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Pubertal Development Measurement in Children with and without Autism Spectrum Disorder: A Comparison Between Physical Exam, Parent- and Self-Report

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Abstract

Adolescence is a time of remarkable biopsychosocial change, which may be particularly challenging for youth with autism spectrum disorder (ASD), necessitating enhanced understanding and accurate assessment of pubertal maturation. The study compared physical examination to parent- and self-report measures in 200 participants (134 males and 66 females) ages 10.0–13.5-years. Both participants with typical development (TD; n=78) and ASD (n=122) were included. Concordance ranged from slight-to-fair for self-assessments (κ=.17–.32) and slight-to-moderate for parent-report (κ=.21–.44). Concordance of physical exam with self- and parent-report of the ASD group was somewhat lower than for the TD group. Findings indicate pubertal assessments by parent or child are not reliable indices of precise pubertal staging.

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Author Contributions

BAC conceived of the study, supervised the implementation of study protocols and data collection, contributed to diagnostic assessments, analyzed and interpreted statistical analyses, and drafted and finalized the manuscript. RAM participated in study protocols and neuropsychological assessments, contributed to statistical analysis and interpretation of findings, and contributed to the drafted and finalized manuscript. YT performed the majority of the physical examinations for the study and contributed to the final manuscript. EM recruited participants, organized study visits, assisted with study protocols, and contributed to the final manuscript. SI contributed to statistical analysis and interpretation, and contributed to the drafted and finalized manuscript.

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Disclosure of Potential Conflicts of Interest

The authors declare that they have no conflict of interest.

Ethical Approval

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent

Informed written consent and assent was obtained from all parents and study participants, respectively, prior to inclusion in the study.

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Keywords

Autism Spectrum Disorder; pubertal development; Tanner; adolescence

Adolescence, the transition between childhood and adulthood, is a time of remarkable physiological, psychological and social changes (Chrousos et al. 1998; Spear 2000). During this developmental period, pubertal maturation contributes to significant alterations in morphology, cognition, emotion regulation and physiological stress (e.g., Chrousos et al. 1998; Spear 2000). Indeed, puberty is a time of considerable plasticity of the brain when various biobehavioral changes coincide with the dynamic transition, which may be pivotal albeit understudied in adolescents with autism spectrum disorder (ASD).

Autism spectrum disorder (ASD) is defined by APA (2013) as a neurodevelopmental disorder characterized by significant difficulty with reciprocal social communication, sensory dysfunction and psychological and behavioural inflexibility (APA 2013). The sex ratio is estimated to be 4:1, males to females (APA 2013). Many individuals show poor adaptation to change including developmental transitions from adolescence to adulthood (e.g., Taylor and Seltzer 2010; Taylor et al. 2017). Although relatively little attention has been paid to the transition from childhood to adolescence, extant literature suggests that many individuals with ASD show improvement in core symptomology (Seltzer et al. 2004) and social cognition (Anderson et al. 2007; Anderson et al. 2009). In addition, there is often a reduction in irritability and hyperactivity between 9 to 18 years of age (Anderson et al. 2011). In one of the largest prospective, population-based studies in which 120 individuals with ASD were followed from childhood to adulthood, roughly a third of individuals experienced significant problems during the adolescent period, and of those 17% had profound deterioration during puberty (Billstedt et al. 2005). In girls with ASD, the onset of menses in puberty has been shown to bring significant new challenges with emotion regulation and heightened sensory experiences (Steward et al. 2018). While there is significant heterogeneity, social withdrawal tends to worsen over the adolescent period (Anderson et al. 2011). Taken together, there appear to be areas of both improvement and decline in youth with ASD.

A similar paradox is evident in neurotypical youth in which adolescence is marked by significant gains in cognitive and physical health; yet, it is also marked by serious behavioural risks (e.g., drug use, pregnancy), which is why it has been conceptualized as a period of striking opportunities and vulnerabilities (Dahl 2004). Over the past two decades there has been a rise in the interest and study of this transition due to the collective neurobiobehavioural changes associated with pubertal onset. Differences have been identified in the development of these changes, including notable variation in the timing of pubertal milestones across a range of demographics (Mendle et al. 2019). Hence, the careful measurement of pubertal stages is clearly warranted.

Adolescence vs. Puberty

Although adolescence and puberty are often used interchangeably, they represent distinct maturational phenomena. Adolescence refers to the developmental transition of juvenile

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social and cognitive processes to their adult versions and is more associated with chronological age and experience (Spear 2000; Steinberg 2005). It may also be characterized as the evolution from parental dependence to relative independence.

Puberty, on the other hand, refers to biological maturation, particularly that of sexual systems, and the physiological effects of resultant changes to the endocrine system including activation of the hypothalamic pituitary gonadal (HPG) axis (Sisk and Foster 2004) contributing to the development of secondary sexual characteristics. The age of pubertal onset is influenced by a variety of biobehavioral (e.g., genetic, environmental) factors, which can result in precocious or delayed pubertal onset. For example, the level of body fat can influence pubertal onset. Explicitly, obesity can contribute to accelerated pubertal onset (Karlberg 2002) whereas anorexia (Munoz and Argente 2002) or low body fat (Roemmich et al. 2001) can contribute to delayed pubertal onset. Also, early pubertal onset can contribute to higher risk for mental health problems, increased delinquency, substance abuse and precocious sexual behavior (Bratberg et al. 2007; Deardorff et al. 2005; Graber et al. 1997; Kaltiala-Heino et al. 2003; Waylen and Wolke 2004). Since age is not a proxy for pubertal development, the careful determination of pubertal onset is vital. It is important to attempt to disambiguate these constructs for an enhanced understanding of the adolescent period and influential environmental and physiological factors. Moreover, without accurate measures of pubertal development it is difficult to disentangle the influence of age and social context from maturational factors (e.g., Forbs and Dahl 2010).

Puberty and Autism

Despite the relevance of pubertal development for a host of medical, psychological and environmental factors, relatively little research has been conducted looking at the timing or consequences of puberty in youth with ASD, and the majority has been conducted in females. Findings regarding timing have been largely mixed (Tordjman et al. 1997) with some studies suggesting precocious development (Mouridsen 1989; Pohl et al. 2014) whereas others have reported delayed pubertal maturation (Harper and Collins 1979; Knickmeyer et al. 2006), which correlated with autistic traits (Herguner and Herguner 2016; Whitehouse et al. 2011). Recently, May and colleagues (2017) reported no difference in pubertal timing between a large population sample of ASD vs. TD participants based on parent-report (at ages 9–10, 10–11, 12–13) and self-report (14–15 years). Collectively, the vast differences in the approach (e.g., retrospective self-report, online survey, clinical vs. community referred), characterization of the samples (e.g., case studies, clinic-referred, community-referred) and limited rigor in the assessment of pubertal maturation, underscore the need to methodically test measures of pubertal development. Such determination of best practice is especially relevant for clinical research in which accurate staging is necessary.

Pubertal Assessment

Tanner (1962) first classified pubertal development into five stages of breast (B1–B5) and genital (G1–G5) development and pubic hair growth (G1–G5). Since then, clinicians have conducted physical exams employing Tanner staging method (Dorn et al. 2006). Pubertal staging was originally done by visual inspection by Tanner; however, recent consensus has

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been that a physical examination involving both inspection and palpation helps to distinguish between breast and adipose tissue or accurately assess the size of the testis (Dorn and Biro 2011). While physical exam can be considered the gold standard, it only takes into account outward signs of physical growth and is often not used in research because it may be time consuming, experienced by some as invasive, and costly for large studies. Various methodological issues have been discussed with the physical examination (Dorn et al. 2006). Therefore, many investigations have employed self-assessment, parental-report or a combination of these measures. Even though more efficient and less costly, the inclusion of such methods has resulted in reduced standardization and inconsistency in methodology, definitions, conceptualization and implementation. It has been recommended that the exact method chosen should be tailored to the study setting and population (Dorn et al. 2006).

Arguably the most widely-used measure of pubertal status in research is the Pubertal Development Scale (PDS; Petersen et al. 1988). It has been used in numerous studies implemented as a self-report (e.g., Herting et al. 2017; Lawrence et al. 2015) or as a parental-report (Corbett and Schupp 2014; Edmiston et al. 2017a; Edmiston et al. 2017b) measure. The PDS asks a series of questions that may be considered less invasive than a physical exam; however, it does not directly map onto Tanner staging. Previous research comparing the PDS to physical examination has been mixed with some showing reasonable agreement (Duke et al. 1980) whereas others report limited agreement (e.g., Desmangles et al. 2006; Rasmussen et al. 2015). For example, in a relatively large sample, Shirtcliff and colleagues (Shirtcliff et al. 2009) reported the concordance between physical exam and the PDS to be relatively low (kappa (κ)=0.36).

Another approach has been to use drawings that map directly onto Tanner staging (Marshal and Tanner 1970; Marshall and Tanner 1969; Tanner 1962) for males and females. After an explanation of the task, subjects simply mark the stage of anatomical drawings that most resembles their body for pubic hair (P1–P5) as well as breast (B1–B5) in females and genitalia (G1–G5) in males. Simple text often accompanies the pictures to further clarify stages. While efficient and easy to use, the average agreement is moderate between Tanner schematic drawings and physical exam (κ=.50; Coleman and Coleman 2002; Desmangles et al. 2006; Hergenroeder et al. 1999; Schmitz et al. 2004) and some studies report lower agreement (e.g. κ=.32; Wu et al. 2001) or (κ=.36; Shirtcliff et al. 2009), although a few studies report substantial agreement (κ > 70; Boas et al. 1995; Brooks-Gunn et al. 1987; Carskadon et al. 1980; Duke et al. 1980; Morris and Udry 1980; Norris and Richter 2005).

Collectively, the aforementioned review highlights the importance of the careful measurement of pubertal development. There are multiple methods employed with varying degrees of reliability to include physical examination, parent-report and self-report measures as well as a combination of these approaches. To date, there has been limited rigor in the assessment of pubertal maturation in ASD, underscoring the need to methodically test measures of pubertal development. Additionally, developmental considerations and distinctions between age and puberty have not been well characterized, and age is not a proxy for puberty. When studies do consider the assessment of puberty they generally employ self-assessment or parental-report measures. However, the validity of such measures as reliable indices of precise pubertal staging is questionable especially if compared to

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standardized measures such as Tanner stages conducted by physical exam. The use of reliable indices of pubertal development is critical for research especially in longitudinal studies of puberty or endocrine functioning. The purpose of the current investigation was to compare physical examination to both parent- and self-report measures.

To more carefully examine pubertal staging, the current study employed three different methods for examining pubertal development as part of a longitudinal study of children with and without ASD (Corbett 2017). We chose an inspection-only physical exam combined with time spent on building rapport and explaining the study in order to maximize the participant's willingness to consent while still making an accurate assessment. Physical exam was compared to two other established approaches using self-report and parental-report described below. The study aimed to compare staging during early pubertal development across these measures based on informant (self and parent), gender (females and males) and diagnostic group (ASD and TD).

Methods

Participants

The data for this study was collected as part of a longitudinal study on pubertal development and stress (Corbett 2017). The current paper includes data from the initial year of enrollment when the children were between 10-years, 0-months, to 13-years, 5-months of age. The total sample included 200 early adolescents, 134 males and 66 females, 122 with ASD (mean age = 11.31) and 78 TD (mean age = 11.41). In the ASD group, there were 88 males and 34 females, and in the TD group, there were 46 males and 32 females. The sample included 81.5% Caucasians, 9.7% African Americans, 0.5% Asian, and 8.2% Mixed race. Regarding ethnicity, 5.6% of the sample was Hispanic. Recruitment efforts were aimed at a broad community sample from a 200-mile radius that targeted research registries, medical and health-related network services, well-check and diagnostic clinics, regional autism/disability organizations, schools, and social media platforms. For inclusion in the study, participants were required to have an intelligence quotient (IQ) score ≥ 70 in order to adequately complete the psychological measures used in the current and longitudinal study (Corbett 2017). Exclusion criteria, which was reviewed at phone screen, included current use of medications known to alter the Hypothalamic Pituitary Adrenal (HPA) axis (e.g., corticosteroids; see (Granger et al. 2009) or HPG axis (e.g., growth hormone), or a current neurological (e.g., seizures) or medical condition known to impact pubertal development (e.g., Cushing's Disease). There were 24 participants not enrolled, most of whom were identified at phone screening as being ineligible due to low IQ, insufficient language level as required for the longitudinal study, extreme aggression, or for TD children, having a sibling with an ASD diagnosis. Two male participants with ASD were prescribed Risperidone. A serious side effect of this medication in males is gynecomastia (abnormal growth of breast tissue); however, this was not observed in either subject. Demographic information for each group is presented in Table 1.

The diagnosis of ASD was based on the Diagnostic and Statistical Manual-5 (APA 2013) and established by: (1) a previous diagnosis by a psychologist, psychiatrist, or behavioral pediatrician with autism expertise, (2) current clinical judgment, and (3) corroborated by the

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Autism Diagnostic Observation Schedule (ADOS-2; Lord et al. 2012), administered by research-reliable personnel, an approach consistent with standards set by the NICHD/NIDCD Collaborative Programs of Excellence In Autism (Lainhart et al. 2006).

The research was carried out in accordance with the Code of Ethics of the World Medical Association (Declaration of Helsinki). The Vanderbilt Institutional Review Board approved the study. Informed written consent and assent was obtained from all parents and study participants, respectively, prior to inclusion in the study. During the consenting process, the purpose of the physical exam and all study procedures was thoroughly explained to children and their parents.

Procedures

All study procedures were conducted during a single visit that lasted approximately three hours. Parents completed the questionnaires immediately prior to or at the visit whereas youth participants completed self-report at the visit independently without parental influence. Physicians' assessments were blinded to parental and self-assessment measures.

Diagnostic Procedures

Autism Diagnostic Observation Schedule-Second Edition (ADOS-2; Lord et al. 2012) is a semi-structured, play and interview-based instrument used to support the diagnosis of autism spectrum disorder. The ADOS was administered by research-reliable clinicians. A score of 7 or above on Module 3 (fluent speech) was required for inclusion in the study.

Social Communication Questionnaire (SCQ) (Rutter et al. 2003) is a screener for symptoms of ASD. It was administered to both groups, but served as an exclusionary measure for the TD sample to ensure an absence of ASD symptoms. A score of 15 is suggestive of ASD and a score of 22 is suggestive of autistic disorder. TD children with a score ≥ 10 were excluded from the study.

Wechsler Abbreviated Scale of Intelligence, Second Edition (WASI-II, Wechsler 2011) is a measure of cognitive ability that was used to obtain an efficient, reasonable estimate of the child's intellectual functioning (IQ ≥ 70 required).

Dependent Measures

Pubertal development was rigorously measured using three different approaches; namely, physical exam, a parent-report measure, and self-report based on visual representation of Tanner stages (Marshal and Tanner 1970; Marshall and Tanner 1969).

Physical Examination (PE).—Pubertal assessment was conducted for boys and girls by physical examination and Tanner staging by three trained and licensed study physicians, one male and two females. Physicians, blinded to parental and self-reports, conducted a brief physical exam to more reliably identify pubertal development and assign Tanner stage (Marshal and Tanner 1970; Marshall and Tanner 1969). Stages range from 1–5 for both Pubic hair (P1–P5 for both genders) and Genitals (G1–G5 for boys) and Breasts (B1–B5 for girls). The exam consisted of visual inspection and categorization of pubertal and genital

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maturation. As previously discussed, palpation of breasts or measurement of testes was not conducted in order to maximize participation in the physical exam.

Completion of the PE was requested but not required. It was conducted in a university clinic exam room. A companion was offered to all youth, which consisted of a parent or same-gender research personnel member who accompanied the participant during the exam. The majority of the exams were conducted by a male physician; however, two female study physicians were available for female participants when requested. While it is widely believed that adolescents prefer same-sex physician exams, this is not supported by the extant literature as research suggests that the sex of the physician is generally not an important factor (Dorn et al. 2006).

The extent to which an adolescent is willing to participate is largely due to the comfort level of the examiner explaining the study and exam as well as the experience in performing it (Dorn et al. 2006). Thus, prior to the exam, study physicians spent approximately 5 minutes with each participant to establish rapport, explain the rationale for the exam (i.e., to establish the developmental stage of puberty) and answer any questions or concerns. In most cases, the conversation helped to normalize the experience. Additionally, the adolescent was requested to loosen clothing to fully expose breast and lower genital region, rather than disrobing, which aided in the level of comfort for the participants. For the current study, the exam was completed on 184 participants or 92% of the sample. Participants who refused to participate in the exam were primarily female (2 ASD, 4 TD); the remaining participants did not return following the eligibility visit (3 ASD males), did not meet criteria (2 males with suspected ASD) or were due to scheduling conflicts (1 female ASD, 1 female TD, 2 ASD males, 1 TD male).

Pubertal Development Scale (PDS; Petersen et al. 1988).—The PDS is a widely-used parent (or self-report) questionnaire of pubertal status in which responses range from 1 (has not begun) to 4 (is complete) examining growth, skin changes, pubic hair and breast/voice changes across gender. Additionally, for females, determination of menses status was also asked. The study team has employed the PDS across several studies of individuals with and without ASD to get a general estimate of pubertal development based on parental report (Corbett 2010, 2012, 2013).

Gender-Specific Self-Assessment Questionnaire for Children Based on Tanner Stage Drawings (GSSQ; Rasmussen et al. 2015).—The questionnaire contains gender-specific illustrations and text based on Tanner's five stages (Marshal and Tanner 1970; Marshall and Tanner 1969), each represented in female and male anatomical drawings. The rationale for using the GSSQ was based on the idea that schematic drawings and text are more closely aligned with five Tanner stages, and some previous studies reported good convergent validity coefficients with PE (Brooks-Gunn et al. 1987; Duke et al. 1980; Morris and Udry 1980). Importantly, the GSSQ is based on drawings rather than answering questions pertaining to puberty as measured in the PDS. The pictures and text were explained to each child. Subsequently, children were asked to self-rate their own stage of pubertal development. They were encouraged to take their time and ask questions, if needed. The drawings were kept in a manila envelope and the child was asked to

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independently mark an "X" on the image of Pubic stage and Breast/Genital stage for females and males, respectively. Once completed, the child placed the drawing back into the envelope. Before and after the administration, children were informed that their information was confidential and would not be shared with others outside of the research team. The questionnaire was completed before the physical exam and without the input of a parent or clinician.

Body Mass Index (BMI).—Physiological indices may be impacted by BMI (Shirtcliff et al. 2012) and weight (Dallman et al. 2004). Therefore, as part of the physical exam, the physician measured the youth's height and weight. BMI was calculated using the standard formula (Ib/in^2) x 703 for use with the CDC growth charts for children and adolescents (2 through 19 years; https://www.cdc.gov/healthyweight/bmi/calculator.html). Height was measured to the nearest inch and weight was measured to the nearest 0.1 lb using a Health o meter TM Professional 499KL Waist High Digital Scale with Height Rod.

Statistical Analyses

Analyses were conducted using SPSS software (version 25; IBM SPSS Statistics, IBM Corporation). For statistical analysis of BMI, age- and sex-adjusted Z-scores and percentiles were calculated based on the 2000 CDC growth charts (Kuczmarski et al. 2002). Pubertal stage outcomes were analysed as ordinal data (Tanner stages 1–5). Statistical approach was largely based on previous studies (e.g., Rasmussen et al. 2015; Schlossberger et al. 1992; Shiffman et al. 2016). Agreement between exam and the two reports were calculated using Crosstabs; specifically, Cohen's kappa (κ) and percent (%) accuracy calculated the precise agreement between the three measures of pubertal development. Accuracy was operationalized as self-report (GSSQ) or parent-report (PDS) agreement at the same stage as the physical exam (PE). Strength of agreement for Cohen's κ was interpreted as: <0.00, poor; 0.00 to 0.20 slight; 0.21 to 0.40, fair; 0.41 to 0.60, moderate; 0.61 to 0.80, substantial; >80, almost perfect (Landis and Koch 1977). Separate group analyses were also conducted. Hierarchical linear regression was used to assess whether age, gender, pubertal stage or diagnosis affected accuracy of agreement. Finally, precise pubertal staging for the total sample was compared across the three measures using Spearman rank correlations.

Results

There were no differences between the groups based on age, height, and weight; however, there was a significant difference for BMI-for-age percentile ($t(185) = -2.67$, $p = 0.01$, $d = 0.38$), with the ASD group evidencing higher values (see Table 1).

Physical Exam (PE) and Gender-Specific Self-Assessment Questionnaire (Table 2)

Girls: As shown in Table 2, there was poor concordance between PE and GSSQ Breast for girls, $\kappa = -.06$, $p = 0.41$ and accuracy was 22.6%. There was fair agreement between PE and GSSQ Pubic stage for girls, $\kappa = .32$, $p < 0.005$, with 48.1% accuracy.

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Boys: There was slight concordance with GSSQ Genital Stage, κ = .17, p = 0.001 and accuracy was 39.9%. There was fair agreement between PE and GSSQ Pubic stage, κ = .23, p < 0.005 and accuracy was 43.7%.

PE and Pubertal Development Scale (Table 2)

Girls: There was fair concordance between PE and parental PDS Breast stage, κ = .34, p< 0.005 and accuracy was 52.7%. There was moderate agreement with Pubic stage, κ = .44, p < 0.005 and accuracy was 58.9%.

Boys: There was only slight concordance between PE and parental PDS Genital stage, κ = .21, p = 0.001 and accuracy was 53.8% agreement. There was fair agreement between PE and parental PDS Pubic stage, κ = .29, p < 0.005 and accuracy was 62.6% agreement. Given that participants were primarily in the earlier stages of pubertal development with only three participants reported by the physician as reaching Tanner stage 5, Tanner stages 4 and 5 were combined when assessing PE vs PDS concordance. For the three participants classified in stage 5 by PE, parent ratings were substantially underestimated, with all parents selecting a stage 2 rating on the PDS.

Group (ASD vs. TD) Agreement

To determine the extent to which participants and parents demonstrated agreement with physical exam based on diagnosis, separate analyses were conducted for the ASD and TD groups.

PE and GSSQ: ASD (Table 3)

Girls: For females with ASD there was poor concordance for GSSQ Breast, κ = −.06, p = 0.52 and accuracy was 23.3%. There was fair concordance for GSSQ Pubic stage, κ = .30, p = 0.002, and accuracy was 46.6%.

Boys: For ASD males there was slight concordance for GSSQ Genital stage, κ = .16, p = 0.01 and accuracy was 36.1%. For Pubic stage there was fair concordance, κ = .33, p <0.005, and accuracy was 50.6%.

PE and PDS: ASD (Table 3)

Girls: Examining agreement within the ASD group, parents of females showed fair PDS concordance for Breast stage at κ = .24, p = 0.02, and accuracy was 46.6%. Concordance for Pubic stage was moderate, κ = .41, p < 0.005, and accuracy was 56.7%.

Boys: Parents of males with ASD showed slight concordance for Genital stage, κ = .15, p = 0.03, with 47.3% accuracy. Parents reported fair concordance for Pubic stage, κ = .27, p < 0.005 and accuracy was 57.1%.

PE and GSSQ: TD (Table 4)

Girls: For females with TD there was poor concordance for GSSQ Breast stage, κ = −.02, p = 0.87 and 21.7% accuracy. For Pubic stage there was fair concordance, κ = .34, p = 0.003 and accuracy was 50%, which was comparable to ASD participants.

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Boys: For TD males GSSQ Genital stage, there was poor concordance, κ = .15, p = 0.17 with 47.5% accuracy, which was comparable to ASD males self-report. For Pubic stage there was poor agreement, κ = .03, p = 0.71 with 32.5% accuracy, which was lower than ASD males.

PE and PDS: TD **(Table 4)**

Girls: For TD females, parent-rated Breast stage showed moderate concordance, κ = .41, p = 0.001 and accuracy was 59.2%. For Pubic stage, there was moderate concordance, κ = .47, p < 0.005 and 61.6% accuracy.

Boys: For TD males Genital stage, there was fair concordance, κ = .33, p = 0.002 and 65.2% accuracy. For Pubic stage there was fair agreement, κ = .33, p = 0.004 and 72.1% total accuracy.

Hierarchical linear regression was used to examine factors that contributed to accuracy of staging for the physical exam. Separate two-step hierarchical regressions with age, sex, diagnosis and BMI as predictors were performed for Breast/Genital and Pubic stage. For Pubic stage, the first model was significant (F=71.89, p<0.005), with age accounting for 28.4% of the variance in the outcome. When the additional predictors were added in the second step, an additional 10.5% of the variance in Pubic stage was explained, with the change in R^2 reaching statistical significance (F=10.23, p<0.005). Age, diagnosis, sex, and BMI were all significant predictors in the second model (see Table 5).

In regards to Genital/Breast stage, the first model including only age as a predictor was statistically significant (F=64.91, p<0.005), with age accounting for 26.4% of the variation. Including the other predictors significantly contributed to the model (F=6.32, p= <0.005), explaining an additional 7.1% of Genital/Breast variance. While age, diagnosis, and sex were significant predictors of Genital/Breast stage (p<0.05, see Table 6), BMI did not significantly predict reported stage on the physical exam (β=0.10, t=1.66, p=0.10).

To directly compare the three measures on the same five-point scale, the PDS was converted to Puberty Category Scores, which are comparable to Tanner stages, using previously established criteria (Crockett 1988; Carskadon and Acebo 1993). Categories were separated into Prepubertal, Early Pubertal, Midpubertal, Late pubertal and Postpubertal. These were subsequently compared to PE and GSSQ using Spearman rank order correlations, which are presented in Table 7. Results revealed relatively good agreement with the total sample between PE and PDS (ρ = .71, p < 0.001); however, there was only fair agreement between PE and GSSQ (ρ =.51, p < 0.001).

Discussion

The aim of the current study was to compare three measures of pubertal assessment in a relatively large sample of children with and without ASD in early stages of puberty and between 10 to 13 years of age. Regarding demographics, there was no difference between the groups for age, height or weight. However, there was a significant difference between the groups for BMI such that children with ASD were higher in average age- and sex-adjusted

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BMI percentile. Previous research has shown that many children with ASD have higher BMI. In an early study, Whiteley and colleagues (2004) found that based on parent-report of height and weight, the majority of patients in their study with pervasive developmental disorder had BMI at the 80th percentile. In a more recent study, Criado, Sharp and colleagues (2018) reported BMI percentiles in ASD (79.6) to be considerably higher than a comparison sample of 276 youth. These elevated rates of overweight and obesity appear especially prevalent in the teen years (Hill et al. 2015), and are frequently associated with sleep disturbance, affective problems, and other general health conditions (e.g. Hill et al. 2015; Phillips et al. 2014).

The aforementioned demographic indices were examined as potential predictors of pubertal development. Not surprisingly, the best predictor of pubertal stage was age which accounted for approximately 25% of the variance. Even so, other factors play at least some role to include height, weight and to some extent BMI and, likely, other undetermined factors (Wu et al. 2001). While age is a key determining factor in pubertal onset, it is not a perfect proxy for defining puberty. As seen here and elsewhere (e.g. Karlberg 2002), many biobehavioral factors can impact the timing of pubertal onset, as well as the timeline of transition through developmental stages until reaching full pubertal maturation. As such, accurate measures for defining pubertal stage are critical in studies examining biopsychosocial change during the adolescent transition.

Physical exams, considered in the current study as the relative gold standard for pubertal staging, were completed by the majority (92%) of the sample. Self-report using the GSSQ (e.g., Rasmussen et al. 2015) and parental report using the PDS (Petersen et al. 1988) were compared to Tanner staging via physical exams conducted by trained study physicians to determine concordance and accuracy.

Self-Assessment Ratings:

In general, concordance for self-assessments compared to physical exam ranged from poor to fair. In particular, there was a lack of agreement for girls in terms of breast stage ($\kappa=-.06$) and boys showed only slight agreement regarding genital stage ($\kappa=.16$). For both genders, there was better agreement for pubic stage although still falling within the fair range. It is plausible that the presence and extent of pubic hair is easier to distinguish for children than specific breast or genital stage. Boys tended to overestimate both genital and pubic stages, which has been previously reported (Rasmussen et al. 2015).

Based on group, ASD and TD girls' reports of pubic stage were largely comparable. For breast stage, there was poor concordance for girls with and without ASD; however, girls with ASD tended to underestimate whereas TD girls often overestimated their breast stage. These differences are likely due to social norms such that girls with ASD may not feel the same pressure to emphasize their physical size in an effort to be more acceptable. Alternatively, it is plausible that a difference exists in the pubertal timing and maturation between girls with and without ASD, such that girls with ASD may experience earlier pubertal maturation (Pohl et al. 2014). In such cases, girls in later stages of development tend to underestimate, while those in earlier stages often overestimate pubertal stage (Schlossberger et al. 1992). Boys with and without ASD showed slight to fair concordance

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for genital and pubic stage, and both groups tended to overestimate their Tanner stage. The overestimation in the boys is consistent with previous research, although an explanation for the overestimation is unclear (e.g. Schlossberger et al. 1992; Rasmussen et al. 2015; Rollof and Elfving 2012).

Parental ratings:

In general, the current results show reasonable agreement between the caregiver responses on the PDS and the physician's exam, which is broadly consistent with some reports (Duke et al. 1980; Shirtcliff et al. 2009). Concordance for parent ratings for the total group ranged from slight (κ=.15 male genital) to moderate (κ=.41 female pubic), which is largely consistent with some previous reports (Shirtcliff et al. 2009). Overall, the results show relatively higher agreement between physical exam and parent report compared to self-report shown above. Accuracy for the combined sample ranged from 52.7% to 62.6%. Additionally, there was better parental accuracy for girls than boys with regards to breast and genital stage, respectively, likely because it is visually easier to estimate breast development. However, agreement within the ASD parental group was more mixed and somewhat limited in absolute agreement as demonstrated in other studies of typically developing youth (Brooks-Gunn et al. 1987; Desmangles et al. 2006; Rasmussen et al. 2015). While comparable to other studies, the physician/parent agreement may be considered marginal when absolute precision of staging is needed in research (e.g., a longitudinal study of pubertal development) or clinical practice (e.g., endocrine functioning) (Mendle et al. 2019).

Regarding the within-group comparison, concordance for the ASD parent group ranged from slight to moderate whereas the TD parent group were generally higher ranging from fair to moderate. Furthermore, parents of TD children were significantly more accurate than parents of children with ASD regardless of gender, although the differences were particularly notable in male children. For example, with regards to pubic stage, parent ratings of TD children (72.1%) fell within the substantial range compared to parents of ASD children (57.1%) which were in the moderate range, resulting in roughly a twenty percent difference. In general, parents tended to underestimate rather than overestimate their child's pubertal stage especially parents of children with ASD. As an illustration, 47.3% of parents of ASD youth underestimated male genital stage whereas 34.9% of parents of TD males underestimated.

The precise reasons for the underestimation are unknown. Although purely hypothetical, factors may include parental differences in adaptation, perceptions and communication regarding development. Regarding the former, many parents worry about the storm and stress of adolescence (Hall 1904). This concern is undoubtedly heightened for parents of children with ASD who may worry about increased anxiety and depression, social withdrawal or deterioration of functioning in adolescence (Billstedt et al. 2005; Brown 1969; Eisenberg 1956; Gillberg and Schaumann 1981; Rutter 1970). There could be an incongruence between the social or cognitive challenges of the adolescent with ASD and their prototypical physical, sexual and health status, which is normative. We hypothesize that the parents of ASD youth may inadvertently underestimate the child's developmental stage as an adaptation or defence against the perceived risk of the adolescent period. In other

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words, they may have an adaptive attentional bias to developmental threats, including puberty and sexuality.

While previous research in sexual development is somewhat limited, parents of boys with ASD have been shown to underestimate, or be unaware of, their child's sexual knowledge and experiences (Dewinter et al. 2016) and tend to be more future-oriented with regards to their child's sexuality (Teti et al. 2019). There is some evidence that parents may avoid relevant topics of physical development and sexual relationships, especially in girls. In a recent study by Sedgewick and colleagues, some parents of daughters with ASD acknowledged that despite concern about their daughter's sexual relationships and fears of exploitation, they avoided engaging in relevant discussions about these topics (Sedgewick et al. 2018). Similarly, it has been shown that parents of children with ASD provide sexual education less often and later than parents of TD presumably because they incorrectly assume their ASD children will have limited interest in sexual relationships (Mehzabin and Stokes 2011; Stokes and Kaur 2005). Therefore, underestimation of a child's maturation can alter the timing of parent-led sexual education and age-appropriate communication. In turn, it could be hypothesized that the lack of communication regarding sexual maturation and education may contribute to the greater inaccuracy in self-reporting evidenced for children with ASD as shown in the current study. Finally, communication is often reduced, insufficient or inadequate between parent and child during adolescence (Steinberg 2001) and this may be magnified in a population marked by reduced social communication ability principally regarding puberty related topics such as sexual development (Ballan 2012; Ruble and Dalrymple 1993; Nichols and Blakely-Smith 2009).

In light of the current and aforementioned findings regarding underestimation of physical development in both children and parents, education pertaining to physical and sexual maturation for youth with ASD is important to consider. As noted, underestimation of physical development could result in delayed sexuality education. Researchers and clinicians in the Netherlands developed the first evidence-based psychosexual education program for adolescents with ASD, called Tackling Teenage Training (TTT) (Dekker et al. 2015; Visser et al. 2015). The goals of the program are to develop understanding of and practical tools for psychosexual functioning in youth with ASD; topics include puberty, sexual behaviour, sexual development, boundaries, intimacy, and related topics (Dekker et al. 2015; Visser et al. 2015). Results across these studies have revealed that participants' scores on a sexual education test were significantly higher post-intervention, suggesting increased psychosexual knowledge as well as increased knowledge of appropriate boundaries and decreased inappropriate sex behaviours (Dekker et al. 2015; Visser et al. 2015). Collectively, these studies highlight the potential value of sexual intervention for youth with ASD (Escalona et al. 2016).

Despite the strengths of the study, which include methodical comparison of three measures of pubertal development in a prospective study of youth with and without ASD, there are limitations to acknowledge. Firstly, as part of the Tanner physical, examination of the breast (palpation) and genitalia (measurement) is considered good clinical care; nevertheless, visual inspection alone was used. This decision was made because the procedure was part of a large longitudinal study in which participants and families complete several measures

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during the visit. It is believed that the decision to use visual inspection and the establishment of good rapport prior to the exam, contributed to the high completion rate of the exam in the sample. It may also be important to acknowledge that a direct comparison between parent- vs. self-report questionnaires was not conducted (e.g., PDS-parent and PDS-self). Similarly, it is unclear if pictorial representation or answering questions pertaining to pubertal development are more optimal for individuals with ASD. Future studies may be needed to compare participant responses using drawings vs. questionnaire format to determine if one is more useful. Another limitation is the lack of inclusion of individuals with ASD and intellectual disability, which limits the generalizability of the findings. Participants are part of a longitudinal study that involves cognitive and language demands requiring higher functioning capability.

In summary, the results demonstrate that parent- and self-reports are inadequate proxies for determining specific levels of pubertal development. While parental estimates for pubic stage showed the best estimate with moderate agreement, it was only marginally better than self-assessments. There were significant discrepancies regarding developmental stage for both genders based on self-assessment, including overestimation in boys. Moreover, there were notable differences in parental report to include underestimation of pubertal stage, especially in caregivers of children with ASD. Taken together, pubertal assessments by parent or child are not reliable indices of precise pubertal staging. Future studies will determine if the reliability of such measures improves or declines as the current sample advances from early through later pubertal stages. It is predicted that increases in age and physical development will contribute to improved accuracy in both parents and self-reports.

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References

Anderson DK, Lord C, Risi S, DiLavore PS, Shulman C, Thurm A, et al. (2007). Patterns of growth in verbal abilities among children with autism spectrum disorder. J Consult Clin Psychol, 75(4), 594–604, 10.1037/0022-006X.75.4.594. [PubMed: 17663613]

Anderson DK, Maye MP, & Lord C (2011). Changes in maladaptive behaviors from midchildhood to young adulthood in autism spectrum disorder. Am J Intellect Dev Disabil, 116(5), 381–397, 10.1352/1944-7558-116.5.381. [PubMed: 21905806]

Anderson DK, Oti RS, Lord C, & Welch K (2009). Patterns of growth in adaptive social abilities among children with autism spectrum disorders. J Abnorm Child Psychol, 37(7), 1019–1034, 10.1007/s10802-009-9326-0. [PubMed: 19521762]

APA (2013). Diagnostic and statistical manual of mental disorders, Fifth Edition (DSM-5) Washinton, D.C: American Psychiatric Association.

Ballan MS (2012). Parental perspectives of communication about sexuality in families of children with autism spectrum disorders. J Autism Dev Disord, 42(5), 676–684, 10.1007/s10803-011-1293-y. [PubMed: 21681591]

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Billstedt E, Gillberg IC, & Gillberg C (2005). Autism after adolescence: population-based 13- to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. J Autism Dev Disord, 35(3), 351–360. [PubMed: 16119476]

Boas SR, Falsetti D, Murphy TD, & Orenstein DM (1995). Validity of self-assessment of sexual maturation in adolescent male patients with cystic fibrosis. J Adolesc Health, 17(1), 42–45, 10.1016/1054-139X(95)00042-Q. [PubMed: 7578162]

Bratberg GH, Nilsen TI, Holmen TL, & Vatten LJ (2007). Perceived pubertal timing, pubertal status and the prevalence of alcohol drinking and cigarette smoking in early and late adolescence: a population based study of 8950 Norwegian boys and girls. Acta Paediatr, 96(2), 292–295. [PubMed: 17429923]

Brooks-Gunn J, Warren MP, Rosso J, & Garguilo J (1987). Validity of self-report measures of girl's pubertal status. Child Development, 58, 829–841. [PubMed: 3608653]

Brown JL (1969). Adolescent Development of Children with Infantile Psychosis. Seminars in Psychiatry, 1(1), 79-&.

Carskadon MA, & Acebo C (1993). A Self-Administered Rating-Scale for Pubertal Development. Journal of Adolescent Health, 14(3), 190–195, 10.1016/1054-139x(93)90004-9. [PubMed: 8323929]

Carskadon MA, Harvey K, Duke P, Anders TF, Litt IF, & Dement WC (1980). Pubertal changes in daytime sleepiness. Sleep, 2(4), 453–460. [PubMed: 7403744]

Chrousos GP, Torpy DJ, & Gold PW (1998). Interactions between the hypothalamic-pituitary-adrenal axis and the female reproductive system: clinical implications. Ann Intern Med, 129(3), 229–240. [PubMed: 9696732]

Coleman L, & Coleman J (2002). The measurement of puberty: a review. J Adolesc, 25(5), 535–550. [PubMed: 12234559]

Corbett BA (2017). Examining stress and arousal across pubertal development in ASD. National Institute of Mental Health

Corbett BA, & Schupp CW (2014). The Cortisol Awakening Response (CAR) in Male Children with Autism Spectrum Disorder. Horm Behav, 10.1016/j.yhbeh.2014.01.012.

Corbett BA, Schupp CW, & Lanni KE (2012). Comparing biobehavioral profiles across two social stress paradigms in children with and without autism spectrum disorders. Mol Autism, 3(1), 13, 10.1186/2040-2392-3-13. [PubMed: 23158965]

Corbett BA, Schupp CW, Simon D, Ryan N, & Mendoza S (2010). Elevated cortisol during play is associated with age and social engagement in children with autism. Mol Autism, 1(1), 13, 10.1186/2040-2392-1-13. [PubMed: 20875126]

Corbett BA, Swain DM, Newsom C, Wang L, Song Y, & Edgerton D (2013). Biobehavioral profiles of arousal and social motivation in autism spectrum disorders. J Child Psychol Psychiatry, 10.1111/jcpp.12184.

Criado KK, Sharp WG, McCracken CE, De Vinck-Baroody O, Dong L, Aman MG, et al. (2018). Overweight and obese status in children with autism spectrum disorder and disruptive behavior. Autism, 22(4), 450–459, 10.1177/1362361316683888. [PubMed: 28325061]

Crockett LJ (1988). Pubertal Development Scale: Pubertal categories

Dahl RE (2004). Adolescent brain development: a period of vulnerabilities and opportunities. Keynote address. Ann N Y Acad Sci, 1021, 1–22, 10.1196/annals.1308.001. [PubMed: 15251869]

Dallman MF, la Fleur SE, Pecoraro NC, Gomez F, Houshyar H, & Akana SF (2004). Minireview: glucocorticoids--food intake, abdominal obesity, and wealthy nations in 2004. Endocrinology, 145(6), 2633–2638, 10.1210/en.2004-0037. [PubMed: 15044359]

Deardorff J, Gonzales NA, Christopher FS, Roosa MW, & Millsap RE (2005). Early puberty and adolescent pregnancy: the influence of alcohol use. Pediatrics, 116(6), 1451–1456, 10.1542/peds.2005-0542. [PubMed: 16322170]

Dekker LP, van der Vegt EJ, Visser K, Tick N, Boudesteijn F, Verhulst FC, et al. (2015). Improving psychosexual knowledge in adolescents with autism spectrum disorder: pilot of the tackling teenage training program. J Autism Dev Disord, 45(6), 1532–1540, 10.1007/s10803-014-2301-9. [PubMed: 25399394]

Author Manuscript Author Manuscript Author Manuscript Author Manuscript

Desmangles JC, Lappe JM, Lipaczewski G, & Haynatzki G (2006). Accuracy of pubertal Tanner staging self-reporting. J Pediatr Endocrinol Metab, 19(3), 213–221. [PubMed: 16607921]

Dewinter J, Vermeiren R, Vanwesenbeeck I, & Nieuwenhuizen Ch V (2016). Parental Awareness of Sexual Experience in Adolescent Boys With Autism Spectrum Disorder. J Autism Dev Disord, 46(2), 713–719, 10.1007/s10803-015-2622-3. [PubMed: 26481386]

Dorn LD, & Biro FM (2011). Puberty and Its Measurement: A Decade in Review. Journal of Research on Adolescence, 21(1), 180–195, 10.1111/j.1532-7795.2010.00722.x.

Dorn LD, Dahl RE, Woodward HR, & Biro F (2006). Defining the boundaries of early adolescence: A user's guide to assessing pubertal status and pubertal timing in research with adolescents. Applied Developmental Science, 10(1), 30–56.

Duke PM, Litt IF, & Gross RT (1980). Adolescents' self-assessment of sexual maturation. Pediatrics, 66(6), 918–920. [PubMed: 7454482]

Edmiston EK, Blain SD, & Corbett BA (2017a). Salivary cortisol and behavioral response to social evaluative threat in adolescents with autism spectrum disorder. Autism Res, 10(2), 346–358, 10.1002/aur.1660. [PubMed: 27417507]

Edmiston EK, Muscatello RA, & Corbett BA (2017b). Altered Pre-Ejection Period Response to Social Evaluative Threat in Adolescents with Autism Spectrum Disorder. Res Autism Spectr Disord, 36, 57–65, 10.1016/j.rasd.2017.01.008. [PubMed: 29177005]

Eisenberg L (1956). The Autistic-Child in Adolescence. American Journal of Psychiatry, 112(8), 607–612, 10.1176/ajp.112.8.607. [PubMed: 13292547]

Escalona RC, Puig O, Balcells R, Visser K, Amat C, Peran L, et al. (2016). The TTT (Tackling Teenage Training) Spanish Version: A pilot study in adolescents with autism spectrum disorder Paper presented at the American Academy of Child and Adolescent Psychiatry 63rd Annual Meeting, New York, NY,

Forbes EE, & Dahl RE (2010). Pubertal development and behavior: hormonal activation of social and motivational tendencies. Brain and cognition, 72(1), 66–72. [PubMed: 19942334]

Gillberg C, & Schaumann H (1981). Infantile autism and puberty. J Autism Dev Disord, 11(4), 365–371. [PubMed: 7052813]

Graber JA, Lewinsohn PM, Seeley JR, & Brooks-Gunn J (1997). Is psychopathology associated with the timing of pubertal development? J Am Acad Child Adolesc Psychiatry, 36(12), 1768–1776, 10.1097/00004583-199712000-00026. [PubMed: 9401339]

Granger DA, Hibel LC, Fortunato CK, & Kapelewski CH (2009). Medication effects on salivary cortisol: tactics and strategy to minimize impact in behavioral and developmental science. Psychoneuroendocrinology, 34(10), 1437–1448, 10.1016/j.psyneuen.2009.06.017. [PubMed: 19632788]

Hall GS (1904). Adolescnce: In psychology and its relation to physiology, anthropology, sociology, sex, crime, religion, and education (Vol. I & II). Englewood Cliffs: Prentice-Hall.

Harper JF, & Collins JK (1979). Physical growth and development in a sample of autistic girls from New South Wales. Aust Paediatr J, 15(2), 110–112. [PubMed: 485990]

Hergenroeder AC, Hill RB, Wong WW, Sangi-Haghpeykar H, & Taylor W (1999). Validity of self-assessment of pubertal maturation in African American and European American adolescents. J Adolesc Health, 24(3), 201–205. [PubMed: 10195803]

Herguner A, & Herguner S (2016). Association Between Age at Menarche and Autistic Traits in Turkish University Students. American Journal of Human Biology, 28(1), 44–47, 10.1002/ajhb.22739. [PubMed: 25994409]

Herting MM, Kim R, Uban KA, Kan E, Binley A, & Sowell ER (2017). Longitudinal changes in pubertal maturation and white matter microstructure. Psychoneuroendocrinology, 81, 70–79, 10.1016/j.psyneuen.2017.03.017. [PubMed: 28419914]

Hill AP, Zuckerman KE, & Fombonne E (2015). Obesity and Autism. Pediatrics, 136(6), 1051–1061, 10.1542/peds.2015-1437. [PubMed: 26527551]

IBM Corp. Released 2017 IBM SPSS Statistics for Windows, Verson 25.0 Armonk, NY: IBM Corp.

Kaltiala-Heino R, Marttunen M, Rantanen P, & Rimpela M (2003). Early puberty is associated with mental health problems in middle adolescence. Soc Sci Med, 57(6), 1055–1064. [PubMed: 12878105]

Karlberg J (2002). Secular trends in pubertal development. Horm Res, 57 Suppl 2, 19–30, 10.1159/000058096.

Knickmeyer RC, Wheelwright S, Hoekstra R, & Baron-Cohen S (2006). Age of menarche in females with autism spectrum conditions. Dev Med Child Neurol, 48(12), 1007–1008, 10.1017/S0012162206222229. [PubMed: 17109794]

Kuczmarski RJ, Ogden CL, Guo SS, Grummer-Strawn LM, Flegal KM, Mei Z, et al. (2002). 2000 CDC Growth Charts for the United States: methods and development. Vital Health Stat 11(246), 1–190.

Lainhart JE, Bigler ED, Bocian M, Coon H, Dinh E, Dawson G, et al. (2006). Head circumference and height in autism: a study by the Collaborative Program of Excellence in Autism. Am J Med Genet A, 140(21), 2257–2274, 10.1002/ajmg.a.31465. [PubMed: 17022081]

Landis JR, & Koch GG (1977). The measurement of observer agreement for categorical data. Biometrics, 33(1), 159–174. [PubMed: 843571]

Lawrence K, Campbell R, & Skuse D (2015). Age, gender, and puberty influence the development of facial emotion recognition. Front Psychol, 6, 761, 10.3389/fpsyg.2015.00761. [PubMed: 26136697]

Lord C, Rutter M, DiLavore PC, Risi S, Gotham K, & Bishop SL (2012). Autism Diagnostic Observation Schedule (ADOS-2) (2nd ed.). Torrance, CA: Western Psychological Services.

Marshal WA, & Tanner JM (1970). Variations in the pattern of pubertal changes in boys. Archives of Disease in Childhood, 45(239), 13–23. [PubMed: 5440182]

Marshall WA, & Tanner JM (1969). Variations in pattern of puberal development in girls. Archives of Disease in Childhood, 44(235), 291–303. [PubMed: 5785179]

May T, Pang KC, O’Connell MA, & Williams K (2017). Typical Pubertal Timing in an Australian Population of Girls and Boys with Autism Spectrum Disorder. J Autism Dev Disord, 47(12), 3983–3993, 10.1007/s10803-017-3281-3. [PubMed: 28856494]

Mehzabin P, & Stokes MA (2011). Self-assessed sexuality in young adults with High-Functioning Autism. Research in Autism Spectrum Disorders, 5(1), 614–621, 10.1016/j.rasd.2010.07.006.

Mendle J, Beltz AM, Carter R, & Dorn LD (2019). Understanding Puberty and Its Measurement: Ideas for Research in a New Generation. J Res Adolesc, 29(1), 82–95, 10.1111/jora.12371. [PubMed: 30869839]

Morris NM, & Udry JR (1980). Validation of a self-administered instrument to assess stage of adolescent development. J Youth Adolesc, 9(3), 271–280, 10.1007/BF02088471. [PubMed: 24318082]

Mouridsen SE (1989). Pervasive developmental disorder and idiopathic precocious puberty in a 5-year-old girl. J Autism Dev Disord, 19(2), 351–353. [PubMed: 2745399]

Munoz MT, & Argente J (2002). Anorexia nervosa in female adolescents: endocrine and bone mineral density disturbances. Eur J Endocrinol, 147(3), 275–286. [PubMed: 12213663]

Nichols S, & Blakely-Smith A (2009). “I’m Not Sure We’re Ready for This …”: Working With Families Toward Facilitating Healthy Sexuality for Individuals With Autism Spectrum Disorders. Social Work in Mental Health, 8(1), 72–91.

Norris SA, & Richter LM (2005). Usefulness and reliability of tanner pubertal self-rating to urban Black adolescents in South Africa. Journal of Research on Adolescence, 15(4), 609–624, 10.1111/j.1532-7795.2005.00113.x.

Petersen AC, Crockett L, Richards M, & Boxer A (1988). A self-report measure of pubertal status: reliability, validity and initial norms. Journal of Youth and Adolescence, 17(2), 117–131. [PubMed: 24277579]

Phillips KL, Schieve LA, Visser S, Boulet S, Sharma AJ, Kogan MD, et al. (2014). Prevalence and impact of unhealthy weight in a national sample of US adolescents with autism and other learning and behavioral disabilities. Matern Child Health J, 18(8), 1964–1975, 10.1007/s10995-014-1442-y. [PubMed: 24553796]

Pohl A, Cassidy S, Auyeung B, & Baron-Cohen S (2014). Uncovering steroidopathy in women with autism: a latent class analysis. Molecular Autism, 5, 10.1186/2040-2392-5-27.

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Author Manuscript

Rasmussen AR, Wohlfahrt-Veje C, Tefre de Renzy-Martin K, Hagen CP, Tinggaard J, Mouritsen A, et al. (2015). Validity of self-assessment of pubertal maturation. Pediatrics, 135(1), 86–93, 10.1542/peds.2014-0793. [PubMed: 25535262]

Roemmich JN, Richmond RJ, & Rogol AD (2001). Consequences of sport training during puberty. J Endocrinol Invest, 24(9), 708–715. [PubMed: 11716157]

Rollof L, & Elfving M (2012). Evaluation of self-assessment of pubertal maturation in boys and girls using drawings and orchidometer. J Pediatr Endocrinol Metab, 25(1–2), 125–129, 10.1515/jpem.2011.440. [PubMed: 22570961]

Ruble LA, & Dalrymple NJ (1993). Social/sexual awareness of persons with autism: a parental perspective. Arch Sex Behav, 22(3), 229–240. [PubMed: 8494490]

Rutter M (1970). Autistic Children - Infancy to Adulthood. Seminars in Psychiatry, 2(4), 435-&. [PubMed: 5527410]

Rutter M, Bailey A, & Lord C (2003). The Social Communication Questionnaire Los Angeles, CA: Western Psychological Services.

Schlossberger NM, Turner RA, & Irwin CE Jr. (1992). Validity of self-report of pubertal maturation in early adolescents. J Adolesc Health, 13(2), 109–113. [PubMed: 1627576]

Schmitz KE, Hovell MF, Nichols JF, Irvin VL, Keating K, Simon GM, et al. (2004). A validation study of early adolescents' pubertal self-assessments. Journal of Early Adolescence, 24(4), 357–384, 10.1177/0272431604268531.

Sedgewick F, Hill V, & Pellicano E (2018). Parent perspectives on autistic girls' friendships and futures. Autism and Developmental Language Impairments, 3, 1–12.

Seltzer MM, Shattuck P, Abbeduto L, & Greenberg JS (2004). Trajectory of development in adolescents and adults with autism. Ment Retard Dev Disabil Res Rev, 10(4), 234–247, 10.1002/mrdd.20038. [PubMed: 15666341]

Shiffman M, Vanderlaan DP, Wood H, Hughes SK, Owen-Anderson A, Lumley MM, et al. (2016). Behavioral and emotional problems as a function of peer relationships in adolescents with gender dysphoria: A comparison with clinical and nonclinical controls. Psychology of Sexual Orientation and Gender Diversity, 3(1), 27–36, 10.1037/sgd0000152.

Shirtcliff EA, Allison AL, Armstrong JM, Slattery MJ, Kalin NH, & Essex MJ (2012). Longitudinal stability and developmental properties of salivary cortisol levels and circadian rhythms from childhood to adolescence. Dev Psychobiol, 54(5), 493–502, 10.1002/dev.20607. [PubMed: 21953537]

Shirtcliff EA, Dahl RE, & Pollak SD (2009). Pubertal development: correspondence between hormonal and physical development. Child Dev, 80(2), 327–337, 10.1111/j.1467-8624.2009.01263.x. [PubMed: 19466995]

Sisk CL, & Foster DL (2004). The neural basis of puberty and adolescence. Nat Neurosci, 7(10), 1040–1047, 10.1038/nn1326nn1326 [pii]. [PubMed: 15452575]

Spear LP (2000). The adolescent brain and age-related behavioral manifestations. Neurosci Biobehav Rev, 24(4), 417–463, doi:S0149-7634(00)00014-2 [pii]. [PubMed: 10817843]

Steinberg L (2001). Gallagher Lecture. The Family at Adolescence: Transition and transformation. Journal of Adolescent Health, 27(3), 170–178.

Steinberg L (2005). Cognitive and affective development in adolescence. Trends in Cognitive Sciences, 9(2), 69–74, 10.1016/j.tics.2004.12.005. [PubMed: 15668099]

Steward R, Crane L, Roy EM, Remington A, & Pellicano E (2018). "Life is Much More Difficult to Manage During Periods": Autistic Experiences of Menstruation. Journal of Autism and Developmental Disorders, 48(12), 4287–4292, 10.1007/s10803-018-3664-0. [PubMed: 29982893]

Stokes MA, & Kaur A (2005). High-functioning autism and sexuality: a parental perspective. Autism, 9(3), 266–289, 10.1177/1362361305053258. [PubMed: 15937042]

Tanner JM (1962). Growth at adolescence Springfield, IL: Thomas.

Taylor JL, Adams RE, & Bishop SL (2017). Social participation and its relation to internalizing symptoms among youth with autism spectrum disorder as they transition from high school. Autism Research, 10(4), 663–672, 10.1002/aur.1709. [PubMed: 27739234]

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

Taylor JL, & Seltzer MM (2010). Changes in the autism behavioral phenotype during the transition to adulthood. J Autism Dev Disord, 40(12), 1431–1446, 10.1007/s10803-010-1005-z. [PubMed: 20361245]

Teti M, Cheak-Zamora N, Bauerband LA, & Maurer-Batjer A (2019). A Qualitative Comparison of Caregiver and Youth with Autism Perceptions of Sexuality and Relationship Experiences. J Dev Behav Pediatr, 40(1), 12–19, 10.1097/DBP.0000000000000620. [PubMed: 30444737]

Tordjman S, Ferrari P, Sulmont V, Duyme M, & Roubertoux P (1997). Androgenic activity in autism. Am J Psychiatry, 154(11), 1626–1627.

Visser K, Greaves-Lord K, Tick NT, Verhulst FC, Maras A, & van der Vegt EJM (2015). Study protocol: a randomized controlled trial investigating the effects of a psychosexual training program for adolescents with autism spectrum disorder. BMC Psychiatry, 15, 10.1186/S12888-015-0586-7.

Waylen A, & Wolke D (2004). Sex ‘n’ drugs ‘n’ rock ‘n’ roll: the meaning and social consequences of pubertal timing. Eur J Endocrinol, 151 Suppl 3, U151–159. [PubMed: 15554900]

Wechsler D (2011). Wechsler Abbreviated Scale of Intelligence II (Vol. Second Edition). San Antonio, TX: PsychCorp.

Whitehouse AJ, Maybery MT, Hickey M, & Sloboda DM (2011). Brief report: autistic-like traits in childhood predict later age at menarche in girls. J Autism Dev Disord, 41(8), 1125–1130, 10.1007/s10803-010-1129-1. [PubMed: 21184161]

Whiteley P, Dodou K, Todd L, & Shattock P (2004). Body mass index of children from the United Kingdom diagnosed with pervasive developmental disorders. Pediatr Int, 46(5), 531–533, 10.1111/j.1442-200x.2004.01946.x. [PubMed: 15491378]

Wu Y, Schreiber GB, Klementowicz V, Biro F, & Wright D (2001). Racial differences in accuracy of self-assessment of sexual maturation among young black and white girls. J Adolesc Health, 28(3), 197–203. [PubMed: 11226842]

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Table 1.

Demographics

	ASD (n=122)	TD (n=78)	t	*p*
	M (*SD*)	M (*SD*)		
Age	11.31 (0.97)	11.41 (1.07)	0.71	0.48
ADOS Total	12.25 (4.81)	--	--	--
Full Scale IQ*	100.41 (20.59)	118.03 (13.70)	7.21	<0.005
SCQ*	16.93 (8.33)	2.71 (2.43)	−17.67	<0.005
Height (in)	59.58 (4.23)	59.39 (3.53)	−0.32	0.75
Weight (1b)	110.72 (43.39)	100.27 (34.60)	−1.81	0.07
BMI*	21.89 (6.92)	19.91 (5.48)	−2.04	0.04
BMI percentile*	66.73 (31.07)	54.19 (31.96)	−2.67	0.01

Note:

*p<0.05; ADOS, Autism Diagnostic Observation Schedule; BMI, Body Mass Index; SCQ, Social Communication Questionnaire

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Table 2.

Agreement Between Physical Examination (Gold Standard) and Self or Parental Assessments for Total Sample

	Female		Male	
	Breast	**Pubic**	**Genital**	**Pubic**
Self				
κ	−.06	.32***	.17**	.23***
95% CI	.−.21, .08	.14, .49	.05, .30	.12, .34
% Accuracy	22.6%	48.1%	39.9%	43.7%
Estimation Under/Over	39.6% / 37.8%	15.3% / 36.4%	18.1% / 41.8	10.8% / 45.4%
	Breast	Pubic	Genital	Pubic
Parental				
κ	.34***	.44***	.21**	.29***
95% CI	.17, .51	.28, .59	.09, .32	.19, .40
% Accuracy	52.7%	58.9%	53.8%	62.6%
Estimation Under/ Over	40.4% / 7.1%	37.6% / 3.6%	43.0% / 3.4%	33.3% / 4.2%

* $p < 0.05$

** $p < 0.01$

*** $p < 0.005$; 95% CI = 95% Confidence interval

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Table 3.

Agreement Between Physical Examination (Gold Standard) and Self or Parental Assessments for ASD

	Female		Male	
	Breast	**Pubic**	**Genital**	**Pubic**
Self				
κ	−.06	.30***	.16**	.33***
95% CI	−.23, .10	.06, .54	.01, .30	.20, .47
% Accuracy	23.3%	46.6%	36.1%	50.6%
Estimation Under/Over	53.4% / 23.2%	20.1% / 33.2%	21.6% / 41.8%	9.9% / 38.8%
	Breast	Pubic	Genital	Pubic
Parental				
κ	.24*	.41***	.15*	.27***
95% CI	.01, .48	.18, .63	.02, .29	.15, .39
% Accuracy	46.6%	56.7%	47.3%	57.1%
Estimation Under/Over	50% / 3.3%	40.1% / 3.3%	47.3% / 5.3%	37.7% / 5.2%

* $p < 0.05$

** $p < 0.01$

*** $p < 0.005$; 95% CI = 95% Confidence interval

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Table 4.

Agreement Between Physical Examination (Gold Standard) and Self or Parental Assessments for TD

	Female		Male	
	Breast	**Pubic**	**Genital**	**Pubic**
Self				
κ	−.02	.34***	.15	.03
95% CI	−.23, .20	.08, .60	−.07, .38	−.13, .19
% Accuracy	21.7%	50%	47.5%	32.5%
Estimation Under/Over	21.6% / 56.4%	9% / 40.8%	12.5% / 40%	12.5% / 55%
	Breast	Pubic	Genital	Pubic
Parental				
κ	.41***	.47***	.33***	.33***
95% CI	.17, .65	.25, .67	.13, .52	.10, .55
% Accuracy	59.2%	61.6%	65.2%	72.1%
Estimation Under/Over	29.6% / 11.1%	34.6% / 3.8%	34.9% / 0.0%	25.6% / 2.3%

* $p < 0.05$

** $p < 0.01$

*** $p < 0.005$; 95% CI = 95% Confidence interval

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Table 5.

Regression Results for Predictors of Pubic Stage

	Step 1			Step 2		
Variable	**β**	**t-statistic**	**p**	**β**	**t-statistic**	**p**
Age	0.53	8.48	<0.005	0.50	8.39	<0.005
Sex	--	--	--	0.20	3.35	0.001
Diagnosis	--	--	--	0.14	2.36	0.02
BMI	--	--	--	0.20	3.43	0.001
	Step 1			**Step 2**		
ΔR^2	0.284			0.105		
ΔF	71.89*			10.23*		

*p<0.005

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Table 6.

Regression Results for Predictors of Breast/Genital Stage

	Step 1			Step 2		
Variable	**β**	**t-statistic**	**p**	**β**	**t-statistic**	**p**
Age	0.51	8.06	<0.005	0.50	8.01	<0.005
Sex	--	--	--	0.17	2.68	0.008
Diagnosis	--	--	--	0.18	2.91	0.004
BMI	--	--	--	0.10	1.66	0.10
	Step 1			**Step 2**		
ΔR^2	0.264			0.071		
ΔF	64.91*			6.32*		

*p<0.005

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Table 7.

Percentage of Total Sample in Parent- or Self-Reported Pubertal Categories for Each Physician-Assigned Tanner Stage

	PDS Puberty Category Score				
	Pre	**Early**	**Mid**	**Late**	**Post**
PE Combined Tanner Scores					
Pre	55.2	32.3	12.5	0.0	0.0
Early	21.2	33.3	42.4	3.0	0.0
Mid	0.0	15.4	46.2	34.6	3.8
Late	0.0	0.0	35.3	58.8	5.8
Post	0.0	0.0	66.7	33.3	0.0
	Self Combined Tanner Scores				
	Pre	Early	Mid	Late	Post
Pre	45.9	37.6	11.8	4.7	0.0
Early	23.3	40.0	33.3	3.3	0.0
Mid	8.3	37.5	41.7	4.2	8.3
Late	0.0	17.6	41.2	29.4	11.8
Post	0.0	0.0	50.0	50.0	0.0

Note: Combined Tanner Scores calculated as the sum of Tanner rating for Breast/Genital Stage and Pubic Hair Stage divided by two. Tanner score categories were equivalent to stages one through five (i.e. prepubertal = Tanner stage 1, etc.). PDS, Pubertal Development Scale. PE, Physical Exam.