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Parental concerns of children with ASD by age: A qualitative analysis

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ABSTRACT

Background: Eliciting parents' concerns about their children is an important initial step in the ASD diagnostic process. This information is often collected through forced-choice questionnaires utilizing professional terminology and may limit the potential concerns that can be reported. Parent concern studies to date have largely used deductive qualitative methods with only one age group of children. Inductive qualitative studies are needed to examine parental concerns of children with ASD across age groups with one coding scheme.
Method: We used an inductive qualitative analysis process to analyze concerns reported by parents of children ages 1–11 years on intake forms ($n = 455$) at an urban outpatient ASD specialty clinic. Analyses were based on three age groups (toddler, preschooler, middle childhood).
Results: Using conventional content analysis, 12 categories of concerns emerged from parents' responses: communication, social, behavioral/emotional, cognition, life skills, atypical behaviors, sensory, academic, health, seeking diagnostic clarity or resources, developmental, and motor skills. We found that parents reported the same concerns about their children across age groups in six of the 12 categories. The biggest difference in reported concerns across age groups was that parents of children in the preschooler and middle childhood groups reported a greater number of concerns related to mental health than parents of toddlers.
Conclusion: Our analysis yields specific information about similarities and differences in parents' concerns depending on their child's age. Ensuring that ASD evaluations are tailored to children's unique needs has implications for timely diagnosis and access to care.

1. Introduction

Autism Spectrum Disorder (ASD) is a heterogeneous, life-long, neurodevelopmental condition characterized by an impairment in

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social-communication and the presence of restricted and repetitive behaviors (American Psychiatric Association [APA], 2013). Due to the marked heterogeneity of the disorder, children with ASD present with a broad range of impairments spanning the domains of behavior, cognition, and communication (Masi et al., 2017). Common comorbidities include anxiety (White & Roberson-Nay, 2009), Attention-Deficit/Hyperactivity Disorder (ADHD; Ghanizadeh, 2012), intellectual disability (Matson & Shoemaker, 2009; Simonoff et al., 2008), sleep difficulties (Goldman et al., 2012; Mannion & Leader, 2016), and gastrointestinal disorders (Mannion & Leader, 2016). A multidisciplinary approach to diagnostic evaluation is needed to address the complex ASD phenotype (Bölte et al., 2014; Dillenburger et al., 2014; Strunk et al., 2017).

1.1. A multidisciplinary approach to ASD evaluation

Multidisciplinary team members work toward a common goal and embrace the perspectives of each other to deliver the highest quality of care (World Health Organization [WHO], 2010). While multidisciplinary ASD diagnostic evaluations have been recommended as an effective method for making an accurate ASD diagnosis (Volkmar et al., 2014) and ensuring patient-centered practice (WHO, 2010), many of these evaluations are often conducted with a single provider, such as a psychologist or physician working independently (Gerdts et al., 2018). Eliciting parent concerns before an ASD evaluation can be useful to identify additional members needed to form an appropriate multidisciplinary diagnostic team to provide a comprehensive evaluation of the child's needs (Strunk et al., 2017). Tailoring the evaluation to include providers that can address parents' concerns ahead of time may result in a more streamlined and time-efficient way for families to navigate the evaluation process and gain access to appropriate care.

Eliciting parents' concerns about their children is an important initial step in the ASD diagnostic process (Hyman et al., 2020; Volkmar et al., 2014). The most common approach used to evaluate parental concerns, both within research methodology and clinical practice, is with structured or forced-choice parent questionnaires (e.g., Autism Diagnostic Inventory-Revised; Lord et al., 1994; Zablotsky et al., 2017) or researcher-developed schemas utilizing professional terminology (Donohue et al., 2019; Hess & Landa, 2012; Ozonoff et al., 2009; Richards et al., 2016). While each of these methods has utility for collecting parental concerns and contributing meaningful information about the child, these approaches often do not capture parents' concerns in their own words and potentially limit the concerns that parents can share (e.g., choosing from a predetermined list of concerns).

1.2. An inductive approach to parental concerns analysis

Several studies have sorted parental concerns into two broad categories, ASD-concerns and non-ASD concerns (e.g., Donohue et al., 2019; Ozonoff et al., 2009; Richards et al., 2016), using a deductive approach based on the criteria in the *Diagnostic and Statistical Manual of Mental Disorders, 5*th *Edition* (DSM-5; APA, 2013). While this gross categorization is helpful for condensing the variety of parental concerns when conducting quantitative analyses and can be valuable since parents may have difficulty in recognizing behaviors specific to ASD especially during early development (Caronna et al., 2007; Herlihy et al., 2015; Rao & Landa, 2014; Richards et al., 2016), it relies on researcher and/or clinician interpretation of parents' responses as opposed to categories driven by the parents' exact words. Since most parents are not fluent in the medical language used to describe their child's symptomatology, the exact wording of their concerns often differs from the terminology used by researchers and clinicians (Guinchat et al., 2012). This discrepancy emphasizes the importance of ensuring that clinicians work closely with parents as a part of a multidisciplinary team using active and reflective listening techniques to ensure that parents' concerns are understood and a comprehensive evaluation is conducted.

To capture a more thorough understanding of parental concerns without clinical interpretation, an open-ended form of questioning using an inductive method of qualitative analysis is needed. The advantage of this type of analysis, as opposed to the deductive methods used in prior studies examining parental concerns of children with ASD, is gaining direct information from parents without imposing preconceived categories, or professional terminology, onto their responses (Hsieh & Shannon, 2005). This allows for the creation of a more holistic, parent-centered, understanding of parental concerns by permitting all types of concerns to be captured in the coding scheme.

1.3. Parental concerns by age groups

Previous research suggests that parental concerns of younger children with ASD tend to focus on communication and joint attention (Kozlowski et al., 2011; Matheis et al., 2017; Ozonoff et al., 2009), while parental concerns of older children with ASD focus more on behavioral and motor differences (Sivberg, 2003; Zablotsky et al., 2017). However, several qualitative analyses to date have investigated parental concerns of children with ASD with only one age group, such as infants (Ozonoff et al., 2009) or toddlers (Donohue et al., 2019; Hess & Landa, 2012; Kozlowski et al., 2011; Richards et al., 2016). No inductive qualitative studies to our knowledge have been conducted to investigate parents' concerns across age groups using a single coding scheme. Such research is important to better understand the specific language parents use to describe their concerns about children of different ages.

The purpose of this study was to understand parents' concerns about their child with ASD, at the first ASD diagnostic evaluation. Using an inductive approach, we sought to answer the following research questions:

1 What are the concerns reported by parents of children receiving an ASD diagnostic evaluation for the first time?
2 What are the shared concerns reported by parents across different age groups (toddler, preschool, middle childhood)?
3 How do the concerns reported by parents differ across age groups (toddler, preschool, middle childhood)?

2. Methods

2.1. Participants

This work was carried out in accordance with the ethical standards of the responsible committee on human research and with the Declaration of Helsinki as revised in 2000. Data for this study came from an urban multidisciplinary outpatient ASD specialty clinic. The analytic sample consisted of children ages 1–11 years who: a) were seen between March 2014 and December 2019; b) whose parents agreed to join the IRB-approved research registry, which allows for use of the medical records for research (82 % consent rate in this sample); and c) whose parents reported no previous evaluation for, or diagnosis of ASD, but who were ultimately diagnosed with ASD at that visit ($n = 455$).

2.2. Background and history form

The Background and History form is a clinic-specific questionnaire completed by parents upon initiating their child's intake process to the clinic for an ASD diagnostic evaluation. For this analysis, responses ($n = 455$) to the open-ended question, "What are your concerns about your child?" were analyzed.

2.3. ASD diagnostic evaluation

ASD diagnosis was determined by a licensed medical provider (e.g., psychiatrist, developmental behavioral pediatrician or neurodevelopmental pediatrician) or licensed psychologist (clinical or neuro) based on the *DSM-5* (APA, 2013) and clinical judgment as part of an expert diagnostic multidisciplinary team. ASD diagnosis was informed by the child meeting ASD criterion on the *Autism Diagnostic Observation Schedule-Second Edition* (ADOS-2; Lord et al., 2012), which is the gold standard diagnostic measure for ASD, as well as additional medical history and presentation, developmental and family history, and behavioral testing (e.g., cognitive, adaptive, receptive/expressive language, sensory) completed by a multidisciplinary team member, such as a speech-language pathologist or occupational therapist depending on the expressed needs of the family at intake. This method of obtaining a

Table 1
Participant Characteristics.

	Total (all ages) ($N = 455$)	Toddler (1−2 years) ($n = 143$)	Preschooler (3−5 years) ($n = 178$)	Middle Childhood (6−11 years) ($n = 134$)
	M (*SD*) or %			
Child sex				
Female	19.6	21.0	20.8	16.4
Male	80.4	79.0	79.2	83.6
Child race/ethnicity				
White	46.8	39.2	44.4	58.2
Black/African-American	22.4	22.4	23.6	20.9
Multiracial or Other	13.8	13.3	16.3	11.2
Asian	10.5	14.0	11.8	5.2
Hispanic/Latino	6.4	11.2	3.9	4.5
Parent Education				
High school education or less	33.9	31.7	34.7	35.1
Trade school	21.7	23.2	20.2	22.1
Bachelor degree	26.7	28.2	23.1	29.8
Graduate degree	17.7	16.9	22.0	13.0
Insurance				
Private	57.3	60.7	53.1	59.4
Medical Assistance	41.1	39.3	44.6	38.3
ADOS module				
Toddler Module	22.4	71.3	0.0	0.0
Module 1	31.6	28.0	55.6	3.7
Module 2	15.4	0.7	30.9	10.4
Module 3	30.5	0.0	13.5	85.8
ADOS Social Affect	12.5 (4.8)	15.7 (4)	11.9 (4.6)	9.8 (3.9)
ADOS RRB	3.9 (2.1)	4.6 (2)	4.2 (2.1)	2.8 (1.8)
ADOS Calibrated Severity Score	7.4 (1.9)	8.3 (1.6)	7.1 (1.9)	7 (2)
Code* Count	4.8 (3.2)	4.0 (2.4)	4.7 (3.0)	5.9 (3.9)
Category* Count	4.2 (2.0)	3.7 (1.7)	4.2 (2.0)	4.6 (2.1)

Note. *Refers to qualitative data.

diagnosis has been used in other clinic-based studies (Azad et al., 2019, 2020).

ASD severity, in the current study, was measured using the ADOS-2 Calibrated Severity Score (CSS), a derived score to facilitate comparisons across modules (Esler et al., 2015; Gotham et al., 2009). The CSS scores range from 1 to 10, with higher scores reflecting greater ASD symptom severity. See Table 1 for participant demographics and scores on these measures.

Exclusionary criteria consisted of: a) children missing a completed ADOS-2 CSS ($n = 23$ excluded, $n = 520$ remaining); b) parent report of a prior ASD clinical diagnosis when describing concerns ($n = 6$ excluded); and c) a missing response to the question, "What are your concerns about your child?" on the Background and History Form ($n = 25$ excluded, 455 remaining in final analytic sample). Other non-ASD diagnoses prior to this visit were not exclusionary.

2.4. Qualitative coding procedure

Conventional content analysis was conducted using Microsoft Excel (16.38). Coders utilized the constant comparative method during coding, moving synchronously between text and codes to derive recurring categories (Bradley et al., 2007; Glaser & Strauss, 2017). A multidisciplinary team (i.e., the first three study authors) read the parents' responses. This multidisciplinary team consisted of a speech-language pathologist, psychiatric epidemiologist, and a developmental psychologist, all with doctoral degrees and combined 25 years of clinical and research experience with children with ASD. Emergent consensus coding was conducted with each response assigned to two coders, blind to child age (Creswell & Clark, 2017). See Fig. 1 for an illustration of the coding process. During initial coding, coders read each response and completed line-by-line coding independently, identifying key words and phrases to establish initial codes. The codes were parent-derived and not based on clinical definitions or terminology (i.e., codes were generated from the parents' responses without clinical interpretation, such as the DSM-5 criteria). See Table 2 for examples of parents' responses coded using the emergent coding process compared to broad categorization of concerns using the DSM-5, as conducted in previous studies (e.g., Larsen et al., 2018).

Individual codes were not mutually exclusive for parent responses, allowing each of the responses to be coded with all applicable codes (Richards et al., 2016). However, each code was only counted once for responses with multiple statements that could be summarized with the same code (as illustrated in Fig. 1). After initial coding was completed, the coders met and established consensus by identifying key words/phrases relevant to parents' concerns for their child. Initial codes were developed iteratively and combined into subcategories through interpretation and reflection (Charmaz, 2014). Axial coding was then completed, in which the subcategories and their definitions were refined, collapsed, and consolidated into larger categories (Charmaz, 2014; Corbin & Strauss, 2014). The credibility of categories was assessed through the use of triangulation of multiple coders and peer debriefing with a research psychologist with 21 years of experience evaluating and treating children with ASD (Merriam & Tisdell, 2015).

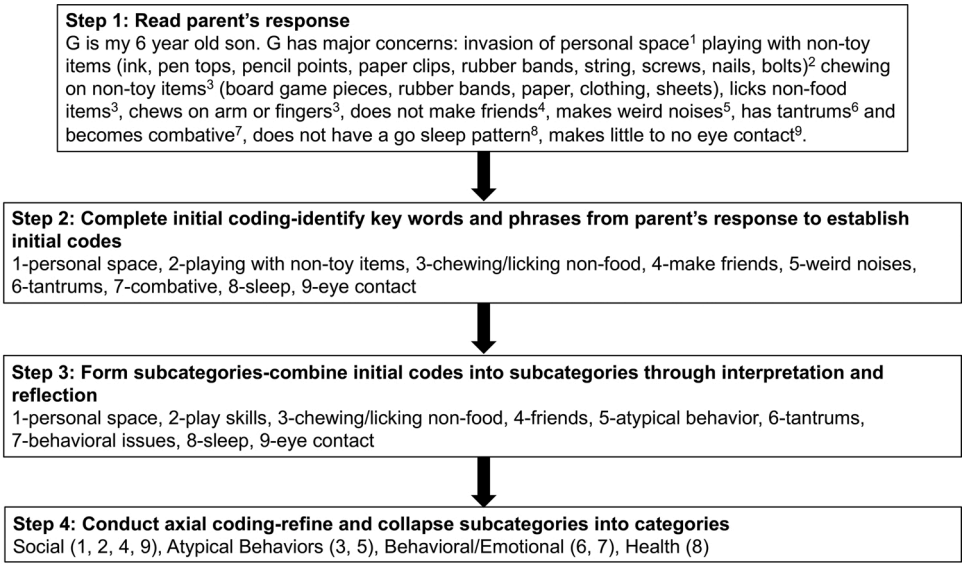

Figure 1. Emergent coding process. The top box indicates a parent's response to the open-ended question, "What are your concerns about your child?" After reading the response, the coders then identified key words and phrases from the responses to establish initial codes. Codes were combined into subcategories and refined during axial coding to establish categories of concerns. Each category was only counted once per response in the frequency counts.

Fig. 1. Emergent coding process. The top box indicates a parent's response to the open-ended question, "What are your concerns about your child?" After reading the response, the coders then identified key words and phrases from the responses to establish initial codes. Codes were combined into subcategories and refined during axial coding to establish categories of concerns. Each category was only counted once per response in the frequency counts.

Table 2
Comparison of Categorizing Parental Concerns Through Emergent Coding Process Versus DSM-5 Criteria.

Parent's Response	Subcategory	Category	*DSM-5* Criteria
"Makes little to no eye contact."	Eye contact	Social	Social Communication
"He doesn't show empathy for others but wants everyone to have regard for his feelings."	Emotions	Behavioral/ emotional	
"She displays unusual nonverbal communication."	Communicate	Communication	
"He also exhibits repetitive behaviors such as pacing hand flapping and toe walking."	Repetitive behavior	Atypical Behavior	Restricted, repetitive behaviors
"I'm concerned for her inability to be flexible."	Inflexibility	Cognition	
"He will get 'stuck' on something and repeat it constantly. One time for four hours."	Repetitive language	Communication	
"He has become extremely sensitive to sounds. He will cover his ears when a sound is overwhelming him."	Sounds	Sensory	

2.5. Age groups for analysis

Parents' concerns were divided into three age groups for analysis based on the Centers for Disease Control and Prevention (2020) categorization: (a) toddler, between one year and two years, eleven months of age; (b) preschooler, between three years and five years, eleven months of age; and (c) middle childhood, between six years and eleven years, eleven months of age.

3. Results

A total of 59 subcategories, reflecting parental concerns, emerged during the analysis. These subcategories were condensed into 12 overall categories. Frequencies of subcategories across age groups are provided in the Supplemental Material. Parents of children in each age group reported concerns in each category with varying frequencies (see Fig. 2). Within each category, there were shared concerns across parents of children in all three age groups as well as concerns that were only discussed by parents in one or two of the groups (see Table 3). Each category is described below in order of its greatest overall frequency of parent report.

3.1. Communication

Parents' concerns about their children's verbal and nonverbal communication skills, not specific to social situations, were captured by the communication category (64.84 %). This concern was most prevalent in the toddler and preschooler groups, 86.01 % and 70.79 % respectively. Parents in all three age groups reported concerns with their children's "limited" or "lack of" communication, speech (e.g., "can't speak clearly enough"), expressive or receptive language, response to name ("he does not answer to his name, although we do know he is hearing"), and repetitive language. One toddler's parent described her child's use of repetitive language, "He is now obsessed with elevators and keeps repeating the word elevator: 'Mommy, elevator. Dada, elevator. Baby, elevator…'" Parents of older children described repetitive language as imitation of others' speech, such as, "She sounds like she's having a conversation, but it's just borrowed from her favorite tv show." The only code that was not shared across all three age groups in this category was the gestures code, which was only present in responses of parents in the toddler and preschool age groups (e.g., "no pointing").

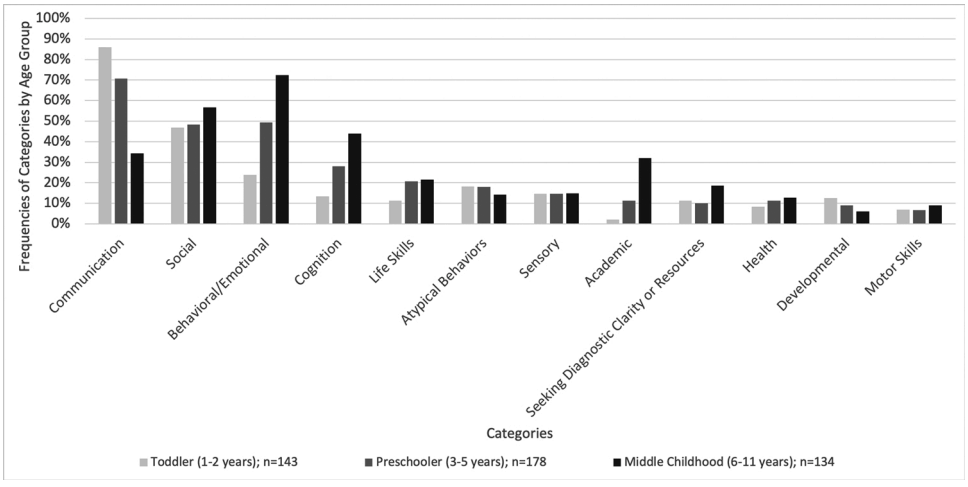

Fig. 2. Frequencies of categories by age group. Each bar represents the proportion of parents within the age group that reported a concern in the respective category.

Table 3
Subcategories of Parental Concerns Across Age Groups.

Category	Toddler (1−2 years)	Preschool (3−5 years)	Middle Childhood (6−11 years)
Communication	communicate, expressive language, **gestures,** receptive language, repetitive language, respond to name, speech/ language	communicate, expressive language, **gestures,** receptive language, repetitive language, respond to name, speech/ language	communicate, expressive language, receptive language, repetitive language, respond to name, speech/language
Social	eye contact, in own world, play skills, prefers being alone, social (general), social awareness, social skills	eye contact, **friends,** in own world, play skills, prefers being alone, social (general), social awareness, social skills	eye contact, **friends,** in own world, play skills, prefers being alone, social (general), social awareness, social skills
Behavioral/ Emotional	anger, anxiety, argumentative/defiant, behavioral issues, emotions, high energy/ hyperactivity, obsessive behavior/interests, physical self-harm, screaming, self-regulation	**aggression,** anger, anxiety, argumentative/ defiant, behavioral issues, **bullied, crying,** emotions, high energy/hyperactivity, **impulsivity,** obsessive behavior/interests, **OCD, physical harm (general), physical harm others,** physical self-harm, screaming, self-regulation	**aggression,** anger, anxiety, argumentative/ defiant, behavioral issues, **bullied, crying,** emotions, harm self, high energy/ hyperactivity, **impulsivity,** obsessive behavior/interests, **OCD, physical harm (general), physical harm others,** physical self-harm, screaming, self-regulation
Cognition	attention, cognition, inflexibility, memory	attention, cognition, inflexibility, memory	**ADHD,** attention, cognition, inflexibility, memory
Life Skills	toileting, eating, safety	toileting, eating, **life skills (general),** safety	toileting, eating, **life skills (general),** safety
Atypical Behaviors	chewing/licking non-food items, atypical behavior (general), repetitive behavior	chewing/licking non-food items, atypical behavior (general), repetitive behavior	chewing/licking non-food items, atypical behavior (general), repetitive behavior
Category	Toddler (1−2 years)	Preschooler (3−5 years)	Middle Childhood (6−11 years)
Sensory	food, sensory (general), sound, textures	food, sensory (general), sound, textures	food, sensory (general), sound, textures
Academic	learning	**academic skills,** learning	**academic skills,** learning
Health	sleep, other conditions	sleep, other conditions	sleep, other conditions
Seeking diagnostic clarity or resources	mention of ASD, seeking diagnostic clarity, seeking resources	mention of ASD, seeking diagnostic clarity, seeking resources	mention of ASD, seeking diagnostic clarity, seeking resources
Developmental	developmentally delayed	developmentally delayed	developmentally delayed
Motor Skills	fine motor, gross motor, motor skills (general)	fine motor, gross motor, motor skills (general)	fine motor, gross motor, motor skills (general)

Note. Subcategories are included that were present in at least one parent's response in each age group. Concerns that are not shared across all three age groups (i.e., present in one or two age groups only) are bolded.

3.2. Social

Parents' concerns in this category related to their children's social and play skills (50.33 %). Social concerns were reported by large proportions of parents in each age group (toddler: 46.85 %, preschooler: 48.31 %, middle childhood: 56.72 %). Parents' general social concerns varied across age groups. Parents of toddlers reported concerns with their children's lack of play with objects, atypical play such as "banging on objects rather than playing as intended," lack of imitation, and lack of pretend play. Parents of preschoolers reported repetitive play, difficulty participating in group activities, comfort with strangers, disinterest in "typical fun kid stuff," dislike of malls or places with a lot of people, difficulty making and keeping friends, and trouble understanding the concept of personal space. Parents of children in the middle childhood group also reported their children's comfort with strangers, dislike of crowded places, difficulty making and keeping friends, and lack of understanding of personal space. In addition, they also described their children's difficulty understanding social cues such as facial expressions and trouble with conversational skills such as having a "balanced conversation" or choosing "socially appropriate conversation topics." One parent described how her child's lack of social awareness impacts her ability to form and sustain friendships with others: "She has trouble making and keeping friends because she does not understand social cues. She has almost no concept of personal space and can't tell when other people don't want to talk or play."

3.3. Behavioral/Emotional

The behavioral and emotional category includes parents' concerns about children's internalizing and externalizing behaviors, as well as their ability to express, understand, or regulate their emotions (48.13 %). This category was the most prevalent in the middle childhood group (72 %). Many parents across age groups described concerns with the following: anger ("tantrums," "meltdowns," or "fits"); argumentative/defiant ("doesn't comply," "refusal to come off of a task until he is allowed enough time to complete it"); anxiety ("strange" or "inconsolable" fears); "behavioral issues;" hyperactivity ("trouble sitting still," or "constantly moving"); obsessive behavior/interests ("fixations"); and physical self-harm ("smack himself," "punching himself in the head"). Parents of children in the preschool and middle childhood groups described additional concerns in this category such as "aggression," being bullied ("other boys in his class are making fun of him"), "crying fits," difficulty understanding or expressing emotions appropriately ("any emotional reactions seem forced," "lack of empathy"), obsessive compulsive disorder (OCD), physical harm to others (biting, hitting, throwing objects), and impulsivity or "impulse control." Parents of children in the middle childhood group also reported additional behavioral concerns: elopement, making threats, and lying. One parent provided a description of his child's lying behavior, "He has begun telling lies [and] sticking to those lies even when presented with evidence that it's a lie, then screaming and crying when his lie isn't believed."

3.4. Cognition

Parent concerns captured in this category included concerns about attention, concentration, executive functioning, and inflexible thinking patterns (28.13 %). This category was most prevalent in the responses of parents of children in the middle childhood group (41.04 %). Parents in each age group reported concerns with children's attention ("issues paying attention"), cognition (including "slow cognitive processing" and executive functions), memory or "retaining information," and inflexibility ("very robotic thought process," "rigid approach to life"). For example, one middle childhood parent discussed how his child established and enforced his own set of unexplained "rules" for others to follow:

> He calls out anyone who is not playing by the same rules of which he is playing… For example, we arrived home once and a person was walking their dog. The dog was in our yard. [He] jumped out of the car and proceeded to yell at the adult woman walking the pooch.

The only code that was not shared across age groups in this category was concerns with ADHD, which was only present in parents' responses of children in the middle childhood group.

3.5. Life skills

Parents' concerns about children's abilities to independently carry out activities of daily living were included in the life skills category (18.02 %). These concerns were mentioned in many parents' responses of children in the preschool (20.79 %) and middle childhood (21.64 %) groups. Parents of toddlers had the most concerns with their children's difficulties feeding themselves ("refusal to pick up and eat food"), while parents of preschoolers had the most concern with their children's safety awareness. One preschool parent provided examples of her child's lack of safety awareness, "[He displays] unsafe behavior like leaving [the] room, house, and sometimes entering the homes of others." Parents of children in the middle childhood group described more general life skills concerns including "lack of common sense with everyday tasks," "weak adaptive skills," "lack of interest in learning appropriate life skills and career interests," and poor personal hygiene habits. One middle childhood parent described a concern with her child's ability to efficiently carry out a personal hygiene task: "To brush his teeth it takes him 20 min and that is with me constantly asking him to hurry."

3.6. Atypical behaviors

Parents' concerns about children's atypical and repetitive behaviors were included in this category (16.92 %). This concern was reported by parents at similar rates across groups (toddler: 18.18 %, preschooler: 17.98 %, middle childhood: 14.18 %). Several of the same "atypical behaviors" were reported by parents in each of the age groups such as flapping hands or arms, making loud sounds or repetitive noises, or toe walking. Parents of toddlers described additional repetitive behaviors such as excessive thumb sucking, spinning in circles, and "strange comforting habits such as rubbing his fingers together [and] closing his eyes as if it hides him." Parents of preschoolers reported stimming with objects such as pens and pencils, and middle childhood parents reported their children lining up objects and "mimick[ing] or parrot[ing] adult behavior, particularly regarding disciplining."

3.7. Sensory

The sensory category included parents' concerns related to any sensory sensitivities (14.73 %). This category was consistently prevalent in parents' concerns across age groups (toddler: 14.69 %, preschooler: 14.61 %, middle childhood: 14.93 %). Parents of children in each of the age groups reported concerns related to sensitivities with food ("picky eaters," "very particular about food and if it's touching or what it looks like"), sound ("trouble with noises that are too loud and hurt his ears like velcro and music"), and the texture of clothing. One preschool parent described her child's sensitivity to the texture of her clothes: "[She] doesn't like wearing pajamas to bed, fidgets in her clothes, and lately will demand to wear loose fitting clothes to school instead of jeans or other pants." In addition to concerns with children's sensitivities to loud noises, food, and clothing textures, parents also reported sensitivities to touch (toddler, middle childhood), light (toddler, preschooler), and temperature (middle childhood).

3.8. Academic

Parents' concerns related to learning, a learning disability, academic skills, or success in school were included in the academic category (14.51 %). This category was most prevalent in the middle childhood group (32 %). Parents of children in each age group reported concerns with their children's learning. While parents of toddlers reported broad concerns with children's learning such as "there is something keeping him from learning as a typical toddler would," parents of preschoolers gave specific examples of academic skills that they were concerned about such as their children's lack of interest in "doing any of the work in [the] classroom [such as] coloring, using scissors," as well as reading and writing. Parents of children in the middle childhood group also voiced specific concerns with their children's academic skills such as reading and writing. They also discussed a variety of other academic concerns including "having a hard time" participating and progressing in school, children's dislike of school, and inconsistencies in their children's academic skills. Some parents, such as the parent of a child in the middle childhood group below, provided examples of these inconsistencies:

He is very smart and retains knowledge. He can recall and verbally give a summary at fast speeds. However…he does not write like a fifth grader. He writes like a pre-k child. The letters are very big and he traces over the letters many times.

3.9. Seeking diagnostic clarity or resources

Parents' comments about seeking diagnostic clarity or additional resources (e.g., academic supports or therapy services) for their children were included in this category, as well as any mention of a specific concern about their child having ASD (12.97 %). This category of concerns was most prevalent in the responses of parents of children in the middle childhood group (18.66 %). Parents in each age group made comments about their children showing "red flags" or "traits" of autism, seeking diagnostic clarity (e.g., if their child has ASD or not), wanting to get the support that their children need to be successful, and other professionals' concerns about their children potentially having ASD.

While most parents across age groups mentioned seeking out an evaluation after they themselves observed signs and symptoms of ASD in their child, other parents mentioned pursuing the evaluation after education or healthcare providers shared their concerns with them about their child. Parents of toddlers reported concerns stated by child care providers, while those of preschool and middle childhood kids reported concerns from a pediatrician, therapist, or educator at the child's school. One toddler's parent described how she did not personally have concerns about her child, but decided to seek out an evaluation after multiple other professionals suggested it to her:

[His] daycare center suggested that we have him evaluated with infants and toddlers. The program [infants and toddlers] suggested we get further evaluations. I did not have true concerns…however I am interested in receiving a professional opinion should there be things I am not seeing.

3.10. Health

Concerns about children's physical health were captured by this category (10.77 %). This category was most prevalent in the preschool and middle childhood groups (11.24 % and 12.69 %, respectively). Parents of children in all age groups reported concerns with children's sleep, such as, "[he] can go days on end sometimes hardly sleeping" and their children's other medical diagnoses or health conditions. Parents of toddlers reported their children's seizures and neck spasms, while parents of preschoolers reported their children's constipation and hearing loss. Parents of children in the middle childhood group had similar concerns of toddler parents (seizures) and preschool parents (constipation, hearing loss).

3.11. Developmental

This category encompasses any parent concerns related to their children having lower skill levels than others (such as peers or siblings) and specific comments about children's diagnosed or suspected developmental delays (9.23 %). This category was most prevalent in the toddler and preschooler groups (12.59 % and 8.47 %, respectively). Parents in each of the age groups wrote concerns about their children's diagnosed or suspected developmental delays. Parents of toddlers described their children as "behind" peers while parents of preschoolers and children in middle childhood discussed their children as displaying "different behaviors" than other children their age. For example, one middle childhood parent described how she was concerned about her child because he "does not think or act like others his age."

3.12. Motor skills

Any concerns about children's fine and/or gross motor skills or body movements were captured under the motor skills category (7.47 %). Concerns about children's motor skills were mentioned with the greatest frequency in the middle childhood group (8.96 %). Parents of toddlers reported "wobbly and uncoordinated movements," apraxia, and delays in sitting up and walking. Parents of preschoolers also reported apraxia as well as "motor control delays" and "complex motor stereotypes." Parents of children in the middle childhood group also reported concerns with coordination similarly to toddler parents and wrote about concerns with children's poor balance, trouble "gripping things with fingers correctly," and the need for occupational therapy services to "help fine tune the finger muscles."

4. Discussion

The purpose of this qualitative study was to explore parental concerns of children with ASD ages one through 11 at the time of their first ASD evaluation. Twelve categories of concern emerged during analysis of parental concerns across age groups.

4.1. Importance of eliciting parents' concerns prior to ASD evaluation

We established a comprehensive coding scheme that can be used to categorize parents' concerns across ages by utilizing an inductive approach to qualitative analysis. Eight of the 12 categories are consistent with concerns reported by other parental concerns studies of children with ASD: communication, social, behavioral/emotional, atypical behaviors, academic, health, developmental, and motor (Donohue et al., 2019; Guinchat et al., 2012; Larsen et al., 2018; Ozonoff et al., 2009; Richards et al., 2016; Zablotsky et al.,

2017). However, four distinct categories of concerns emerged that have not been reported previously in the literature as their own categories in qualitative studies: cognition, life skills, seeking diagnostic clarity or resources, and sensory. Concerns in each of these areas were likely mentioned by parents in other studies but categorized by the researchers into other concern categories, not examined as their own unique categories of concern. Since there was a high prevalence of parents using words that described these concerns in our sample, each of them remained as their own category in our coding scheme, consistent with the emergent coding process (Creswell & Clark, 2017). Establishing these concerns as their own categories permits better understanding of the variety of ways parents may report these concerns across age groups.

4.2. Shared concerns across age groups

Shared concern categories were defined as those in which all subcategories were reported by parents in each of the three age groups. Parents of children in each of the age groups reported the same subcategories of concerns in six of the 12 categories: 'atypical behaviors,' 'sensory,' 'health,' 'seeking diagnostic clarity or resources,' 'developmental,' and 'motor skills.' Concerns in each of these categories could be readily observed in children across age groups, as opposed to some concerns in the categories that differed which were mainly not as relevant to the toddler group (e.g., 'academic skills' in the academic category). This finding is in line with previous research suggesting that symptom presentation is not always clear at young ages (Guthrie et al., 2013).

This is the first study using inductive qualitative methods that has developed a coding scheme to identify parental concerns across age groups. Using this coding scheme, we were able to identify specific parental concerns that remain the same regardless of child age. One example of this is the 'atypical behaviors' category, which has been referred to as 'restricted and repetitive behavior' in other schemes (e.g., Donohue et al., 2019) in line with the *DSM-5* (APA, 2013). We found that parents had concerns about "atypical behaviors" generally across age groups, but also identified the specific behaviors of shared concern: flapping hands or arms, making loud sounds or repetitive noises, and toe walking. This level of detail extends the previous work of researchers to date that have reported parental concerns of only one age group of children using professional terminology (e.g., Ozonoff et al., 2009; Richards et al., 2016) by providing more specific examples of these concerns as well as similarities and differences across child age groups. It is important for providers to give adequate attention to all concerns reported by parents to gain a holistic understanding of both the child's and family's needs and ensure that the necessary team members are present for a comprehensive evaluation addressing all areas of concern (Dillenburger et al., 2014; Herlihy et al., 2015; Strunk et al., 2017; WHO, 2010). Ensuring that the evaluation team can address all of the parents' concerns helps ensure a timely diagnosis and subsequent identification, and provision, of appropriate care.

4.3. Behavioral and emotional concerns as children age

Parents of children in the preschooler and middle childhood groups reported a greater number of different concerns than parents of toddlers, particularly in the behavioral/emotional category. This is in agreement with the broader childhood literature which shows that mental health problems increase as children age into adolescence, with the peak age of onset for having any mental disorder occurring at 14 years old (Giedd et al., 2008; Kessler et al., 2005). Research in the ASD population specifically has also shown increases in behavioral and emotional problems from ages 4–6 to 10–12 (Horiuchi et al., 2014). In our analyses, concerns about aggression and physical harm to self and others were expressed with increasing frequency across the age groups. This may reflect concern of the child's increasing ability to inflict harm as they grow in size and strength (Kanne & Mazurek, 2011), as well as concern about society's views on aggressive behavior in children, as this may be conceptualized as a risk factor for aggression in adulthood (Farmer & Aman, 2011).

Parents of children in the preschool and middle childhood, but not toddler, groups also named bullying a concern, which likely reflects the child's transition into school settings and subsequent interaction with more peers. The victimization literature notes that children with ASD may be targeted due to having poorer social and communication skills and less protection by peers (Delfabbro et al., 2006), as well as atypical interests (Gray, 2004). Having mental health problems is also a risk factor for being bullied (Cappadocia et al., 2012), which can contribute to a cycle of chronic victimization, as intense behavioral or emotional reactions to being bullied may encourage bullying behavior by peers (Cappadocia et al., 2012; Gray, 2004; Mahady Wilton et al., 2000).

Together, these data emphasize the importance of evaluation and treatment of behavioral, emotional, and mental health concerns as children with ASD age. It is critical for healthcare providers to also consider the underlying causes of behavior. Too often, behavioral and mental concerns among individuals with ASD are incorrectly assumed to simply be part of ASD, which reflects in under diagnosis and treatment of distinct medical and mental health disorders (i.e., diagnostic overshadowing (Rosen et al., 2018)). For example, what is perceived as aggressive behavior may be a reflection of a child's pain, sensory abnormalities, and sleep dysregulations (Kanne & Mazurek, 2011), which should be the focus of evaluation and treatment. This further emphasizes the necessity of a multidisciplinary diagnostic team and attention to parent and child concerns.

4.4. Implications

The range of parental concerns across age groups of children in the current study is not typically captured by existing parent concerns studies of children with ASD. The findings of this study suggest the importance of including open-ended questions on ASD screeners and diagnostic evaluation tools. Screening and diagnostic tools may ask about the existence of symptoms over a defined developmental period, but not necessarily current issues. While structured, standardized, or forced-choice parent questionnaires have utility for eliciting parental concerns, parents should also have a way to report their concerns in an open-ended format, allowing researchers and clinicians to capture parents' current concerns in their own words. Further, standardized interview tools also do not

allow clinicians to probe symptoms, challenges, or concerns that parents describe which are not core domains of ASD but are nonetheless commonly related to ASD. If parents assume their concerns are not associated with ASD, they may not report it, delaying further investigation and potential treatment. The inclusion of an open-ended question in screening and diagnostic tools allows parents to discuss concerns or challenges that were not explicitly asked about, but are still important to them, and that have clinical implications. For instruments that do include this open-ended question, such as the Autism Diagnostic Interview-Revised (ADI-R; Rutter et al., 2003), our study provides guidance on how to interpret parents' responses. For those that do not ask this question, it provides information about additional topics to ask parents about (e.g., families' needs). The theme 'seeking diagnostic clarity or resources' was observed in 13 % of our sample, suggesting that many parents were searching for additional information and support during the ASD evaluation process. Together, this suggests that asking parents to describe current concerns can help inform further evaluation needs and identify support services for both the child and family.

As in previous research exploring parental concerns, the current study also highlights the complex phenotype of ASD within child age groups (e.g., Donohue et al., 2019) and adds to it by also capturing detailed information about this complexity across age groups. This complexity requires careful evaluation by several different providers to meet the child's needs, emphasizing the importance of multidisciplinary evaluations. While multidisciplinary ASD diagnostic evaluations are recommended (Volkmar et al., 2014), many ASD evaluations are often conducted with a single provider working independently (Gerdts et al., 2018). Both types of evaluations are often thorough, however, single-discipline evaluations often require multiple visits on separate days likely contributing to delays in the diagnostic process and subsequent access to care (Gerdts et al., 2018). Further, since single-discipline evaluations are only conducted by one person, they may not account for the relevant expertise needed to evaluate all of the complex and multifaceted needs of a child with ASD. This often results in a stressful, time-consuming process for parents of taking the child for additional assessments in the outstanding areas of concern after the ASD evaluation and organizing their child's care across several different providers and locations (Gerdts et al., 2018; Singh et al., 2019). By eliciting detailed parental concerns before the evaluation, burden on both parents and providers may be reduced by identifying the necessary professionals and assessments needed ahead of time to ensure both timely diagnosis and identification of appropriate, comprehensive treatments. This process is in line with the national movement toward precision medicine as well as efforts towards implementing a transdiagnostic approach to evaluation and treatment (Loth et al., 2016; Talbott & Miller, 2020). Providing care coordination for families of children with ASD may help them organize and manage their child's multidisciplinary care more efficiently (Singh et al., 2019; Volkmar et al., 2014).

4.5. Limitations and future research

This study has several limitations. First, the data in this study were collected from only one ASD specialty clinic using only one open-ended question and cannot be generalized to parents pursuing an ASD evaluation in other settings (e.g., school systems). Due to our method of data collection, there was also a potential selection bias in the sample, because only families that agreed to participate in research were included in the study (Kalb et al., 2019). It is also important to acknowledge that individual concerns (e.g., toe walking) were only placed into one category during analysis. Therefore, some parent concerns which could traditionally be thought of as potentially impacting several different areas (e.g., sensory, motor, etc.) were only placed in the category that was most reflective of the way the parents described it (i.e., atypical behavior). In addition, we did not specify which parent should report their concerns on the Background and History form. It is possible that parents of the same child could report different concerns. Lastly, an important caveat in interpreting our findings is that we have described bivariate, unadjusted associations between child age and frequency of categories endorsed. However, as Table 1 shows, child age is associated with other features in our data. For example, Asian children are disproportionately overrepresented among younger children. Therefore, we are not attempting to make any causal statement about the relationship between age and endorsement of particular categories, but rather describe the common categories by age group in this study population. Further, since we did not collect the race of the parent completing the Background and History form, we could not investigate if parental concerns differed by race or cultural background.

This study also had a number of strengths. First, a large sample of parents was included, allowing us to thoroughly examine parental concerns of multiple age groups of children. Second, to maximize credibility of our findings, we utilized triangulation and peer debriefing. Lastly, using an inductive qualitative method of analysis, parents' words drove the creation of concern categories, expanding prior work which largely utilized professional terminology to categorize parents' concerns.

Future research should continue to examine parental concerns about their children at the time of ASD evaluation. Examining these concerns across ASD evaluation settings (e.g., school systems) may be useful in developing a greater understanding of the words parents use to describe their concerns. Future studies should continue to examine how to tailor evaluations to address parental concerns, in an effort to improve coordination of, and access to, care and lessen the financial burden of ASD (Buescher et al., 2014; Rogge & Janssen, 2019). Further, in addition to using inductive qualitative methods to explore parental concerns by age, future inductive studies could explore how parents from various marginalized groups describe their concerns to identify phrasing or ideas that could help enhance screening and assessment tools to reduce disparities in early identification of ASD. Inductive methods could also be used to examine how parents' concerns vary in relation to their children's level of ASD severity.

4.6. Conclusion

No studies to date have examined parental concerns of children with ASD across several age groups using the same coding scheme. Twelve categories of concerns emerged from conventional content analysis of written parental concerns of children from ages one to 11, highlighting the complex phenotype of ASD. These categories yield specific information about similarities and differences in

parents' concerns depending on their child's age. Due to the complex nature of ASD, ensuring that evaluations are tailored to children's unique needs has implications for timely diagnosis, and subsequent access to care.

CRediT authorship contribution statement

Drs. Pfeiffer, **Holingue**, **Dillon**, **Kalb**, and **Reetzke** conceptualized and designed the study. **Drs. Pfeiffer**, **Holingue**, and **Dillon** conducted the qualitative analysis and drafted the initial manuscript. **Danika Pfeiffer**, **Calliope Holingue**, **Emily Dillon**, **Luke Kalb**, **Rachel Reetzke**, **Rebecca Landa** contributed intellectual content and revised the final manuscript. The authors approve the final manuscript as submitted and agree to be accountable for all aspects of the work.

Declaration of Competing Interest

The authors report no declarations of interest.

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.rasd.2021.101817.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (DSM-5)*. American Psychiatric Pub.

Azad, G. F., Dillon, E., Feuerstein, J., Kalb, L., Neely, J., & Landa, R. (2020). Quality of life in school-aged youth referred to an autism specialty clinic: A latent profile analysis. *Journal of Autism and Developmental Disorders, 50*(4), 1269–1280. https://doi.org/10.1007/s10803-019-04353-x.

Azad, G. F., Singh, V., Kalb, L., Pinkett-Davis, M., & Landa, R. (2019). Child and family characteristics that predict autism spectrum disorder specialty clinic appointment attendance and alignment with providers. *Journal of Autism and Developmental Disorders, 49*(8), 3060–3072. https://doi.org/10.1007/s10803-019-04027-8.

Bölte, S., De Schipper, E., Robison, J. E., Wong, V. C. N., Selb, M., Singhal, N., de Vries, P. J., & Zwaigenbaum, L. (2014). Classification of functioning and impairment: The development of ICF core sets for autism spectrum disorder. *Autism Research, 7*(1), 167–172. https://doi.org/10.1002/aur.1335.

Bradley, E. H., Curry, L. A., & Devers, K. J. (2007). Qualitative data analysis for health services research: Developing taxonomy, themes, and theory. *Health Services Research, 42*(4), 1758–1772. https://doi.org/10.1111/j.1475-6773.2006.00684.x.

Buescher, A. V. S., Cidav, Z., Knapp, M., & Mandell, D. S. (2014). Costs of autism spectrum disorders in the United Kingdom and the United States. *JAMA Pediatrics, 168*(8), 721–728. https://doi.org/10.1001/jamapediatrics.2014.210.

Cappadocia, M. C., Weiss, J. A., & Pepler, D. (2012). Bullying experiences among children and youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 42*(2), 266–277.

Caronna, E. B., Augustyn, M., & Zuckerman, B. (2007). Revisiting parental concerns in the age of autism spectrum disorders: The need to help parents in the face of uncertainty. *Archives of Pediatrics & Adolescent Medicine, 161*(4), 406–408. https://doi.org/10.1001/archpedi.161.4.406.

Centers for Disease Control and Prevention. (2020). *Positive parenting tips*. https://www.cdc.gov/ncbddd/childdevelopment/positiveparenting/index.html.

Charmaz, K. (2014). *Constructing grounded theory* (2nd ed.). Sage.

Corbin, J., & Strauss, A. (2014). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (4th ed.). Sage Publications.

Creswell, J. W., & Clark, V. L. P. (2017). *Designing and conducting mixed methods research*. Sage Publications.

Delfabbro, P., Winefield, T., Trainor, S., Dollard, M., Anderson, S., Metzer, J., & Hammarstrom, A. (2006). Peer and teacher bullying/victimization of South Australian secondary school students: Prevalence and psychosocial profiles. *British Journal of Educational Psychology, 76*(1), 71–90. https://doi.org/10.1348/000709904X24645.

Dillenburger, K., Röttgers, H. R., Dounavi, K., Sparkman, C., Keenan, M., Thyer, B., & Nikopoulos, C. (2014). Multidisciplinary teamwork in autism: Can one size fit all? *Australian Educational and Developmental Psychologist, 31*(2), 97–112. https://doi.org/10.1017/edp.2014.13.

Donohue, M. R., Childs, A. W., Richards, M., & Robins, D. L. (2019). Race influences parent report of concerns about symptoms of autism spectrum disorder. *Autism, 23*(1), 100–111. https://doi.org/10.1177/1362361317722030.

Esler, A. N., Bal, V. H., Guthrie, W., Wetherby, A., Weismer, S. E., & Lord, C. (2015). The autism diagnostic observation schedule, toddler module: Standardized severity scores. *Journal of Autism and Developmental Disorders, 45*(9), 2704–2720. https://doi.org/10.1007/s10803-015-2432-7.

Farmer, C. A., & Aman, M. G. (2011). Aggressive behavior in a sample of children with autism spectrum disorders. *Research in Autism Spectrum Disorders, 5*(1), 317–323. https://doi.org/10.1016/j.rasd.2010.04.014.

Gerdts, J., Mancini, J., Fox, E., Rhoads, C., Ward, T., Easley, E., & Bernier, R. A. (2018). Interdisciplinary team evaluation: An effective method for the diagnostic assessment of autism spectrum disorder. *Journal of Developmental and Behavioral Pediatrics, 39*(4), 271–281. https://doi.org/10.1097/DBP.0000000000000549.

Ghanizadeh, A. (2012). Co-morbidity and factor analysis on attention deficit hyperactivity disorder and autism spectrum disorder DSM-IV-derived items. *Journal of Research in Medical Sciences: The Official Journal of Isfahan University of Medical Sciences, 17*(4), 368–372.

Giedd, J., Keshavan, M., & Paus, T. (2008). Why do many psychiatric disorders emerge during adolescence? *Nature Reviews Neuroscience, 9*(12), 947–957. https://doi.org/10.1038/nrn2513.Why.

Glaser, B. G., & Strauss, A. L. (2017). *Discovery of grounded theory: Strategies for qualitative research*. Routledge.

Goldman, S. E., Richdale, A. L., Clemons, T., & Malow, B. A. (2012). Parental sleep concerns in autism spectrum disorders: Variations from childhood to adolescence. *Journal of Autism and Developmental Disorders, 42*(4), 531–538. https://doi.org/10.1007/s10803-011-1270-5.

Gotham, K., Pickles, A., & Lord, C. (2009). Standardizing ADOS scores for a measure of severity in autism spectrum disorders. *Journal of Autism and Developmental Disorders, 39*(5), 693–705. https://doi.org/10.1007/s10803-008-0674-3.

Gray, C. (2004). *Gray's guide to bullying*. Jenison Public Schools.

Guinchat, V., Chamak, B., Bonniau, B., Bodeau, N., Perisse, D., Cohen, D., & Danion, A. (2012). Very early signs of autism reported by parents include many concerns not specific to autism criteria. *Research in Autism Spectrum Disorders, 6*(2), 589–601. https://doi.org/10.1016/j.rasd.2011.10.005.

Guthrie, W., Swineford, L. B., Nottke, C., & Wetherby, A. M. (2013). Early diagnosis of autism spectrum disorder: Stability and change in clinical diagnosis and symptom presentation. *Journal of Child Psychology and Psychiatry, 54*(5), 582–590.

Herlihy, L., Knoch, K., Vibert, B., & Fein, D. (2015). Parents' first concerns about toddlers with autism spectrum disorder: Effect of sibling status. *Autism, 19*(1), 20–28. https://doi.org/10.1177/1362361313509731.

Hess, C. R., & Landa, R. J. (2012). Predictive and concurrent validity of parent concern about young children at risk for autism. *Journal of Autism and Developmental Disorders, 42*(4), 575–584. https://doi.org/10.1007/s10803-011-1282-1.

Horiuchi, F., Oka, Y., Uno, H., Kawabe, K., Okada, F., Saito, I., Tanigawa, T., & Ueno, S. (2014). Age-and sex-related emotional and behavioral problems in children with autism spectrum disorders: Comparison with control children. *Psychiatry and Clinical Neurosciences, 68*(7), 542–550. https://doi.org/10.1111/pcn.12164.

Hsieh, H.-F., & Shannon, S. E. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research, 15*(9), 1277–1288.

Hyman, S. L., Levy, S. E., & Myers, S. M. (2020). Identification, evaluation, and management of children with autism spectrum disorder. *Pediatrics, 145*(1). https://doi.org/10.1542/peds.2019-3447.

Kalb, L., Jacobson, L., Zisman, C., Mahone, E., Landa, R., Azad, G., Menon, D., Singh, V., Zabel, A., & Pritchard, A. (2019). Interest in research participation among caregivers of children with neurodevelopmental disorders. *Journal of Autism and Developmental Disorders, 49*(9), 3786–3797. https://doi.org/10.1007/s10803-019-04088-9.

Kanne, S. M., & Mazurek, M. O. (2011). Aggression in children and adolescents with ASD: Prevalence and risk factors. *Journal of Autism and Developmental Disorders, 41*(7), 926–937. https://doi.org/10.1007/s10803-010-1118-4.

Kessler, R. C., Berglund, P., Demler, O., Jin, R., Merikangas, K. R., & Walters, E. E. (2005). Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the national comorbidity survey replication. *Archives of General Psychiatry, 62*(6), 593–602. https://doi.org/10.1001/archpsyc.62.6.593.

Kozlowski, A. M., Matson, J. L., Horovitz, M., Worley, J. A., & Neal, D. (2011). Parents' first concerns of their child's development in toddlers with autism spectrum disorders. *Developmental Neurorehabilitation, 14*(2), 72–78. https://doi.org/10.3109/17518423.2010.539193.

Larsen, K., Aasland, A., & Diseth, T. H. (2018). Brief report: Agreement between parents and day-care professionals on early symptoms associated with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 48*(4), 1063–1068. https://doi.org/10.1007/s10803-017-3355-2.

Lord, C., Rutter, M., DiLavore, P. C., Risi, S., Gotham, K., & Bishop, S. L. (2012). *Autism diagnostic observation schedule (ADOS-2, modules 1-4)*. Los Angeles, California: Western Psychological Services.

Lord, C., Rutter, M., & Le Couteur, A. (1994). Autism Diagnostic Interview-Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders, 24*(5), 659–685. https://doi.org/10.1007/BF02172145.

Loth, E., Murphy, D. G., & Spooren, W. (2016). Defining precision medicine approaches to autism spectrum disorders: Concepts and challenges. *Frontiers in Psychiatry, 7*. https://doi.org/10.3389/fpsyt.2016.00188.

Mahady Wilton, M. M., Craig, W. M., & Pepler, D. J. (2000). Emotional regulation and display in classroom victims of bullying: Characteristic expressions of affect, coping styles and relevant contextual factors. *Social Development, 9*(2), 226–245. https://doi.org/10.1111/1467-9507.00121.

Mannion, A., & Leader, G. (2016). An investigation of comorbid psychological disorders, sleep problems, gastrointestinal symptoms and epilepsy in children and adolescents with autism spectrum disorder: A two year follow-up. *Research in Autism Spectrum Disorders, 22*, 20–33.

Masi, A., DeMayo, M. M., Glozier, N., & Guastella, A. J. (2017). An overview of autism spectrum disorder, heterogeneity and treatment options. *Neuroscience Bulletin, 33*(2), 183–193. https://doi.org/10.1007/s12264-017-0100-y.

Matheis, M., Matson, J. L., Burns, C. O., Jiang, X., Peters, W. J., Moore, M., de Back, K. A., & Estabillo, J. (2017). Factors related to parental age of first concern in toddlers with autism spectrum disorder. *Developmental Neurorehabilitation, 20*(4), 228–235. https://doi.org/10.1080/17518423.2016.1211186.

Matson, J. L., & Shoemaker, M. (2009). Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities, 30*(6), 1107–1114. https://doi.org/10.1016/j.ridd.2009.06.003.

Merriam, S. B., & Tisdell, E. J. (2015). *Qualitative research: A guide to design and implementation* (4th ed.). John Wiley & Sons.

Ozonoff, S., Young, G. S., Steinfeld, M. B., Hill, M. M., Cook, I., Hutman, T., MacAri, S., Rogers, S. J., & Sigman, M. (2009). How early do parent concerns predict later autism diagnosis? *Journal of Developmental and Behavioral Pediatrics, 30*(5), 367–375. https://doi.org/10.1097/DBP.0b013e3181ba0fcf.

Rao, P. A., & Landa, R. J. (2014). Association between severity of behavioral phenotype and comorbid attention deficit hyperactivity disorder symptoms in children with autism spectrum disorders. *Autism, 18*(3), 272–280.

Richards, M., Mossey, J., & Robins, D. L. (2016). Parents' concerns as they relate to their child's development and later diagnosis of autism spectrum disorder. *Journal of Developmental and Behavioral Pediatrics, 37*(7), 532. https://doi.org/10.1097/DBP.0000000000000339.Parents.

Rogge, N., & Janssen, J. (2019). The economic costs of autism spectrum disorder: A literature review. *Journal of Autism and Developmental Disorders, 49*(7), 2873–2900. https://doi.org/10.1007/s10803-019-04014-z.

Rosen, T. E., Mazefsky, C. A., Vasa, R. A., & Lerner, M. D. (2018). Co-occurring psychiatric conditions in autism spectrum disorder. *International Review of Psychiatry, 30*(1), 40–61. https://doi.org/10.1080/09540261.2018.1450229.

Rutter, M., Le Couteur, A., & Lord, C. (2003). *Austism diagnostic interview-revised*. Western Psychological Services.

Simonoff, E., Pickles, A., Charman, T., Chandler, S., Loucas, T., & Baird, G. (2008). Psychiatric disorders in children with autism spectrum disorders: Prevalence, comorbidity, and associated factors in a population-derived sample. *Journal of the American Academy of Child & Adolescent Psychiatry, 47*(8), 921–929. https://doi.org/10.1097/CHI.0b013e318179964f.

Singh, V., Pinkett-Davis, M., Kalb, L. G., Azad, G., Neely, J., & Landa, R. (2019). A preliminary study of care coordination services within a specialized outpatient setting for youth with autism spectrum disorder. *International Journal of Care Coordination, 22*(3–4), 109–116. https://doi.org/10.1177/2053434519893659.

Sivberg, B. (2003). Parents' detection of early signs in their children having an autistic spectrum disorder. *Journal of Pediatric Nursing, 18*(6), 433–439. https://doi.org/10.1016/S0882-5963(03)00139-8.

Strunk, J., Leisen, M., & Schubert, C. (2017). Using a multidisciplinary approach with children diagnosed with autism spectrum disorder. *Journal of Interprofessional Education and Practice, 8*, 60–68. https://doi.org/10.1016/j.xjep.2017.03.009.

Talbott, M. R., & Miller, M. R. (2020). Future directions for infant identification and intervention for autism spectrum disorder from a transdiagnostic perspective. *Journal of Clinical Child and Adolescent Psychology*, 1–15. https://doi.org/10.1080/15374416.2020.1790382.

Volkmar, F., Siegel, M., Woodbury-Smith, M., King, B., McCracken, J., & State, M. (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*(2), 237–257. https://doi.org/10.1016/j.jaac.2013.10.013.

White, S. W., & Roberson-Nay, R. (2009). Anxiety, social deficits, and loneliness in youth with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 39*(7), 1006–1013. https://doi.org/10.1007/s10803-009-0713-8.

World Health Organization. (2010). A WHO report: Framework for action on interprofessional education and collaborative practice. *Journal of Allied Health, 39*(SUPPL. 1), 196–197.

Zablotsky, B., Colpe, L. J., Pringle, B. A., Kogan, M. D., Rice, C., & Blumberg, S. J. (2017). Age of parental concern, diagnosis, and service initiation among children with autism spectrum disorder. *American Journal on Intellectual and Developmental Disabilities, 122*(1), 49–61. https://doi.org/10.1352/1944-7558-122.1.49.