards consolation. Also, parents described feelings of frustration, sadness, and self-blame.
Reed et al. (2018); United Kingdom	To determine whether diagnostic reaction resolution status varies emotional distraught, anxiety with an individual's health	*N*=120 parents	Quantitative study	Parents acquired feelings of emotional distraught, anger, anxiety and depression.
Reed et al. (2019); United Kingdom	To assess the mother's reaction to the diagnostic process of their children with ASD	*N*=67 mothers	Quantitative study	The diagnosis induced feelings of depression and anxiety in the mother of the children.
Roberts et al. (2017); United States	To determine the effect of sleep deprivation on families with children diagnosed with ASD	*N*=77 parents	Mixed methods	Parents reported feelings of frustration, stress, denial, responsible and also sleep deprived
Rossi (2012); United States	To investigate the historical diagnostic instruments used by physicians and determine their effectiveness	*N*=90 parents	Qualitative study	Parents stated feelings of denial due to the lack of information presented about the diagnostic process as well as the illness itself.

Russell et al. (2012); United Kingdom	To determine parental responses to a diagnosis of ASD for their children and what this diagnosis means for the family	*N*=17 parents	Qualitative study (Grounded Theory)	Parents immediately reacted with denial, forced into a state of shock and a period of grief. This resulted in the invocation of fear
Ryan et al. (1989); United States	To develop initial context on the experience of Chinese American parents of children with developmental disabilities.	*N*=59 parents	Mixed methods	Reactions of parents to the diagnosis were denial, guilt and partial acceptance.
Samadi et al. (2012); Ireland	To identify the information and support system of parents of a child with ASD in Iran	*N*=43 parents	Mixed methods	Parents reported being shocked and depressed (63%). Shocked but rejected the diagnosis (12%), uncertainty (21%) and relief (2%)
Samadi (2020); Ireland	To investigate the origin and beliefs of the parent's who initially discovered their children's onset of ASD	*N*=43 parents	Mixed methods	Parents expressed feelings of guilt regarding ASD as a tragedy.
Slator (2012); United Kingdom	To explore the narratives of parents of children with ASD that attend psycho-education groups.	*N*=5 parents	Qualitative study using narrative methodology. Semi structured interviews.	Impact of the diagnosis on the hopes and dreams for their children and guilt from fear of possibly causing the disorder.
Tait et al. (2015); Hong Kong	To determine the quality of life for Chinese families with children diagnosed with ASD	*N*=75 parents	Mixed methods	Some parents felt a sense of relief, whereas some were in a state of shock and disbelief. There were also feelings of sadness. confusion and eventual acceptance of the diagnosis that occurred post diagnosis.
Tomiyama et al. (2018); Japan	To investigate the mother's emotional shift from the birth of the child to post-diagnosis of the child	*N*=30 children diagnosed with ASD	Mixed methods	Post diagnosis, mothers reported feelings of depression, anxiety, mental distress and acceptance.
Wachtel (2006); United States	To gain a better understanding between resolution of feelings associated with a child's	*N*=63 mother y	Mixed methods	Mothers expressed the experience as a positive one feeling relieved and validated. Other mothers who didn't suspect the diagnosis were shocked and overwhelmed.

	diagnosis of autism and maternal interaction style.			
Wachtel et al. (2008); United States	To explore how the mother accepts the diagnosis of ASD for the children and the conclusion it leads them to	*N*=63 mothers y	Qualitative study	The mothers reported feelings of guilt, confusion, denial, depression, overwhelming and self-blame.
Wayment et al. (2017); United States	To investigate if emotional distress characterized the mother’s response to the diagnosis of ASD	*N*=362 mothers with children diagnosed with ASD	Mixed methods	Mothers reported initial feelings of grief, depression, sadness, anxiety, guilt, as well as regret.
Wong et al. (2016); United States	To investigate the experience of a parent receiving a diagnosis for their child	*N*=78 parents	Mixed methods	Parents began to feel angry, frustrated, shocked, and anxious after the diagnosis
Zuckerman et al. (2014); Portland	To interpret the preconceived notions of ASD in the Latino community	*N*=90 parents	Qualitative study	Parents seemed to initially react to the diagnosis with fear, denial, nervousness, stress, and in some cases embarrassed.
Zuckerman et al. (2014); Portland	To discover the hurdles in society that act as obstacles to a proper diagnosis of Latino children	*N*=33 parents	Qualitative study	Parents in Mexico viewed autism as a sign of weakness or something to be embarrassed about due to a lack of knowledge of the disorder.

Discussion

This review highlights four main findings as a result of our synthesis of existing literature. One of the main findings that emerged was that parents' immediate reactions to their child's autism diagnosis varied considerably, ranging from shock and denial to a sense of relief. Other immediate parental experiences included struggles with confirming a diagnosis, the diagnostic journey itself, the need for immediate emotional and professional support following their child's diagnosis, and the stigma associated with an autism diagnosis, all of which negatively impacted their everyday lives.

The process of acceptance of an autism diagnosis is challenging for many families. In most cases, families learn of their child's diagnosis at an early age and therefore, parents must remain hopeful and focus on their child's future rather than becoming exhausted by the diagnosis and perceived challenges (Chao et al., 2018). Parents' positive attitudes, resiliency towards their child's diagnosis, and ability to cope played a significant role in leading a healthy family life (Fleischmann, 2004) and improved overall quality of life (Alvarado-Heredia, 2017). Resilience was associated with higher levels of adaptation and positive changes such as the ability to develop a solid support system, focus on the positive aspects of their child's attributes, and eliminate negative opinions (Fleischmann, 2004). Moreover, the literature highlights that parental resilience is associated with an improvement in their child's overall behaviour (Roberts et al., 2017).

Challenges with the healthcare system as shown in our second theme focused on communication with healthcare professionals. Interestingly, but not unexpectedly, social determinants come into play specifically with families for whom English was not their first language in English-speaking countries (Zuckerman et al., 2014). Communication with healthcare professionals was in general the most prominent barrier and poor communication left parents with feelings of ambiguity, uncertainty and feeling lost as to what was going on with their child (Abbott et al., 2013).

From this study, it also became evident that healthcare providers were not viewed by these families as the main and most vital support system. Parental social networks, specifically other parents who had autistic children, as well as family and friends, were considered their most significant support system. We argue that the challenges in communication between professionals and families related to the diagnostic process and the diagnosis itself might influence families in not viewing healthcare professionals as a primary support system. This highlights the importance of providing ongoing education for healthcare professionals on communication related to autism in general, including but not limited to encounters with diverse racial minorities and people of different cultural backgrounds, who may lack language proficiency, to decrease barriers to care and avoid discriminatory practices. One simple example to tackle this problem is the incorporation of language interpretation technology in clinical settings. We strongly recommend that healthcare professionals be provided with tools and training to improve communication skills to foster more trusting relationships with families and potentially assist parents with building resiliency related to their child's autism diagnosis.

Strengths and Limitations

A strength of this review is the thorough and specific methodology implemented. To ensure a systematic and extensive exploration of this topic, we used a rigorous process for our initial search, which was conducted by an expert librarian. Articles that were selected underwent a rigorous process of initial screening and in-depth reading of the abstracts to ensure the articles met our inclusion and exclusion criteria. Further, we did not impose any restrictions while conducting our search with the exception of limiting our search to English. Despite these strengths, limiting this review to the English language implies that we might have missed relevant studies that were published in other languages along with possible underlying cultural underpinnings.

Conclusion

Receiving an autism diagnosis caused a range of positive and negative emotions among parents who have an autistic child. Findings from this review highlight the major challenges faced by parents following their child's autism diagnosis. This information can be used to improve diagnostic processes, support, and resource planning for families, especially in the early stages of diagnosis and immediately thereafter.

Key Messages from This Article

Autistic people and their families: might benefit from this scoping review by understanding some of the immediate common reactions and experiences shared by many families.

Professionals: This work efficiently summarizes the current body of literature for professionals regarding immediate parental reactions and responses following their child's autism diagnosis, experiences with the diagnostic process, stigma, and the need for immediate support. It highlights that communication with healthcare providers is often experienced by parents as inadequate or negative. This knowledge can increase the sensitivity of professionals and enhance patient family-centered care.

Messages clés de cet article

Personnes autistes et leur famille : vous pourriez bénéficier de cette revue en comprenant certaines des réactions immédiates communes et des expériences partagées par de nombreuses familles.

Professionnels : Ce travail résume efficacement l'ensemble des écrits scientifiques actuels pour les professionnels concernant les réactions et les réponses immédiates des parents après un diagnostic d'autisme chez leur enfant, les expériences avec le processus diagnostique, la stigmatisation et leur besoin de soutien immédiat. Il souligne que la communication avec les prestataires de soins de santé est souvent vécue par les parents comme étant inadéquate ou négative. Ces connaissances peuvent accroître la sensibilité des professionnels et améliorer les soins centrés sur la famille des usagers.

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