

Grant Final Report to the Honor Society of Nursing, Sigma Theta Tau International

Title of Project: Parent Perceptions of Sexual Education Needs of Children with Autism Spectrum Disorders

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Summary of project aims

This study aimed to 1) describe parent perceptions of sexual education needs of their children aged 10-20 with an ASD diagnosis and 2) determine parent-preferred mechanisms of delivery for tailored educational intervention strategies. Findings contribute to the long-term goal of a program of research that seeks to develop and test ASD-targeted sexual education interventions.

Theoretical/conceptual framework

Social Cognitive Theory (Bandura, 1986) provides the conceptual framework for the overarching program of research and was used to guide the theoretical underpinnings of this project. The concept of self-efficacy lies at the center and emphasizes the role of observational learning and social experience which are critical aspects of sexual education. The model is adapted so that sexual education becomes the means of enhancing the self-efficacy of persons with ASDs.

Methods, procedures and sampling

This study used an exploratory, descriptive design using focus group and telephone interviews to accomplish the project aims. Initially, only focus group interviews were planned, however barriers in scheduling available meeting times for parents of special needs children led to several willing participants being lost to follow-up because of the delay in finding a mutually agreeable meeting time. For this reason, an option was added that included 1:1 telephone interviews. This also proved to be advantageous in the ability to extend invitations to much more extensive geographical area.

Parents or guardians of children age 10-20 with a clinical diagnosis of ASD were recruited from a database held by the UI Children's Hospital Autism Center (UICH-AC) and members of local, regional, and national ASD parent support groups. Study announcements and invitations to participate were extended via e-mail for persons in the UICH-AC database and local support groups and via Facebook for regional and national support groups. The age range was also extended by two years (to age 20) from the original limit of age 18 due to a suggestion of the expert panel of parents to be inclusive of ASD youth who were still in public education environments and reflected the emotional and social developmental delay characteristic of adolescents with ASD.

Final inclusion criteria required participants to be a parent or guardian of a child age 10-20 with a diagnosis of ASD and be able to speak, read, and understand English.

As instructed in the study invitation, interested study participants were asked to contact the principal investigator. Parents were screened for eligibility and contacted by the PI or research assistant to schedule either a focus group or telephone interview. All interviews were tape recorded and transcribed by a professional transcriptionist. Content analysis was used to identify patterns in the data. Each transcript was coded by two members of the research team and then compared for congruence. Any disagreements were resolved by discussion and input by a third member of the research team.

All original and modified procedural changes were approved by the institutional IRB.

Summary of findings

In total there were 15 parents who participated, with one parent having two children diagnosed with ASD, for a total of 16 children who were discussed during the interviews. Parents' age ranged from 36-57 with a mean of 46.3 years. Of parents interviewed 14 were mothers (93%) with one father (7%) participating. Parents resided in 6 states in varying locations across the United States. Ethnic and racial identification of the participants were diverse with 11 (68%) identifying as Caucasian, 1 (6%) as Hispanic, 2 (13%) as Native American, and 2 (13%) did not specify. All parents stated that their children with ASD had a confirmed diagnosis from a health care provider. Children's age ranged from 14-20 with a mean of 16.4 years. Of these 14 were males (88%) and 2 were female (12%). Roughly more than half (56%) were still in high school with 5 children (31%) who had recently graduated from high school. Two of these children continued to receive transition services through the public education system and one child (20%) was enrolled as a college freshman taking regular courses. For children in grades 8-10, the majority were enrolled in public schools (78%), 1 child (11%) was enrolled in a private school, and one child (11%) was enrolled in a charter school.

The majority of parents (n=13) had had sexuality-focused conversations with their child with ASD and n=10 reported that their children had received some sexual education content from their school setting. Most commonly parents (n=12) did not know or were not specific about particular topics that their child had learned from any setting. Of those parents who were able to identify specific topics that had been covered anatomy/physiology (N=5), changes of puberty (N=5), and pregnancy (n=4) were most commonly mentioned. A total of five parents also reported that they had done some education about pornography with their child.

Most parents (n=10) stated that sexual education of their child with ASD was primarily their role, three parents said that it needed to be a team approach and one thought it was the school's responsibility. When asked who besides parents should provide

sexual education for their children, nine identified the school, eight identified health care providers, and three thought the church had an important role.

Parents were asked what content areas they thought were the most important for their children to know. The most frequent responses were navigating and developing relationships (N=9) and self-protection and self-advocacy (N=8). Self-protection and self-advocacy were most often discussed in the context of protecting themselves from exploitation and begin able to state what their boundaries and comfort were with any sexual behavior. In regards to boundaries, four parents also thought that their child needed education on respecting personal boundaries of others and discussed concerns regarding inappropriate touching, sexual harassment, and stalking. The consequences of sexual activity and birth control were each noted by four parents. Consequences of sexual activity included sexually transmitted infections, pregnancy, and emotional considerations. Parents were also asked what topics they did not want their children to learn about. These included pornography (n=5), fetishism (n=3), and prostitution or sex trafficking (n=1).

Universally, parents reported a lack of resources and welcomed any assistance in providing their children with sexual education. When asked what they thought might be optimal features of an ASD-targeted sexual education intervention, the majority of parents (N=10) thought a technology-based platform would be most engaging for their adolescent with ASD. Parents often discussed their child's frequent and competent use of computers for education and leisure in addition to mobile devices such as tablets and smart phones. One parent specifically did not want a technology-based intervention due to lack of a household computer or smart device and internet services. Parents also reported that they wanted an intervention that could be tailored to their child's abilities that included a need for visual appeal (n=8), repetition in presentation of information (n=8), and something that the children could complete independently and at their own pace (n=7). Although parents wanted independent completion of any educational activity, several (n=5) wanted a way to evaluate their child's knowledge and understanding and could provide direct feedback to the children.

Recommendations

Findings were consistent with reports in the literature regarding a lack of sexual education resources, inconsistencies in opportunities for adolescents with ASD to receive sexual education, and primacy of the parent role in the sexual education of adolescents with ASD.

Parent preferences for content, for any intervention, would need to be considered in future development and testing. However, specific deficits and risks and preferences of the adolescents themselves would also need consideration. All are potential directions for future research and in larger, more representative samples.

Parents were enthusiastic about the prospect of an ASD-specific sexual education intervention and had several ideas based on their experiences with their children would

be most useful and helpful. Many suggestions were consistent with reports of ASD strengths such as comfort with technology, attention to detail, and visual learning. The suggestion of a technology-based intervention that could be visually engaging and allow for tailoring would be a novel approach to sexual education for this population.

Like all research studies, this project did have limitations. First, the preferred method of focus group interviews made subject recruitment difficult. Future research needs to consider the time availability of caregivers with special needs children when determining data collection methods and recruitment strategies. Second, the sample size consisted of 15 parents. Although small, generalizable data was not a goal of this preliminary qualitative study and the parent interviews provided important foundational knowledge that can be further tested in future research. Certainly any discussion of sexuality can be sensitive and it is possible that only people with interest and a level of comfort in speaking on such topics sought participation. It would certainly be of interest to assess interest and comfort of parents, providers, and educators in discussing sexual education.

Grant Testimonial

Receipt of the joint STTI/MNRS grant was critical to conducting this research by providing financial to be able to compensate participants and allow for personnel assistance for data collection, transcription, and analysis. In addition to these immediate benefits, completing this preliminary research has provided a beginning foundation to my program of research. These findings have been the catalyst for submission of a NIH K23 application and internal funding opportunity. Both are pending review. These findings also contribute to the dearth of literature that examines or considers sexual education needs of adolescents on the autism spectrum. Submission of findings to a peer-reviewed journal is expected to be completed before year-end.

References

Bandura, A. (1986). Social foundations of thought and action: A social cognitive theory. Englewood Cliffs, N.J.: Prentice-Hall.