Review Journal of Autism and Developmental Disorders (2021) 8:334–349
https://doi.org/10.1007/s40489-020-00224-9

REVIEW PAPER

A Systematic Review of Factors Relating to Parental Satisfaction with the Diagnostic Process for Autism Spectrum Disorder

Adam W. McCrimmon[1] · **Shawna M. Gray**[1]

Received: 4 July 2019 / Accepted: 5 October 2020 / Published online: 16 October 2020

Abstract

Diagnostic assessment for autism spectrum disorder (ASD) is a complex and often stressful process for parents. This systematic review synthesized results of 26 articles that reported on factors related to parental (dis)satisfaction with the diagnostic process for ASD. The results are described in terms of factors related to satisfaction and those related to dissatisfaction (with some overlap between these), in the context of temporality within the diagnostic process. Subsequently, factors are described in terms of those that can be directly influenced by clinicians and those that are outside of direct clinician control. Implications of the findings and directions for future research are provided.

Keywords Autism spectrum disorder · Diagnosis · Parents · Satisfaction

Autism spectrum disorder (ASD) is a complex neurodevelopmental disorder whose prevalence has increased dramatically over the past several decades (Baio et al., 2018). In alignment with this increase, research efforts have targeted effective assessment processes and related clinical activities to identify individuals with ASD. This paper will systematically review literature pertaining to an essential assessment-related consideration—the diagnostic assessment process and factors related to parental (dis)satisfaction with it. This topic has been explored by many researchers; however, the information arising from these studies has yet to be formally reviewed and synthesized for the benefit of clinicians and researchers. We begin by providing a brief description of ASD and an overview of common assessment approaches. We then report on literature pertaining to parental (dis)satisfaction with the assessment process and conclude with implications for clinical practice and suggestions for further research.

ASD Assessment

ASD is a pervasive (i.e., lifelong) neurodevelopmental disorder characterized by impairment of socio-communicative functioning in conjunction with restricted and/or repetitive patterns of behaviours, activities, or interests as described in the current *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (*DSM-5*; American Psychological Association [APA], 2013). Affected individuals experience qualitative impairment of social reciprocity, nonverbal communication, and peer relationships in addition to the demonstration of stereotyped or repetitive speech, motor movements, or use of objects, insistence on sameness or adherence to routines/rituals, fixated interests, and/or sensory interests or sensitivities. There is heterogeneity in phenotypic expression of these behavioural symptoms with varying severity and number of symptoms across individuals and, in some cases and domains, across time (Richler et al., 2010; Szatmari et al., 2002). As such, ASD is considered a 'spectrum' disorder with affected individuals demonstrating differential cognitive, language, social, and behavioural abilities (National Research Council, 2001).

As a result of the variability of symptom presentation, clinical assessment and diagnostic practices for ASD are complex. Assessment and diagnosis of ASD most often, though not always, occurs before elementary school (Centers for Disease Control and Prevention, 2007; Shea & Mesibov, 2009). Clinicians often strive to diagnose children as early

---

✉ Adam W. McCrimmon
awmccrim@ucalgary.ca

[1] Werklund School of Education, University of Calgary, Calgary, Alberta, Canada

as possible (i.e., at or before the age of 2), as formal assessment and earlier diagnosis result in enhanced prognosis (Fernell et al., 2013), enabling children to access interventions and supportive services at an earlier stage in development, thus improving developmental outcomes (Remington et al., 2007).

The diagnostic process typically begins when a parent or another individual (i.e., a relative, family friend, teacher) notices developmental or behavioural atypicalities in the child. Such atypicalities may include delayed or lack of imitation, sharing of attention and focus with social partners, orienting to socially important stimuli, and/or atypical language development (APA, 2013). These concerns may subsequently lead parents to seek out professional opinion on the nature of the behavioural differences, including a possible diagnosis (Mansell & Morris, 2004). Although there are many domains to be assessed (i.e., behavioural atypicalities, cognitive development, language development, sensory needs, gross and fine motor development) and approaches to assess each domain (Klin et al., 2005), best practice standards dictate a comprehensive and developmental assessment that ascertains an accurate picture of the child's behaviours in relation to both normative and ipsative standards of development (Campbell et al., 2014; National Institute for Health and Care Excellence, 2011). In addition, the use of a multidisciplinary team (i.e., paediatricians, psychologists, speech-language pathologists, occupational therapists, etc.) is recommended so that professionals with specific yet unique training and experience can evaluate the child's skills and abilities across a variety of domains (Volkmar et al., 2014). Parents then typically receive the results of the assessment upon its conclusion and seek support and services for their child.

Parental (Dis)Satisfaction with the ASD Assessment Process

Raising a child is a difficult endeavour that can be made more challenging when the child has a neurodevelopmental condition, such as ASD. Indeed, this additional struggle can enhance stress regarding parents' skills and decisions (Huws et al., 2001). Researchers have indicated that parents of children with ASD experience substantial stress (Schieve et al., 2007), even more than parents of children with other developmental disorders (Sanders & Morgan, 1997). One potential source of this stress is the process of receiving a formal diagnosis for the child—a context that clinicians can influence directly by their professional approach, demeanour, and skill. A deeper understanding of the factors that can influence parents' experience of the assessment process holds promise to inform clinical approaches to diagnosis and enhance care provided to families of a child with ASD. To that end, this systematic review (1) summarizes research on factors pertaining to satisfaction and/or dissatisfaction with an ASD assessment for their child, (2) provides considerations for enhancement of assessment processes based on this summary, and (3) outlines future potential research in this area.

Methods

A systematic review of the literature as of February 2019 was conducted following PRISMA guidelines (Moher et al., 2009). PRISMA guidelines highlight the process of using pre-determined search terms to identify articles through databases and/or other sources (e.g., journals; Moher et al., 2009). All duplicates are removed, and articles are screened for inclusion based on specific inclusion/exclusion criteria (Moher et al., 2009). At all stages, the number of articles found, excluded, and included for analysis is reported (Moher et al., 2009). In alignment with these guidelines, the *Medline* & *Psych-Info* databases were searched concurrently for the combination of the following keywords: (1) autism spectrum disorder or autism, (2) diagnosis, and (3) satisfaction. The search was limited to articles involving humans, written in English, and that were peer reviewed. The search yielded 50 identified articles whose abstracts were screened for inclusion in the review by both authors. The criteria for inclusion were as follows: (1) diagnosis of autism, ASD, Asperger's disorder/syndrome, or pervasive developmental disorder—not otherwise specified was a primary topic and (2) parental satisfaction or dissatisfaction with the diagnostic assessment was described.

Seventeen articles met the inclusion criteria. To ensure full inclusion of relevant studies in this review, these articles were reviewed to identify cited articles on the topic of parental (dis)satisfaction with the ASD diagnostic process for consideration in the review. This search yielded an additional 3 articles. As well, five prominent journals (the *Journal of Autism and Developmental Disorders*, *Autism*, *Focus on Autism and Other Developmental Disabilities*, *Research on Autism Spectrum Disorders*, and *Autism Research*) dedicated to research on ASD were also searched for "satisfaction". The abstracts of identified papers were screened; this search produced an additional 14 articles, for a total of 34. Upon closer inspection of these articles, it was determined that 8 did not align with the inclusion criteria outlined above (e.g., (dis)satisfaction was not directly addressed). If there was disagreement regarding article inclusion, the authors met to reach a consensus. The final count after this analysis of the articles yielded 26 articles (see Table 1) that met criteria to be included within this systematic review. Figure 1 outlines this process.

Data Extraction

Data extraction was completed independently by each author who then met to discuss findings and reach consensus.

Table 1 Identified factors and their relation to satisfaction/dissatisfaction

Reference	Article type	*N*	Mean age of sample	Sample demographics	Time from diagnosis to satisfaction ratings	Diagnostic professional/ environment	Measurement method
Abbott, Bernard, & Forge (2012)	Qualitative	9 families	11.2 years (child)	White British ethnicity, range of socio-economic backgrounds	Within 6 months	Psychiatrists	Semi-structured interviews analysed through a general inductive approach to create themes. Inter-rater reliability present
Andersson, Miniscalco, & Gillberg (2014)	Quantitative	Parents and teachers of 34 children	3.1 years (child)	73% Swedish, 26% immigrants to Sweden. 15% single parent	Following feedback meeting and 1 year after	Neuropsychiatry clinic	12–15-question questionnaire given to parents and pre-school teachers. Statistical analysis was completed through Fisher's exact test, Mantel-Haenszel chi-square exact test, and Mann-Whitney *U* test
Brogan & Knussen (2003)	Quantitative	126 parents	7.2 years (child)	Living in Scotland. 12% single mothers. Various parents, ages, and socio-economic backgrounds were represented	91% within 5 years	Hospitals	5-point scale questionnaire. Chi-square or one-way analysis of variance was used to analyse the data. Questionnaire adapted from Sloper and Turner (1993) self-report questionnaire and interview schedule
Chamak & Bonniau (2013)	Combined methods	248 parents (questionnaire) 43 parents (interview)	Not provided	France	Not provided	Not provided	Questionnaire included closed and open-ended questions. Questions were coded by two researchers independently. Participants were randomly selected for in-depth interviews. Narrative analysis was used for the interviews
Chamak, Bonniau, Oudaya, & Ehrenberg (2011)	Combined methods	248 parents (questionnaires) 43 parents (interview)	Age range from 20 to > 60 (parent) Age range from 4 to 18 (child)	France. Range of socio-economic states; however, higher socio-economic status more strongly represented	Not provided	Range of professionals	Questionnaire included closed and open-ended questions. Questions were coded into 5 categories (negative effects, positive effects, mixed emotions, questioning, no effect). Participants were randomly selected for in-depth interviews. Interviews were

Table 1 (continued)

Reference	Article type	*N*	Mean age of sample	Sample demographics	Time from diagnosis to satisfaction ratings	Diagnostic professional/ environment	Measurement method
							analysed using grounded theory
Crane et al. (2018)	Qualitative	10 adults with ASD, 10 parents, 10 professionals	42.89 years 10.6 years	Across the UK. 9 White, 1 Chinese ethnicity (parents). All adults with ASD were of White ethnicity Professionals were mostly White (9) with one Black ethnicity	Within 5 years	Not provided	Semi-structured interviews analysed through thematic analysis by two independent researchers
Crane, Chester, Goddard, Henry, & Hill (2016)	Quantitative	1047 parents	43.4 years (parents) 11.8 years (child)	Across the UK. 95% from White ethnicity	Within 5 years	Paediatrician (34%), psychologist (21%), child psychiatrist (19%), multidisciplinary team (9%), other (e.g. speech language pathologist, unknown; 17%)	Online questionnaire including demographic/general information and 5- or 4-point Likert scale answers. Multiple regression was used to analyse factors predictive of overall satisfaction. Adapted from Howlin and Moore (1997), Brogan and Knussen (2003), and Siklos and Kerns (2007)
Goin-Kochel, Mackintosh, & Myers (2006)	Quantitative	494 parents	37.8 years (parent) 8.3 years (child)	Average parent education 15.2 years (3rd year post-secondary). 87.7% White/Caucasian. 76.3% from the USA, 6.5% from England/Ireland, 6.1% from Canada, 3.6% from Australia/New Zealand, 1.2% other. Range of socio-demographic status	Not provided	Not provided	Online questionnaire containing demographics/general information and 4-point scale of satisfaction levels. A logistic regression analysis was used to predict satisfaction as a result of child age of diagnosis and number of professionals seen
Hackett, Shaikh, & Theodosiou (2009)	Combined methods	40 families (11 interviewed)	Not provided	Children: 20 White, 8 Asian, 3 Black, 7 mixed, 1 Chinese, 1 other ethnic background	Within 4 years	Clinic utilizing a multidisciplinary team	Researcher developed questionnaire composed of 28 questions. Participants were invited to interviewed; translators were provided for those who did not speak English
Hidalgo, McIntyre & McWhirter (2015)	Combined methods	46 families	Not provided	76% White/Caucasian, 13% Latino/Hispanic,	Not provided	Not provided	A researcher-developed questionnaire containing closed and open-ended questions was

Table 1 (continued)

Reference	Article type	*N*	Mean age of sample	Sample demographics	Time from diagnosis to satisfaction ratings	Diagnostic professional/ environment	Measurement method
				4% Asian, 7% Black or mixed ethnicity 67% 12 years or less of education. 28% at or below US poverty line. 70% received Medicaid or health insurance through state health plan, 30% had private insurance			used. Closed-ended questions were based on dichotomous variables or Likert-type items; chi-square analyses were used. Thematic analysis was used to analyse the open-ended questions.
Ho, Miller, & Armstrong (1994)	Combined methods	28 families	5.9 years (child)	65% high school education and born in North America, 29% two or more years of college education, 6% less than eighth-grade education. 60% both parents worked full time	2 weeks prior and 2 weeks following assessment	Interdisciplinary assessment within a hospital	Researcher-created structured interviews and questionnaires were administered 2 weeks prior and 2 weeks following assessment. Descriptive analysis was performed, and the kappa statistic was used to determine statistical significance.
Howlin & Asgharian (1999)	Quantitative	770 families	13.03–13.84 years (child)	Across the UK. No other information was collected	Not provided	Paediatricians, child psychiatrists, and psychologists most common single professionals seen. Most saw multiple professionals	Questionnaire containing demographic/general information and 3-point scale questions.
Howlin & Moore (1997)	Quantitative	1295 parents	12.17 years (child)	Across the UK. No other information was collected	Not provided	Majority saw a combination of professionals. Child psychiatrist, psychologist, or paediatrician were the most common single professionals seen	Questionnaire containing demographic/general information and 4-point scale questions.
Jashar et al. (2019)	Mixed methods	288 families	2.86 years (child)	76.5% non-minority parents, 21.4% minority parents. Range of educational experiences (from no degree/diploma to PhD) and socio-economic backgrounds	Range from 2 to 5 weeks	Six clinical psychologists, one developmental-behavioural paediatrician within a clinic	Parents were recruited from a study validating the MCHAT/F and M-CHAT-R/F screening tools. If results indicated a child might be at risk for ASD, the parents were contacted for a structured interview/ASD evaluation. Following this, parents were given a researcher-created 30-item post-evaluation satisfaction questionnaire containing 4-point Likert-scale and

Table 1 (continued)

Reference	Article type	*N*	Mean age of sample	Sample demographics	Time from diagnosis to satisfaction ratings	Diagnostic professional/ environment	Measurement method
							open-ended questions. Exploratory factor analysis, correlations, and a coding system to identify themes were used to analyse data
Keenan, Dillenburger, Doherty, Byrne, & Gallagher (2010)	Mixed methods	95 parents/carers 67 professionals	40 years (parents/carers) 8 years (child)	Parents were from 73% Northern Ireland, 27% Republic of Ireland. 16% single parent, 25% had medical problems, 48% unemployed, 32% worked part time, 18% worked full time	Not provided	Not provided	Two questionnaires were created by researchers, one for caregivers and one for professionals. Questionnaires included closed and open-ended questions. Small focus group discussions were also held
Mansell & Morris (2004)	Quantitative	55 parents	4–5 years (child)	Not provided	Not provided	Clinic utilizing a multidisciplinary approach	Questionnaire containing 4-point Likert scale questions and spaces for open-ended comments. Data was group by content to provide a generalized picture.
Midence & O'Neill (1999)	Qualitative	4 families	Not provided	North Wales	Not provided	Not provided	Interviews based on semi-structured questionnaires. grounded theory was used to analyse the data.
Minnes & Steiner (2009)	Qualitative	17 parents (3 of children with ASD)	Not provided	Canada	Not provided	Not provided	Focus groups were obtained and interviewed through purposeful sampling. Questions were open-ended and structured. Grounded theory was used to analyse the data; inter-rater reliability present
Moh & Magiati (2012)	Quantitative	104 parents/carers 17 professionals	39.8 years (caregivers) 7.3 years (child) 37.9 years (professionals)	China. 97% married. 73% Chinese, 9% Malay, 7% Indian, 10% other ethnic backgrounds. Range of educational and socio-economic backgrounds	Diagnosed in 2001 or after	Not provided	Questionnaires were given to parents/carers and professionals containing both closed- and open-ended questions. The relationship between caregivers and professionals was measured using an existing 20-item scale of 4-point Likert-type items (Family/Professional Collaboration Scale). An

Table 1 (continued)

Reference	Article type	*N*	Mean age of sample	Sample demographics	Time from diagnosis to satisfaction ratings	Diagnostic professional/ environment	Measurement method
							existing 77-item scale about ASD severity was used containing 3- and 4-point questions (Autism Treatment Evaluation Checklist). A 5-point scale of stressed was also used. ANOVA, regression analysis, and Pearson's correlation were used to analyse the data
Potter (2017)	Combined methods	306 fathers 184 (fathers who answered the open-ended)	Not provided	Across the UK. 94% biological father. 79% married, 12% in partnership, 6% divorced/widowed, 2% single. 52% degree/postgraduate qualifications, 20% passes at GCSE/A level, 19% vocational qualifications, 9% primary/secondary school education. 62% work full time, 15% retired/not in paid work, 14% self-employed, 9% part-time. 95% White, 2% mixed, 1% Black, 1% Asian, 1% Chinese ethnic background	Not provided	Not provided	Online surveys were given, containing closed- and open-ended questions. Survey development was informed by the Inventory of Father Involvement, the Brief COPE, and other research studies on father involvement. Data was coded; open-ended questions were analysed using Thematic Analysis.
Renty & Roeyers (2006)	Mixed methods	224 parents (questionnaire) 15 parents (interview)	8.87 years (child)	60% lower socio-economic status	1 year	Multidisciplinary team	A survey was developed, based on literature on consumer satisfaction, containing demographic/general information and 5-point Likert scale questions. Interview data was analysed thematically.
Ryan & Salisbury (2012)	Qualitative	24 parents	Not provided	Across the UK. 15 married, 3 separated/divorced, and 1 single. Nine worked full-time, 5 part-time, 8 full-time career, and 2 students.	Not provided	Not provided	Semi-structured interviews were conducted. Interviews were analysed thematically by two independent researchers.

Table 1 (continued)

Reference	Article type	*N*	Mean age of sample	Sample demographics	Time from diagnosis to satisfaction ratings	Diagnostic professional/ environment	Measurement method
				20 were White and 4 were Other ethnic backgrounds			
Sansosti, Lavik, & Sansosti (2012)	Mixed methods	16 families	31–35 years (caregivers) 5.5 years (child)	US. 62.5% Caucasian, 81.3% biological mothers. 12 complete bachelor's degree or higher, 4 received high school diploma or equivalent. Mean range of income was \$85,000–\$99,000, 13% qualified for government aid programs	Not provided	Not provided	The VABS-II, GARS-2, GADS, TABS, and EIFS were used to obtain quantitative data. Descriptive statistics, independent *t* tests, chi-square, and correlational analyses were used to explore this data. Qualitative data was obtained through semi-structured interviews containing closed and open-ended questions. This data was analysed using grounded theory.
Siklos & Kerns (2007)	Quantitative	56 parents	38.54 years (parent) 7.98 years (child)	Canada. 85.7% were two parent households, 50.0% lived in urban areas, mean age mother education 14.85	2.96 years	30.9% clinical psychologist, 30.9% paediatrician/family doctor, 13.2% child psychiatrist, 19.1% multidisciplinary.	Three questionnaires were given: The Diagnostic Survey (Howlin & Moore, 1997; 33-items), Child Characteristics Questionnaire (82-items), and Demographics questionnaire (15-items).
Whitaker (2002)	Qualitative	Not provided	Under 5	UK	Not provided	Not provided	Semi-structured interviews, including open-ended and rating scale questions, were conducted.

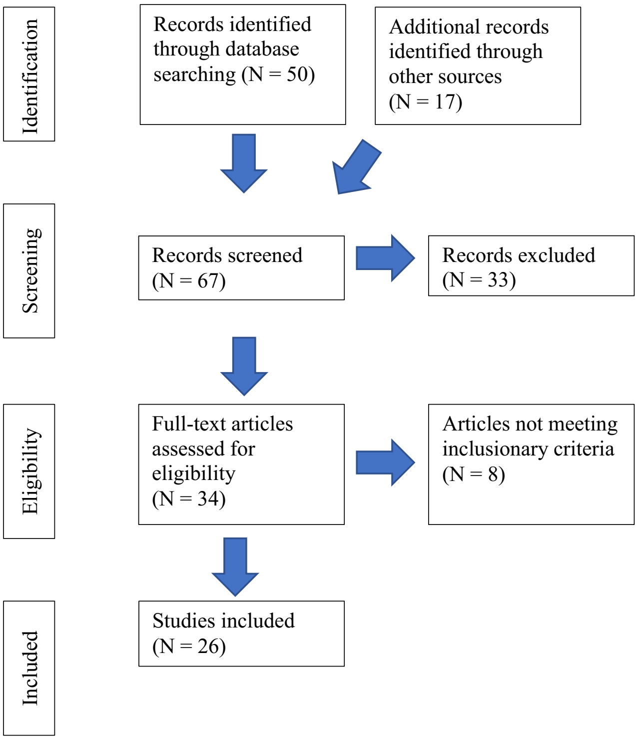

Fig. 1 Flow chart diagram illustrating the identification and selection of articles. This diagram is a minorly adapted version of the PRISMA flow diagram (Moher, Liberati, Tetzlaff, Altman, & the PRISMA Group, 2009)

Extraction categories included (1) factors related to satisfaction and (2) factors related to dissatisfaction. Following this, the first author (A. M.) grouped extracted data into factors related to (1) satisfaction within pre-assessment, assessment, diagnostic disclosure, and post-assessment, and (2) dissatisfaction within pre-assessment, assessment, diagnostic disclosure, and post-assessment. The second author (S. G.) extracted data from articles pertaining to (1) article type (e.g., quantitative), (2) sample size, (3) mean age of sample, (4) sample demographics, (5) time from diagnosis to satisfaction assessment, (6) diagnostic professionals and environment, and (7) measurement method. Tables 1 and 2 outline this process.

Article Characteristics

Articles came from various journals including *Autism* (8); *Child: Care, Health and Development* (2); *Journal of Autism and Developmental Disorders* (2); and *Research in Developmental Disabilities* (2). Published years ranged from 1994 to 2019. From the articles that reported time elapsed between ASD diagnosis and parent ratings of satisfaction, five took place within a year or less from diagnosis and 10 were within five years following a diagnosis. A range of countries and socio-economic backgrounds was represented; however, White/Caucasian was the predominant ethnic background represented by these articles. Diagnostic assessment was most common using a multidisciplinary team (9), with paediatricians (5), psychiatrists (5), and psychologists (5) being the most common single professions seen. Most studies created their own questionnaires to determine levels of parental (dis)satisfaction. Examined articles included qualitative, quantitative, or a combination of these to measure parental satisfaction. Generally, measures sought information on when parents first became concerned, the diagnostic process, care from medical professionals, concerns parents had during/following the diagnostic process, and reasons for (dis)satisfaction. Qualitative measures were frequently analysed by at least two researchers and focused on identifying themes that appeared across participants. Quantitative measures frequently utilized a 4- or 5-point Likert scale (e.g., very dissatisfied to very satisfied) and analysed via chi-square, ANOVA, or regression. Although the articles included in this review span multiple decades and recognizing that the assessment and treatment of ASD has advanced throughout the years, general study designs, sample characteristics, and findings followed consistent themes (e.g., length of time on a wait-list was a significant factor related to dissatisfaction throughout the decades).

Results

The results of the included studies were initially categorized into factors pertaining to satisfaction and those related to dissatisfaction. There was some overlap across these two terms (i.e., the presence of a factor could be reported to lead to satisfaction and an absence of the same factor to dissatisfaction); however, this connection between the two outcomes was not consistent and each appears to have uniquely related factors (see Table 2). As such, this initial categorisation was seen to fit the data effectively. Subsequently, topics relating to pre-assessment, assessment, the process of diagnostic disclosure, and post-assessment were identified within each category. Statistical significance of results is stated for quantitative studies when available.

Factors Related to Parental Satisfaction

Pre-assessment

Eight articles contained information pertaining to factors related to parental satisfaction with pre-assessment aspects of the clinical process(es) for their child. Participants reported significantly greater satisfaction when their initial concerns for their child’s development were accepted by professionals (Brogan & Knussen, 2003; Moh & Magiati, 2012), and generally when their referral to a diagnostic team was facilitated by their family doctor in a seamless manner (Minnes & Steiner, 2009; Ryan & Salisbury, 2012). Once the referral was initiated, families indicated significantly greater satisfaction when they were provided information about the process

Table 2 Identified factors and their relation to satisfaction/dissatisfaction

	Related to satisfaction	Related to dissatisfaction
Pre-assessment		
Acceptance/minimization of parental concerns	X	X
Seamless referral to diagnostic team	X	
Provided information about the process and time commitment	X	
Greater education and family income	X	
Multiple visits to the clinic		X
Felt blamed for their child’s behaviours		X
Difficulties accessing the diagnostic service		X
Child presented with more severe symptomatology		X
Assessment		
Child’s age at time of diagnosis	X	
Speed of diagnosis	X	X
Interdisciplinary team	X	
Specialists in ASD assessment	X	X
Definitive diagnosis	X	
Collaboration with educational personnel	X	
Comprehensive assessment	X	
Feelings of collaboration with the clinical team	X	X
Child with greater communication impairments	X	
Greater number of professionals		X
Lack of perceived professionalism by clinicians		X
Child with greater behavioural difficulties		X
Disclosure		
Easily understandable report provided	X	X
Opportunity to ask questions	X	
Easily understandable rationale for diagnostic outcome	X	X
Sufficient time for disclosure afforded	X	X
Clinical team acted professionally and with sensitivity	X	X
Lack of a definitive diagnosis		X
Lack of a disclosure process		X
Lack of a system to resolve uncertainties		X
Lack of detail regarding prognosis		X
Too much information to process		X
Post-assessment		
Link to community services	X	X
Information about local treatment options		X
Receipt of support from community services	X	
Access to other parents for support	X	
Offer of a follow-up session	X	X
Lack of child-specific supports		X

and time commitment required (Abbott et al., 2012; Hackett et al., 2009; Moh & Magiati, 2012). Finally, parents who self-reported as having greater education and family income reported significantly greater satisfaction with the diagnostic process (Goin-Kochel et al., 2006; Hidalgo et al., 2015; Ho et al., 1994), presumably arising from enhanced ability to access health and clinical services.

Assessment

Seventeen articles described factors related to parental satisfaction with the process of diagnosis. Specifically, parents reported significantly greater satisfaction when their child was diagnosed earlier in development (Andersson et al., 2014; Goin-Kochel et al., 2006; Howlin & Moore, 1997;

Renty & Roeyers, 2006; Ryan & Salisbury, 2012; Siklos & Kerns, 2007) and when their child demonstrated greater communication impairment (Siklos & Kerns, 2007). Parents also experienced significantly greater satisfaction when the diagnostic process was speedy and efficient (Crane et al., 2016; Ryan & Salisbury, 2012), with one study suggesting that less than a year was ideal (Howlin & Moore, 1997) and another indicating two months to be an ideal amount of time (Andersson et al., 2014). Parents appreciated when the assessment was perceived as comprehensive (Abbott et al., 2012) and significantly preferred collaboration between themselves and the clinicians (Abbott et al., 2012; Brogan & Knussen, 2003; Chamak et al., 2011; Hackett et al., 2009; Moh & Magiati, 2012). Parents were more satisfied when the assessment was conducted by multidisciplinary teams (Andersson et al., 2014; Hidalgo et al., 2015; Ho et al., 1994) whose members were perceived as specialists in ASD assessment (Howlin & Moore, 1997; Midence & O'Neill, 1999; Sansosti et al., 2012). Parents significantly appreciated receipt of a definitive diagnosis upon conclusion of the assessment (Abbott et al., 2012; Brogan & Knussen, 2003; Howlin & Moore, 1997) and when teachers or other school personnel were involved in the assessment (Andersson et al., 2014).

Diagnostic Disclosure

Twelve articles described factors related to parental satisfaction with disclosure of the diagnosis upon completion of the assessment. Parents reported that receipt of a written report at the time of disclosure (Abbott et al., 2012; Brogan & Knussen, 2003), which did not contain too may confusing medical terms (Hackett et al., 2009), significantly enhanced their satisfaction with the process. Parents were most satisfied when provided understandable and detailed information as to why their child met the diagnostic criteria for ASD (Abbott et al., 2012; Andersson et al., 2014; Crane et al., 2016; Hackett et al., 2009; Jashar et al., 2019; Moh & Magiati, 2012; Renty & Roeyers, 2006; Siklos & Kerns, 2007; Whitaker, 2002) and significantly when afforded the opportunity to ask questions of the clinical team during disclosure (Abbott et al., 2012; Brogan & Knussen, 2003; Hackett et al., 2009). Finally, parents expressed greater satisfaction when there was sufficient time allocated for the disclosure meeting (Abbott et al., 2012; Chamak et al., 2011; Hackett et al., 2009) and when the clinical team was perceived as professional and sensitive to parental needs (Jashar et al., 2019).

Post-assessment

Seven articles discussed factors related to parental satisfaction regarding post-assessment issues. Specifically, parents reported that provision of detailed information regarding community-based supports for their child led to greater satisfaction with the assessment process (Andersson et al., 2014; Moh & Magiati, 2012; Renty and Roeyers, 2006). Similarly, parental satisfaction was improved when they were able to connect with, and receive support from, such agencies (Whitaker, 2002), and significantly when they were able to be connected to other parents who have completed the diagnostic process for their child(ren) who could provide advice/guidance to families of a newly diagnosed child (Chamak & Bonniau, 2013; Crane et al., 2016; Renty and Roeyers, 2006; Whitaker, 2002). Finally, parents described greater satisfaction when afforded the opportunity for a follow-up session with the diagnostic team subsequent to disclosure to discuss issues or questions that may have arisen (Abbott et al., 2012).

Factors Related to Parental Dissatisfaction

Pre-assessment

Twelve articles described factors related to parental dissatisfaction with the pre-assessment phase. Parents experienced greater dissatisfaction when their concerns for their child's development were minimized or not appreciated by clinical care providers (Chamak & Bonniau, 2013; Chamak et al., 2011; Crane et al., 2018; Ho et al., 1994; Ryan & Salisbury, 2012; Sansosti et al., 2012). Parents also experienced heightened dissatisfaction when they visited medical clinics multiples times before their concerns were taken seriously (Andersson et al., 2014) and when they felt blamed for their child's symptomatic behaviours (Chamak et al., 2011; Crane et al., 2018; Midence & O'Neill, 1999). They were also dissatisfied when they experienced difficulty in referral to, or access of, the ASD diagnostic clinic (Chamak et al., 2011; Goin-Kochel et al., 2006; Hidalgo et al., 2015) and when their child presented with more severe ASD symptomatology (Moh & Magiati, 2012).

Assessment

The most common factor discussed was parental dissatisfaction with the diagnostic process, with 16 articles describing this issue. Parents were dissatisfied when their child was assessed by professionals they perceived of as non-specialists, such as general practitioners or professionals who were perceived as being disconnected from contemporary understandings of ASD (Midence & O'Neill, 1999; Sansosti et al., 2012) and when their child presented with greater behavioural difficulties during the assessment (Crane et al., 2018), potentially reflecting the diagnosticians' challenges with working with those with ASD. Parents also became significantly distressed with a greater number of different professionals involved in the diagnostic team (Goin-Kochel et al., 2006; Renty & Roeyers, 2006). They expressed frustration when the diagnostic team presented as unprofessional or uncaring of the parents' concerns (Chamak et al., 2011; Crane et al., 2018), and when they did not feel as though rapport with the clinical team had been appropriately established (Crane et al., 2018). The most common variable described in the review was significant parental dissatisfaction with the length of time the family remained on a wait list to undergo the diagnostic assessment (Abbott et al., 2012; Brogan & Knussen, 2003; Chamak & Bonniau, 2013; Chamak et al., 2011; Crane et al., 2016; Howlin and Asgharian, 1999; Keenan et al., 2010; Moh & Magiati, 2012; Potter, 2017; Renty & Roeyers, 2006; Sansosti et al., 2012; Whitaker, 2002). Specific timelines were not often reported; however, dissatisfaction increased following as little as a 1.5-year delay from referral to diagnosis (Keenan et al., 2010).

Diagnostic Disclosure

Eleven articles provided information relating to parental dissatisfaction with the diagnostic disclosure process. Parents experienced frustration when there was not a formal and effective process of diagnostic disclosure (Chamak et al., 2011). Specifically, parents disliked feeling overwhelmed by too much information (Jashar et al., 2019; Keenan et al., 2010), or when the clinical team was perceived as insensitive to parental needs during the feedback (Potter, 2017). Parents also expressed dissatisfaction when the outcome of the assessment was a lack of definitive diagnosis (Abbott et al., 2012; Chamak & Bonniau, 2013; Jashar et al., 2019) and when they did not receive specific details regarding how their child met the criteria for the diagnosis (Chamak et al., 2011; Jashar et al., 2019; Whitaker, 2002). Parents also disliked receiving vague details about what ASD is and when the clinical team used confusing terminology during the feedback session (Crane et al., 2018; Sansosti et al., 2012; Whitaker, 2002). Lack of sufficient time for the disclosure meeting and a process to clarify misunderstandings or uncertainties during the disclosure also reduced parental satisfaction (Whitaker, 2002). Finally, parents sought details regarding developmental outcomes for their child and were significantly dissatisfied when they did not receive such information (Mansell & Morris, 2004).

Post-assessment

Eight articles reported on factors related to parental dissatisfaction subsequent to the assessment process. Ho et al. (1994) reported that parents desired interventions specific to their child's unique needs and were dissatisfied if none were provided. Parents also sought information about local/regional treatment or support options for their child and were significantly dissatisfied if they did not receive sufficient leads to follow up on (Crane et al., 2018; Mansell & Morris, 2004; Potter 2017; Sansosti et al., 2012; Siklos & Kerns, 2007; Whitaker, 2002). Finally, parents indicated a desire for a follow-up session with the clinical team to discuss issues or questions that had arisen subsequent to the disclosure meeting; a lack of such opportunity was related to dissatisfaction (Crane et al., 2018; Jashar et al., 2019).

Discussion

The increase in prevalence of ASD has led to greater focus on research to identify effective assessment processes. Such research serves to highlight important elements of parental experiences with clinical practices related to the assessment of ASD. This systematic review was undertaken to provide a synthesized examination of factors related to parental (dis)satisfaction with the assessment process and to provide important suggestions for clinical practice and future research. Thirty-six indicators of parental (dis)satisfaction with the assessment process were identified that can be considered through the context of a timeline (pre-assessment, assessment, diagnostic disclosure, and post-assessment), with 10 of these indicators spanning both positive and negative parental experiences (i.e., the presence of a factor contributes to satisfaction and the lack of a factor to dissatisfaction).

Given that the actual assessment process is typically a brief period of time in a family's life (and that speed of referral, reduced time on a wait list, and speed of the assessment process were all indicators of satisfaction), a second context in which to consider the indicators can be discerned—those indicators that clinicians have (at least some) direct control over and those that they do not. Seen in this way, aspects of parental (dis)satisfaction vary in the degree to which clinicians may have direct influence. As clinicians operate within organizations that establish policies and practices around how referrals are received, the timelines for wait lists, team composition, and how assessments are conducted, some indicators of parental (dis)satisfaction are organizational in nature and so clinicians may have little influence in addressing them. As well, factors related to the severity of the child's symptoms, or their degree of challenging behaviour coming into assessment, are outside of clinician control. When considering this context of clinician influence as embedded within the timeframe of assessment, the quality and effectiveness of clinician communication and relationship building with parents can be differentiated as more directly influenced by clinicians.

Communication and Relationship Building

Clinicians can influence parental (dis)satisfaction, ultimately aiming to increase satisfaction, by managing the communication between clinician(s) and parents and striving to enhance working relationships with parents and other professionals. A collaborative relationship between clinicians and parents that involves open and effective communication throughout the process may increase parental satisfaction. The reviewed studies indicated that clinicians, including those who are in initial receipt of parental concerns such as family doctors, can enhance parental satisfaction by first acknowledging and accepting parental concerns and reducing parental stress regarding assessment by having open discussions about the referral and diagnostic process (Abbott et al., 2012; Moh & Magiati, 2012). By explaining this information adequately and affording parents opportunities to ask questions, parents can enter the assessment process knowing what to expect and feeling as though their concerns were heard and appreciated. This avenue of open communication may allow clinicians to understand and recognize how parents are responding to the assessment process, as well as address possible misunderstandings (e.g., parents feeling blamed for their child's behaviours), leading to greater satisfaction. Furthermore, parental satisfaction increases when clinicians create effective working relationships with parents and other professionals (e.g., teachers, occupational therapists, speech language pathologists, etc.; Andersson et al., 2014). Although multiple professionals involved in the assessment may enhance satisfaction (use of a multidisciplinary team), the involvement of too many professionals may decrease satisfaction (Goin-Kochel et al., 2006).

When assessment activities end and feedback regarding diagnostic outcome is initiated, effective communication again plays a key role in parental (dis)satisfaction. A formal feedback process that allows the clinician/clinical team time to explain diagnostic conclusions, supports parental processing of this information, and allows time for questions can lead to satisfaction (Abbott et al., 2012; Mansell & Morris, 2004). By engaging in an effective feedback process, clinicians demonstrate care and sensitivity to the needs of parents, facilitate stronger working relationships, and address possible misunderstandings and uncertainties (Jashar et al., 2019; Whitaker, 2002).

The reviewed articles indicated that parents desire an understanding of what ASD is and how their child does or does not meet the diagnostic criteria (Abbott et al., 2012; Chamak et al., 2011; Whitaker, 2002). Clinicians may increase satisfaction by ensuring appropriate language is used in both the feedback and written report (Crane et al., 2018; Hackett et al., 2009) to encourage open communication with parents and enhance parental understanding of the diagnosis. However, too much information can become overwhelming and stressful for parents (Mansell & Morris, 2004); clinicians should check in with parents frequently, help them to process information, and possibly separate the feedback process across multiple sessions to minimize information overload and increase parents' perception of the clinician/clinical team as caring and open (Crane et al., 2018; Jashar et al., 2019).

Finally, after the assessment process comes to a close, clinicians may aim to increase satisfaction by providing parents with next steps. The outcome of an ASD diagnosis is likely to be a stressful and overwhelming experience that may lead parents to feel at a loss. Clinicians who provide information about next steps send parents a message of caring for the family that can enhance satisfaction. These next steps may include information regarding support groups, community and/or financial supports, and information about interventions that may help meet their child's unique needs (Chamak & Bonniau, 2013; Moh & Magiati, 2012; Whitaker, 2002). Ultimately clinicians who seek to connect the parents with continual information and support may be perceived as more sensitive and caring, leading to higher parental satisfaction.

External Influences

As with any clinical work with families, there are some elements of the assessment process that are influenced by factors external to clinicians (e.g., organization, familial). However, these factors are important as they play a role in parental satisfaction.

Before parents even see clinicians regarding an ASD assessment, satisfaction is influenced by parental education, family income, and family doctors. Families report having gone to many clinics and seeing many professionals while being on lengthy waitlists before finally coming to the diagnostic team (Chamak et al., 2011; Renty & Roeyers, 2006; Sansosti et al., 2012). As access to effective healthcare and clinical teams is related to parental (dis)satisfaction, it will be important the efforts are dedicated to enhancing access to quality diagnostic services for a diverse population that varies in terms of race/ethnicity, religion, socioeconomic status, insurance coverage, etc. These factors influence parental (dis)satisfaction despite occurring prior to the initial clinician-parent meeting.

Another factor pertaining to parental (dis)satisfaction is the length of time needed for the assessment (Crane et al., 2016). Although clinicians can make many efforts to ensure that the assessment process is done in a timely manner, this is not always possible as there are organizational factors that influence the length and timing of the process (e.g., contacting other professionals, scheduling conflicts, etc.). One possible avenue to address this issue is greater training and awareness of primary care providers, such as family doctors, paediatricians, daycare and school teachers, etc., who interact with children frequently. Greater awareness of signs of ASD by these individuals may facilitate earlier referral for assessment and, subsequently, earlier age of diagnosis. Formal partnerships between educational and clinical professionals may also facilitate referral processes and ease of transition into the diagnostic process. As well, additional training to enhance the competence and/or number of available clinicians to conduct

ASD assessment may increase parental satisfaction due to reduction in wait times. In line with this, healthcare systems need to be mindful that families with varying financial resources will try to access diagnostic services and so effort should be dedicated to addressing this need regardless of insurance coverage (e.g., the development of diagnostic teams in free clinics).

Clinicians are also unable to control when in development children come to get assessed (Andersson et al., 2014; Goin-Kochel et al., 2006; Howlin & Moore, 1997; Renty & Roeyers, 2006; Ryan & Salisbury, 2012; Siklos & Kerns, 2007), the severity of childrens' presenting symptoms (Moh and Magiati 2012), or the presence of problematic behaviours (Siklos & Kerns, 2007), all of which influence parental (dis)satisfaction. Although these factors influence parental dissatisfaction prior to initial contact with diagnostic clinicians, clinicians can seek to employ strategies to lessen the impact of these factors. For example, screening of at-risk children may help to increase early detection and clinicians can demonstrate effective strategies for managing difficult behaviours.

Lastly, parental (dis)satisfaction is influenced when it is unclear if the child meets the criteria for an ASD diagnosis (Abbott et al., 2012; Chamak et al., 2011). Although children may be referred for assessment, there are many cases in which the families walk away without a diagnosis due to influences outside of clinician control (e.g. incomplete assessments due to external factors, co-occurring conditions overshadowing symptoms, etc.).

Implications

Parents of a child undergoing a diagnostic assessment for ASD experience many stressors in their life that can be exacerbated by the timeline and process of assessment, and the ways in which the clinician/clinical team engages with the family. Clinicians who establish effective rapport and send a message of responsible caring for the family throughout the process of assessment can enhance parents' satisfaction. When considering the factors able to be influenced by clinical teams, the inclusion of multidisciplinary teams and options for additional feedback sessions produces financial and insurance implications. Organizations and clinicians must work collaboratively to determine the most effective pathways into and through diagnostic processes so that services can be accessed by the most people in the most cost-effective and efficient manner so as to promote satisfaction with the process.

Future Research

Researchers may wish to examine how many clinicians parents perceive as "appropriate" to complete the assessment effectively and how many is too many before parental satisfaction is negatively influenced. Researchers could also explore ways in which clinicians may address children's presenting symptoms and problematic behaviours appropriately so that parents do not experience dissatisfaction on that basis. Researchers may also wish to explore effective means of increasing the accessibility of health and clinical services for parents of diverse backgrounds. Another avenue of research could be investigation of the negative feelings that parents experience upon receipt of an inconclusive diagnostic outcome and how clinicians can help families experiencing such emotions to process the information, including next steps. Finally, researchers could seek to identify the length of time on a wait list, and to complete the assessment, after which parents report feelings of dissatisfaction, with the goal of mobilizing that knowledge to enact change to organizational policies/practices.

Limitations

As majority of the articles included within this review opted to create their own questionnaires to assess parental (dis)satisfaction, it is difficult to determine the reliability and validity of the scales used. This creates a barrier for generalizing results to other populations and made it more challenging to determine the quality of the research conducted. Future research should consider developing a consistent and robust parental (dis)satisfaction scale to strengthen the research done on this topic. Furthermore, the majority of articles did not include specific timelines when discussing factors related to parental (dis)satisfaction (e.g. when in development is satisfactory for assessments to happen, how long is too long on waitlists/from assessment start to end). This makes it difficult to draw definitive recommendations for clinicians pertaining to factors related to time. As well, the majority of articles relied on retrospective parental report at least one year post-diagnosis; this carries the potential for parental reports to be incorrectly recalled and/or modified by confounding factors (e.g. difficulties faced after the process).

Conclusions

This systematic review has summarized the literature on parental (dis)satisfaction with the ASD assessment process. Factors related to parental (dis)satisfaction can be understood as embedded along a timeline as well as being influenced either by the clinician(s) working with the families or by external factors. Clinicians who seek to increase parental satisfaction may do so through facilitating good communication and appropriate relationships. Furthermore, clinicians who are aware of and understand external factors influencing parental (dis)satisfaction may be better able to respond appropriately and minimize the impact of such factors on the working relationship between parents and clinicians. Ultimately, it is hoped that this review will reduce the potential negative impact of the diagnostic process and enhance quality of care and clinical approach with families.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflict of interest.

References

Abbott, M., Bernard, P., & Forge, J. (2012). Communicating a diagnosis of autism spectrum disorder-a qualitative study of parents' experiences. *Clinical Child Psychology and Psychiatry, 18*(3), 370–382. https://doi.org/10.1177/1359104512455813.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Author: Washington, D.C.

Andersson, G. W., Miniscalco, C., & Gillberg, C. (2014). Preschoolers assessed for autism: parent and teacher experiences of the diagnostic process. *Research in Developmental Disabilities, 35*, 3392–3402. https://doi.org/10.1177/1362361319833676.

Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J., Warren, Z., … Dowling, N. F. (2018). Prevalence of autism spectrum disorder among children aged 8 years - autism and developmental disabilities monitoring network, 11 sites, United States, 2014. *Morbidity and mortality weekly report. Surveillance Summaries (Washington, D.C. : 2002), 67*(6), 1–23. :https://doi.org/10.15585/mmwr.ss6706a1.

Brogan, C. A., & Knussen, C. (2003). The disclosure of a diagnosis of an autistic spectrum disorder: determinants of satisfaction in a sample of Scottish parents. *Autism, 7*(1), 31–46. https://doi.org/10.1177/1362361303007001004.

Campbell, J. M., Ruble, L. A., & Hammond, R. K. (2014). Comprehensive developmental approach assessment model. In L. A. Wilkinson (Ed.), *Autism spectrum disorder in children and adolescents: evidence-based assessment and intervention in schools*. Washington DC: American Psychological Association.

Centers for Disease Control and Prevention (2007). Prevalence of autism spectrum disorders – Autism and Developmental Disabilities Monitoring Network, six sites, United States, 2000. *MMWR Surveillance Summaries, 56*(SS01), 1–11.

Chamak, B., & Bonniau, B. (2013). Changes in the diagnosis of autism: how parents and professionals act and react in France. *Culture, Medicine and Psychiatry, 37*(3), 405–426. https://doi.org/10.1007/s11013-013-9323-1.

Chamak, B., Bonniau, B., Oudaya, L., & Ehrenberg, A. (2011). The autism diagnostic experiences of French parents. *Autism, 15*(1), 83–97. https://doi.org/10.1177/1362361309354756.

Crane, L., Batty, R., Adeyinka, H., Goddard, L., Henry, L. A., & Hill, E. L. (2018). Autism diagnosis in the United Kingdom: perspectives of autistic adults, parents and professionals. *Journal of Autism and Developmental Disorders, 48*(11), 3761–3772. https://doi.org/10.1007/s10803-018-3639-1.

Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2016). Experiences of autism diagnosis: a survey of over 1000 parents in the United Kingdom. *Autism, 20*(2), 153–162. https://doi.org/10.1177/1362361315573636.

Fernell, E., Eriksson, M. A., & Gillberg, C. (2013). Early diagnosis of autism and impact on prognosis: a narrative review. *Clinical Epidemiology, 5*, 33–43. https://doi.org/10.2147/CLEP.S41714.

Goin-Kochel, R. P., Mackintosh, V. H., & Myers, B. J. (2006). How many doctors does it take to make an autism spectrum diagnosis? *Autism, 10*(5), 439–451. https://doi.org/10.1177/1362361306066601.

Hackett, L., Shaikh, S., & Theodosiou, L. (2009). Parental perceptions of the assessment of autistic spectrum disorders in a tier three service. *Child and Adolescent Mental Health, 14*(3), 127-132. : https://doi.org/10.1111/j.1475-3588.2008.00508.x.

Hidalgo, N. J., McIntyre, L. L., & McWhirter, E. H. (2015). Sociodemographic differences in parental satisfaction with an autism spectrum disorder diagnosis. *Journal of Intellectual and Developmental Disability, 40*(2), 147–155. https://doi.org/10.3109/13668250.2014.994171.

Ho, H. H., Miller, A., & Armstrong, R. W. (1994). Parent-professional agreement on diagnosis and recommendations for children with developmental disorders. *Children's Health Care, 23*(2), 137–148. https://doi.org/10.1207/s15326888chc2302_6.

Howlin, P., & Asgharian, A. (1999). The diagnosis of autism and Asperger syndrome: findings from a survey of 770 families. *Developmental Medicine and Child Neurology, 41*(12), 834–839.

Howlin, P., & Moore, A. (1997). Diagnosis in autism: a survey of over 1200 patients in the UK. *Autism, 1*(2), 135–162. https://doi.org/10.1177/1362361397012003.

Huws, J. C., Jones, R. S., & Ingledew, D. K. (2001). Parents of children with autism using an email group: a grounded theory study. *Journal of Health Psychology, 6*(5), 569–584.

Jashar, D. T., Fein, D., Berry, L. N., Burke, J. D., Miller, L. E., Barton, M. L., & Dumont-Mathieu, T. (2019). Parental perceptions of a comprehensive diagnostic evaluation for toddlers at risk for autism spectrum disorder. *Journal of Autism and Developmental Disorders, 49*(5), 1763–1777. https://doi.org/10.1007/s10803-018-3851-z.

Keenan, M., Dillenburger, K., Doherty, A., Byrne, T., & Gallagher, S. (2010). The experiences of parents during diagnosis and forward planning for children with autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities, 23*(4), 390–397. https://doi.org/10.1111/j.1468-3148.2010.00555.x.

Klin, A., Saulnier, C., Tsatsanis, K., & Volkmar, F. R. (2005). Clinical evaluation in autism spectrum disorders: psychological assessment within a transdisciplinary framework. In F. R. Volkmar, R. Paul, A. Klin, & D. Cohen (Eds.), *Handbook of autism and pervasive developmental disorders* (3rd ed., pp. 772–798). Hoboken: Wiley.

Mansell, W., & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service access to information and use of services. *Autism, 8*(4), 387–407. https://doi.org/10.1177/1362361304045213.

Midence, K., & O'neill, M. (1999). The experience of parents in the diagnosis of autism: a pilot study. *Autism, 3*(3), 273–285. https://doi.org/10.1177/1362361399003003005.

Minnes, P., & Steiner, K. (2009). Parent views on enhancing the quality of health care for their children with fragile X syndrome, autism or Down syndrome. *Child: Care, Health and Development, 35*(2), 250–256. https://doi.org/10.1111/j.1365-2214.2008.00931.x.

Moh, T. A., & Magiati, I. (2012). Factors associated with parental stress and satisfaction during the process of diagnosis of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *293–303*. : https://doi.org/10.1016/j.rasd.2011.05.011.

Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & The PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Medicine, 6*(7), e1000097. https://doi.org/10.1371/journal.pmed1000097.

National Institute for Health and Care Excellence. Autism: recognition, referral and diagnosis of children and young people on the autism spectrum. (Clinical guideline 128.) 2011. http://guidance.nice.org.uk/CG128

National Research Council. (2001). Educating children with autism. In C. Lord & J. P. McGee (Eds.), *Committee on educational interventions* *for children with autism* (pp. 211–229). Washington, DC: National Academy Press.

Potter, C. A. (2017). “I received a leaflet and that is all”: Father experiences of a diagnosis of autism. *British Journal of Learning Disabilities, 45*(2), 95–105. https://doi.org/10.1111/bld.12179.

Remington, B., Hastings, R. P., Kovshoff, H., degli Espinosa, F., Jahr, E., Brown, T., Alsford, P., Lemaic, M., & Ward, N. (2007). Early intensive behavioral intervention: outcomes for children with autism and their parents after two years. *American Journal on Mental Retardation, 112*(6), 418–438.

Renty, J., & Roeyers, H. (2006). Satisfaction with formal support and education for children with autism spectrum disorder: the voices of the parents. *Child: Care, Health and Development, 32*(3), 371–385. https://doi.org/10.1111/j.1365-2214.2006.00584.x.

Richler, J., Huerta, M., Bishop, S., & Lord, C. (2010). Developmental trajectories of restricted and repetitive behaviours and interests in children with autism spectrum disorders. *Development and Psychopathology, 22*, 55–69. https://doi.org/10.1017/S0954579409990265.

Ryan, S., & Salisbury, H. (2012). ‘You know what boys are like’: Prediagnosis experiences of parents of children with autism spectrum conditions. *British Journal of General Practice, 62*(598), e378–e383. https://doi.org/10.3399/bjgp12X641500.

Sanders, J. L., & Morgan, S. B. (1997). Family stress and adjustment as perceived by parents of children with autism or Down syndrome: Implications for intervention. *Child and Family Behavior Therapy, 19*(4), 15–32. https://doi.org/10.1300/J019v19n04_02.

Sansosti, F. J., Lavik, K. B., & Sansosti, J. M. (2012). Family experiences through the autism diagnostic process. *Focus on Autism and Other Developmental Disabilities, 27*(2), 81–92. https://doi.org/10.1177/1088357612446860.

Schieve, L. A., Blumberg, S. J., Rice, C., Visser, S. N., & Boyle, C. (2007). The relationship between autism and parenting stress. *Pediatrics, 119*(supplement 1), S114–S121.

Shea, B., & Mesibov, G. (2009). Age-related issues in the assessment of autism spectrum disorders. In S. Goldstein, J. Naglieri, & S. Ozonoff (Eds.), *Assessment of autism spectrum disorder* (pp. 117–137). New York: Guilford.

Siklos, S., & Kerns, K. A. (2007). Assessing the diagnostic experiences of a small sample of parents of children with autism spectrum disorders. *Research in Developmental Disabilities, 28*(1), 9–22. https://doi.org/10.1016/j.ridd.2005.09.003.

Szatmari, P., Merette, C., Bryson, S. E., Thivierge, J., Roy, M., Cayer, M., & Maziade, M. (2002). Quantifying dimensions in autism: a factor-analytic study. *Journal of the American Academy of Child and Adolescent Psychiatry, 41*(4), 467–474. https://doi.org/10.1097/00004583-200204000-00020.

Volkmar, F., Siegel, M., Woodbury-Smith, M., King, B., McCracken, J., & State M & American Academy of Child and Adolescent Psychiatry (AACAP) Committee on Quality Issues (CQI). (2014). Practice parameter for the assessment and treatment of children and adolescents with autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry, 53*, 237–257. https://doi.org/10.1016/j.jaac.2013.10.013.

Whitaker, P. (2002). Supporting families of preschool children with autism: what parents want and what helps. *Autism, 6*(4), 411–426. https://doi.org/10.1177/1362361302006004007.