

THE IMPACT OF COMMUNICATION DEFICITS ON PUBERTY AND SEXUAL DEVELOPMENT IN ADOLESCENTS ON THE AUTISM SPECTRUM

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INTRODUCTION

A diagnosis of autism spectrum disorder (ASD) is largely established by quantifying impediments in social and communication skills through observation. There is strong evidence in the literature supporting the saliency of communication in facilitating appropriate sexual development. Therefore, it can be inferred that deficiencies in the ability to communicate effectively would vastly contribute to the increase of difficulties during this period of development for individuals with ASD.

Additionally, there is literature demonstrating complexities that individuals with ASD face during sexual development:

- Individuals with ASD generally had limited sex education knowledge compared to others who are of the same age and not on the spectrum.¹
- A comparative study regarding sexual knowledge basis in men and women with and without ASD found that both groups of individuals with ASD had less knowledge compared to the comparison groups without ASD.²
- Adolescents not on the autism spectrum displayed significant improvement in sexual education and behaviors with the progression of age, whereas the individuals with high-functioning ASD remained stagnant in their sexual development knowledge and behaviors.³
- Establishing relationships and friendships are fundamental in appropriate social development. Therefore, difficulties in developing adequate social skills can lead to difficulties navigating sexual relationships and desires.⁵

METHODS

PARTICIPANTS

- Parent or guardian of an adolescent (10 – 18 years old) with ASD
- Recruitment for study was conducted through social media sites (e.g. Facebook) and autism societies

SURVEY DESIGN

- 34 male specific questions
- 37 female specific questions
- Self-administered through SurveyMonkey.com

SURVEY MEASURES

- Autism severity⁶ ($\alpha = 0.75$)
- Functional communication⁶ ($\alpha = 0.80$)
- Understanding of sex education
- Sexual behavior frequency⁶ ($\alpha = 0.78$)
- Male pubertal development⁴ ($\alpha = 0.74$)
- Female pubertal development⁴ ($\alpha = 0.94$)
- Utility of healthcare provider

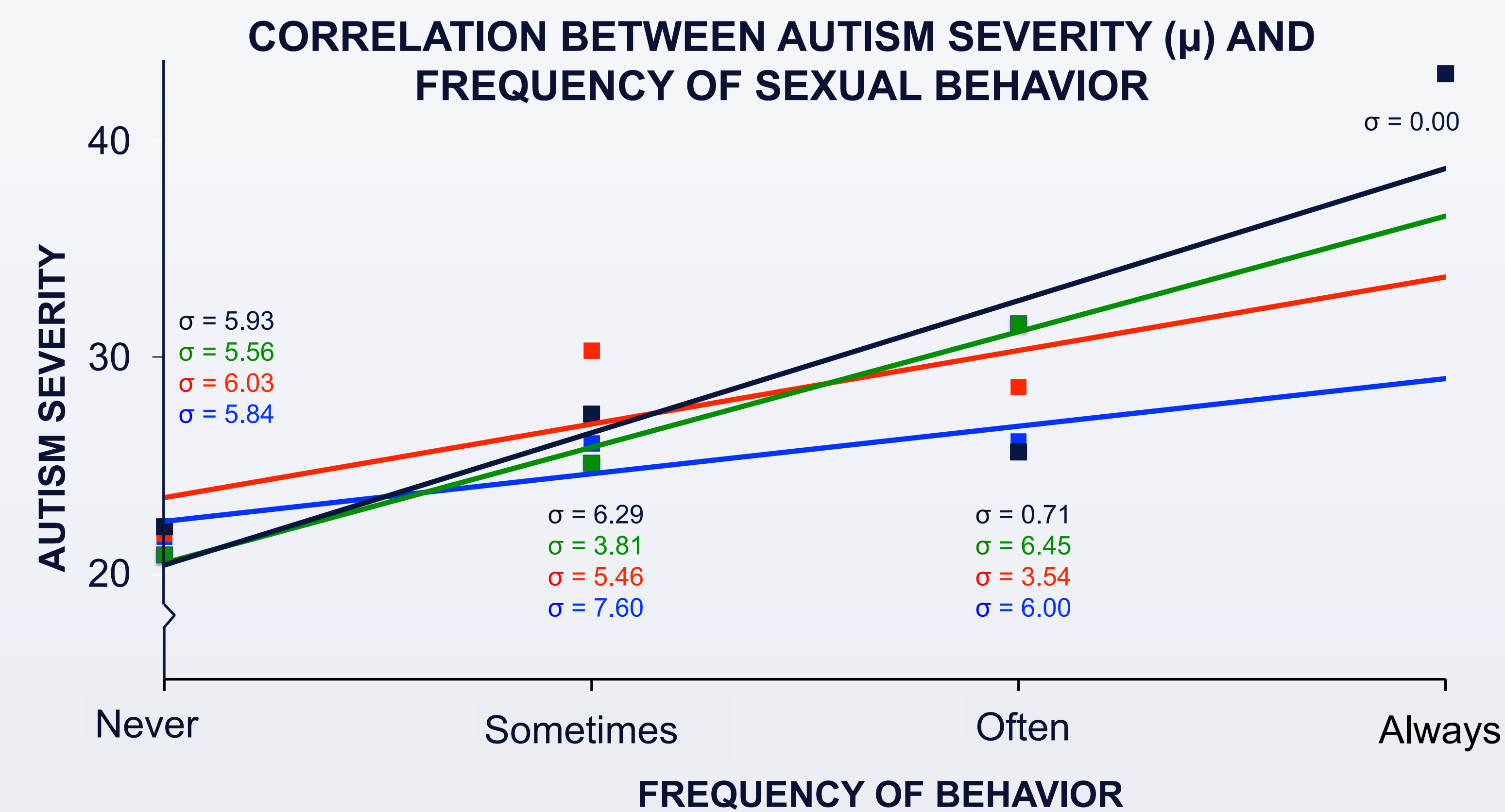
INTERVIEW DESIGN

- Participants were given the option to provide their contact information following the survey
- Semi-structured six question telephone interview

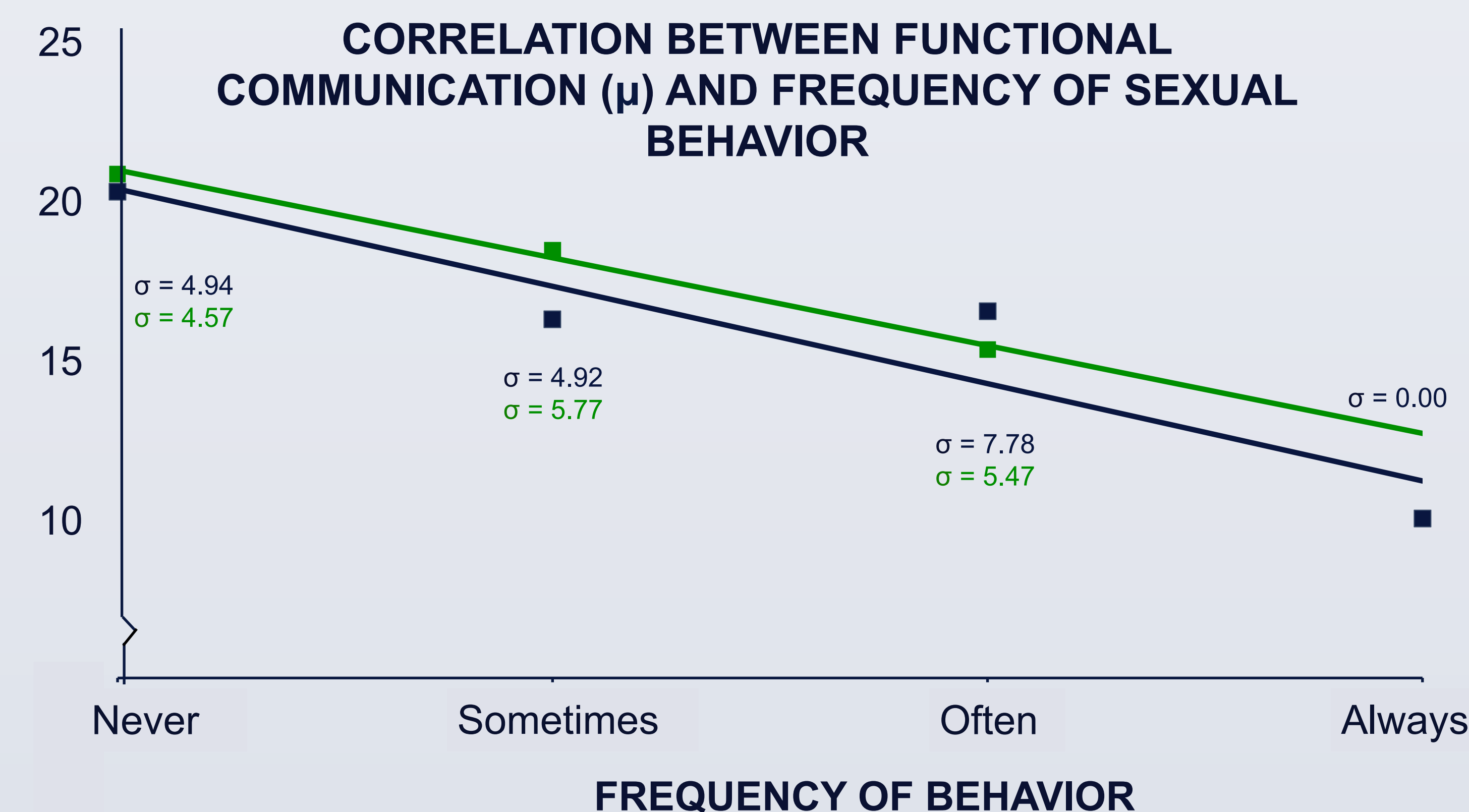
DEMOGRAPHICS

- 57 participants completed survey
- 11 participants completed interviews
- Data is reflective of 41 male adolescents with ASD and 11 female adolescents with ASD

RESULTS



- Indicates concern about sexual physical responses ($R^2 = 0.084$)
- Removes clothing inappropriately in public ($R^2 = 0.161$)
- Touches private body areas in public ($R^2 = 0.330$)
- Touches others inappropriately ($R^2 = 0.191$)



- Touches private body areas in public ($R^2 = 0.141$)
- Touches others inappropriately ($R^2 = 0.117$)

THEMES FROM INTERVIEW ANALYSIS

- Features of ASD that make sexual development challenging: **social cues, communication, and difficulty defining appropriate versus inappropriate behavior**
- The best time to discuss sexual development is **prior to puberty beginning**.
- Helpful and/or effective approaches to education regarding sexual development include **fact based curriculum, developmentally appropriate curriculum, and supplemental resources**.
- Having a sibling in the household who has completed sexual development **has (N = 3)/has not (N = 5)** impacted the sexual development of the adolescent with ASD.

CONCLUSIONS

Puberty and sexual development in adolescents with ASD is impacted by:

- Functional communication
- Autism severity
 - Social communication
- Sexual education

Our study determined that the adolescent's ability to communicate effectively has impact on their sexual development. While this study used a direct assessment of functional communication to determine the implications of communication on sexual development, autism severity was used as a measure to make inferences on the role of social communication due to the weight social and communication deficits have on establishing a diagnosis.⁷ One interviewee's response summarizes the impact of communication:

Since he [has ASD] my greatest concern is that he won't understand the subtleties of communication and the nonverbal communication that goes on in relationships...in other words he might think that a relationship is more serious than it is and...get himself into a situation that would be at best embarrassing and at worse result in some sort of accusation (interview 5).

Furthermore, communication has implications on sexual education. While parents and teachers were the most commonly reported sources of sexual education, participants were more likely to report:

- Adolescents with more severe autism would not benefit from sexual education
- Adolescents with greater functional communication would benefit from sexual education

Six percent of participants reported utilizing a healthcare provider as a source of sexual education. Healthcare providers could be valuable sources of sexual education by:

- Providing educational resources to the parent/guardian
- Providing factual, developmentally appropriate information to the adolescent

REFERENCES

- Nichols S & Blakeley-Smith A (2010). "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.
- Brown-Lavoie SM, Vecili MA & Weiss JA (2014). Sexual Knowledge and Victimization in Adults with Autism Spectrum Disorder. *J Autism Dev Disord*, 44: 2185-2196.
- Stokes MA & Kaur A (2005). High-functioning autism and sexuality. *Autism*, 9(3), 266-289.
- Crockett LJ. Pubertal Development Scale: Pubertal categories. Unpublished manuscript 1988.
- Stokes, M., Newton, N., & Kaur, A. (2007). Stalking, and Social and Romantic Functioning Among Adolescents and Adults with Autism Spectrum Disorder. *J Autism Dev Disord*, 37, 1969-1986.
- Reynolds, C. R. & Kamphaus, R. W. (2015). *Behavior Assessment System for Children, Third Edition (BASC-3)*. San Antonio, TX: Pearson.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)*. Washington, DC: Author.

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