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Medical Therapy for Inappropriate Sexual Behaviors in a Teen With Autism Spectrum Disorder

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Teens with autism spectrum disorder often exhibit sexual behaviors in public that are disturbing to parents, teachers, and peers. Some have proposed that such behaviors can be curtailed with hormonal suppression. There is information on the Internet suggesting that such medications work, and some reports in the peer-reviewed medical literature support these claims. Such medications can have serious side effects. In this paper, we present a case in which parents requested such treatment of their teenage son with autism spectrum disorder.

Teens with autism spectrum disorder (ASD) often exhibit sexual behaviors in public that are disturbing to parents, teachers, and peers. Some have proposed that such behaviors can be curtailed with hormonal suppression. In this month's *Ethics Rounds*, we present a case in which parents request such treatment from a pediatric endocrinologist. We then asked experts in pediatric endocrinology and developmental pediatrics to comment on the appropriate response to such a request.

THE CASE

The mother of a 12-year-old male, Brad, makes an appointment in the pediatric endocrinology department because her son has been exhibiting inappropriate sexual behaviors (public exposure, masturbation, and inappropriate touching of his younger siblings). Brad has been diagnosed with ASD. He has cognitive impairment and is currently in school at the kindergarten grade level. He cannot read. He is able to communicate and follow simple

directions. His parents are now afraid to leave him unattended with younger children because of his sexual behaviors.

Brad sees a psychiatrist who has tried behavioral therapy as well as medication (olanzapine and fluoxetine). These have been ineffective in reducing Brad's sexual behaviors. His parents have done research on the Internet and found reports that hormonal therapy to suppress luteinizing hormone (LH) and testosterone levels can decrease inappropriate sexual behaviors in cognitively impaired teens.

On examination, he is in mid-puberty. Gonadotropins and testosterone level show evidence of central puberty and are consistent with this exam. Bone age is 1 year greater than chronological age but within normal limits. Therefore, although his pubertal onset was earlier than average, there is no evidence of endocrine pathology.

The parents are concerned that, unless effective treatment can be found, Brad may cause harm to the other children in the house or at school. Brad himself

abstract

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is unable to consent due to cognitive limitations. Would it be appropriate to try hormonal therapy as a means to reduce or eliminate Brad's inappropriate sexual behavior?

**Loyal Coshway, MD, and
Leena Nahata, MD, Pediatric
Endocrinologists, Comment**

In this case, a question has been raised about using luteinizing hormone releasing hormone (LHRH) agonists to reduce sexual behavior. LHRH agonists are typically used for the suppression of centrally mediated precocious puberty, defined as puberty occurring before 9 years of age in a male. They are administered via monthly or 3 monthly injections and are also available as a 1 year depot implant. LHRH agonists, such as leuprolide and triptorelin injections, have been used for the court-ordered treatment of adult paraphilia (off-label indication).^{1,2} Use of leuprolide in an adult autistic male living in a group home was reportedly successful in reducing inappropriate behaviors and allowing him to continue to live in the community.³ Treatment measures, including sexual education and the antiandrogen flutamide, had been ineffective, resulting in temporary police custody for public sexual behaviors toward other people.³ Despite these reports, it is unclear if pubertal suppression for inappropriate sexual behaviors in this young autistic child is ethically sound. There is minimal evidence supporting the use of LHRH agonist therapy for pediatric hypersexual behavior. In addition, there are possible side effects, and this patient would be unable to consent to therapy because of age and cognitive limitations. Thus, the decision to use this treatment would need to be made carefully after ensuring that benefits outweigh possible harm and acknowledging that the efficacy would be uncertain.

In terms of potential benefits, LHRH agonists induce hypogonadism (ie, lower testosterone levels) and may therefore suppress hypersexual behaviors. Treatment of hypersexual behaviors with these agents has mainly been reported in adults who have committed sexual crimes, including pedophilia, exhibitionism, sadism, rape, and voyeurism. Based on review of 13 studies, Briken et al¹ concluded that LHRH agonists offer a reasonable treatment option for adult paraphilia; however, conclusions were weakened due to the lack of randomized controlled trials, differing methodology, and the use of patient self-report as opposed to objective measures of behavior. The authors ultimately advised that LHRH agonist use could be justified if the individual poses a danger to others, but that patients should give informed consent because of the risk of side effects.¹

There are increased risks of using LHRH agonists in a growing child, as pubertal suppression interrupts several natural processes. Testosterone is required for pubertal growth spurt, increase in lean muscle, decrease in fat, and increase in bone density. In the case of someone with chronic mental disability, it is unclear when such treatment could be successfully discontinued, and side effects of longstanding hypogonadism include osteoporosis and higher incidence of fracture.⁴ Short term side effects include injection site pain, abscess or local reaction, and growth suppression from loss of testosterone-mediated growth.⁵ Of note, most families cannot afford leuprolide without insurance approval due to the high cost (single injections range from \$1413 to \$8481 depending on the dose and duration).

Additionally, it is important to acknowledge the difference between adults with sex addictions/criminal behavior and children with autism and hypersexual behavior. Based on

a survey of 100 parents of children age 9 to 38 years with autism, inappropriate sexual behaviors were frequent; 65% touched their private parts in public, 23% masturbated in public, 18% touched the opposite sex inappropriately, and 14% masturbated with an unusual object.⁶ Other problem behaviors include undressing or touching body parts in public and sexual fetishism.⁷ Increased masturbation in autism may be a self-stimulatory behavior and related to sensory abnormalities.⁸ Such behaviors can be challenging for parents, teachers, and other caregivers, leading to curtailment of routine activities.

For individuals with autism, underlying problems are lack of social competence and poor communication. Because of an inability to pick up on social cues, moderate and severely autistic patients may be unaware that public exposure or masturbation is taboo.³ Koller⁹ writes that sexual desire is a natural part of human behavior, and that appropriate expression is enabled by age and developmentally appropriate education on pubertal development, sexual desires, pregnancy, and sexually transmitted diseases. Newer literature suggests that high-functioning autistic individuals have fairly typical sexual experiences as adults. However, individuals with autism were far less likely to receive education about sexuality, contraception, and sexually transmitted diseases from their parents or teachers; instead, higher-functioning individuals with autism obtained information from media such as television.⁸ Parents of low-functioning autistic children often failed to teach even basic sexual education: puberty, reproduction, reporting sexual victimization, and that it is wrong to coerce sexual activity.⁸ Koller outlines specific protocols for excessive public masturbation, including interrupting the behavior,

reminding the person of appropriate time and place, redirection, and allowing masturbation in private because it may be the only type of sexual satisfaction available to that person in their lifetime. Specialists do caution that adult sexual relationships involving a person with autism should be viewed with great caution because sexual relationships require empathy, tenderness, and care, and one must recognize that the majority of individuals with autism have great difficulty relating to other people.⁹ Developmentally appropriate sexual education and behavior expectations should be taught by parents and teachers and reinforced by physicians.

When behavioral therapy has not been effective alone, pharmacotherapy in autistic adolescents has been reported in several case series with variable rates of success. Two studies describe the successful use of mirtazapine and β -blockers to reduce inappropriate sexual behavior and excessive masturbation.^{6,7} However, in a case series of 25 autistic males aged 15 to 21 years, medications, including neuroleptics and selective serotonin reuptake inhibitors (SSRIs), were not universally effective.¹⁰ Sajith et al¹¹ reviewed pharmacologic treatment of inappropriate sexual behaviors in intellectually disabled men and reported that testosterone suppressing medications, including LHRH agonists, were successful in reducing inappropriate sexual behaviors in adult males with intellectual disability (ID). However, the authors advised against use in children <18 years old because of the concern for side effects.

Based on review of these studies, Brad's family's concerns about his behavior are understandable, but the risks associated with LHRH agonists in a growing child appear to outweigh the benefits. Though committing to weekly therapy and waiting several weeks to months to see potential

benefit from the SSRI may be difficult, this seems to be the most optimal approach for the patient.

Kruti Acharya, MD, Michael E. Msall, MD, and Karen Fried, PsyD (Developmental Pediatrics and Child Psychology) Comment

The scenario presented is not uncommon. Parents of children with IDs often reach out to medical providers around the onset of puberty for guidance, education, and support. Some parents seek care to learn what to expect to prepare themselves; others, as in this case, want to know if a specific treatment or procedure is indicated. If the latter, parents often request a drastic procedure like hormonal therapy because of confusion and fear. Brad's parents are fearful that Brad could harm himself or others and because of their fear, they are considering limiting his reproductive rights. Their fears are not groundless; individuals with IDs have faced criminal charges and potential legal action for sexual offenses.¹²

Nevertheless, we feel that it would not be appropriate to try hormonal therapy. Used in males to suppress gonadotropins and androgens, hormonal therapy is a form of chemical sterilization even if used for the sole intent of curtailing inappropriate behavior. As such, this decision must be viewed in the long historical context of involuntary sterilization of individuals with IDs. In the early 20th century, surgical sterilization was part of a nationwide eugenics program designed to prevent reproduction in individuals with IDs. In 1927, these eugenic practices were upheld by the US Supreme Court decision in *Buck v. Bell*.¹³ After World War II, forced sterilization of individuals with IDs gradually lost favor. Now, many states advocate for self-determination and have statutes regulating sterilization, banning the procedure altogether or requiring

additional legal protections. The United Nations Convention of the Human Rights of People with Disabilities recognizes fertility as an inherent human right.¹⁴

Brad is a preadolescent with ASD and cognitive impairment. He clearly lacks capacity to consent to medical treatment. It is not only critical to understand what Brad's limitations are in communication and learning, but also what his functioning is with respect to self-care, communication, social interaction with siblings and peers, and participation in educational, family, and community activities. Individuals with ID/ASD have a range of strengths and limitations in communication and adaptive skills. Understanding if Brad can do basic toileting, dressing, bathing, and grooming allows us to understand what Brad's touching or masturbation might mean to him. We should know if he has exhibited other challenging behaviors.

The central question in his management should focus on what Brad can do safely without supervision. This will turn on his ability to understand and communicate. Because of his impaired cognition and potential social impairment related to his ASD diagnosis, Brad likely does not possess the insight that his behavior is socially unacceptable. But could he come to understand this? Because people with ID are often viewed as asexual, they often do not receive robust education about sexual health³ and, therefore, have limited sexual knowledge. Galea et al¹⁵ reported that 96 Australian adults with ID had low knowledge scores about puberty, menstruation, menopause, sexuality, safe sex practices, sexual transmitted infections, and contraception. Yet many people with ID have happy and rewarding sexual experiences. Chamberlain et al¹⁶ found that one half of the sample of 11- to 23-year-old women with mild ID, 32% of women with moderate ID, and 9%

of women with severe ID attending a multiservice clinic in the United States and living in the community had engaged in consensual intercourse. Brad's actions may represent normal sexual urges being acted on in inappropriate settings.

Before hormonal therapy is considered, Brad should receive intensive behavior analysis treatment.¹⁷ Behavioral therapy is a broad term that, generally speaking, recognizes that human behavior is the product of external environmental feedback and that behavior can be altered by manipulating the environmental cues and input. Provided by trained behavioral professionals rather than psychiatrists, applied behavioral analysis therapy is a specific type of behavioral therapy that can be very successful for individuals with ASD to reduce or control problematic behavior.¹⁸

In addition, before hormonal therapy is considered, Brad should receive developmentally appropriate sexual health education that includes discussion of the basic facts of life, reproduction, sexual intercourse, human growth and development, human reproduction and anatomy, and self-pleasuring/masturbation.¹⁹ Individuals with ID, regardless of cognitive level, can be taught what is or is not appropriate and healthy sexual behavior. They can generally be taught how to engage in sexual behavior within socially appropriate limits. There are evidence-based educational resources about puberty and healthy sexuality for individuals with ID, including children. Centers for independent living can provide resources and allies for providing education and peer mentoring around relationships, intimacy, sexuality, sexual expression, and parenting. Curricula need to be explicit and should be adapted to the individual's level of cognition. When discussing sexual issues and developing education programs for

people with ID, plain language but accurate terms should be used to describe body parts. Matching the person's language with accurate terms, visual material, and models may be very helpful, particularly for individuals with limited verbal skills.

His parents may argue that hormonal therapy could benefit Brad because it will reduce the likelihood that he will face legal or criminal action because of his behavior. Because other treatments are available, the risk to Brad's fertility and of unknown long-term side effects outweighs the short-term benefit that Brad may experience. Moreover, hormonal therapy will reduce normal sexual feelings, which arguably could negatively impact Brad's quality of life.

Providers should educate parents about the potential risks of the requested treatment and offer alternate choices (ie, developmentally appropriate sex education and intensive applied behavioral analysis therapy). Sexuality is closely related to a person's self-concept and self-esteem. The issue of sexuality as a human right for all individuals, including persons with ID, should be normalized, not ignored or avoided.²⁰

Julia Broussard, Pediatric Endocrinologist, Comment

Brad is a 12-year-old male with ASD and cognitive impairment who has been exhibiting inappropriate sexual behaviors. Behavioral therapy and pharmacological therapy with olanzapine and fluoxetine have been ineffective in reducing Brad's sexual behaviors. On physical exam, he is in mid-puberty and gonadotropins and testosterone levels are consistent with exam and show central puberty, normal for his age. Bone age is within normal limits for his chronological age. He can communicate and follow simple directions but is unable to consent due to cognitive limitations. Because of Brad's inappropriate sexual behaviors, his parents are

afraid to leave him unattended with younger children. They are concerned that, unless effective treatment can be found, Brad may cause harm to other children in the house or at school. Parents did research on the Internet and found reports that hormonal therapy can decrease inappropriate sexual behaviors in cognitively impaired teens.

There are a number of values and principles in conflict. We cannot apply the principle of respect for autonomy because Brad's cognitive impairment limits his ability to act autonomously. Instead, we look to the principle of beneficence. In this case, though, it is difficult to determine what is best for Brad. His parents think that medication to suppress his sexual desires and behavior would be best. But they may be thinking more about the harms that might occur to other children.

In this case, both Brad and the children he inappropriately touches are vulnerable entities. Brad's sexual behavior in public is against society's norms. His parents are rightfully concerned about Brad's and the other children's safety.

Would hormonal medication help? Geier and colleagues²¹ have reported a "Lupron protocol" for people with autism. Hormonal therapy for this purpose was mainly described in late adolescents and adults, where the side effects of such therapy are less worrisome than they are for younger teens.³ There are no evidence-based studies in the literature to support the use of hormonal therapy in teenagers with autism for the purpose of reducing aggressiveness and inappropriate sexual behaviors. Multiple pediatric endocrinologists dismissed this kind of treatment in a consensus statement on the use of gonadotropin-releasing hormone analogs in children.²² Lupron treatment in adolescents with autism is not approved by the US Food and Drug Administration for the above

mentioned purpose. It poses significant risks such as: decreased linear growth velocity with subsequent short stature and transitory decreased bone mineral density during gonadotropin-releasing hormone analogs treatment. Also, it is not a long-term treatment option, and it will not lead to a longstanding improvement in the patient's inappropriate sexual behaviors. Thus, it seems that hormonal therapy for Brad is more likely to cause harm than benefit.

What, then, can be done? In Brad's case, behavioral intervention and psychotropic medications did not have a positive impact on his inappropriate sexual behaviors. But they may not have been the right medications or therapies. Griffiths et al,²³ Schopler et al,²⁴ and Ward et al,²⁵ suggest that treatment approaches for a case like Brad's include inappropriate behavior suppression using structured teaching approaches, reinforcing alternative behaviors, development of social skills, and coping strategies. Children with autism may benefit from early education on social skills and sexual behavior; this can be accomplished by a concerted effort involving family, teachers, peers, and other community members. In addition, alternative medications from the same class that includes fluoxetine (an SSRI) may be trialed for an adequate period of time. The doctor in this case needs to explain to the parents the inaccuracy of the data on the Internet and the lack of evidence that would make hormonal treatment indicated for this purpose. They need to help the parents find appropriate resources to institute an individualized behavior management plan.

John D. Lantos, MD, Pediatrician and Bioethicist, Comment

This case highlights 3 important points. First, parents today get a lot of information, and misinformation,

on the Internet. Physicians need to be prepared to answer questions that arise from Internet searches and to do so with both respect and humility. Sometimes the information will be wrong. But sometimes parents can gain important insights that improve patient care. Second, there are many myths surrounding autism and cognitive delay that might interfere with good patient care. As in other areas, pediatricians should consult with experts who can help separate myth from fact. One problem that may arise for many providers is in finding experts. Pediatricians outside of major cities or without access to major academic centers may have trouble finding consultants. Parents may have to travel hours to see a knowledgeable specialist. This is an area in which telemedicine could be beneficial. Finally, the respondents in this case all endorse a process of shared decision making and staged interventions. It is usually best to try less invasive treatments before more invasive ones. Most parents will understand and support this if we take the time to explain our reasoning. In the care of children with complex chronic conditions, parents and pediatricians need to work together.

The following Web sites can serve as resources for sexual health education:

- www.shfpa.org.au/
- www.agac.org.au/links/
- www.cddh.monash.org/assets/supporting-women-gp.pdf
- www.sexualhealth.com
- www.kc.vanderbilt.edu/healthybodies/ (includes a free online packet entitled "Healthy Bodies for Boys: A parent's guide for Boys with disabilities.")
- www.stwwgepublications.com/pages/publications.html (includes a brochure entitled "Sex Education for Parents of Children with Autism Spectrum Disorders")
- www.lookingglass.org

ABBREVIATIONS

- ASD: Autism spectrum disorder
- ID: intellectual disability
- LH: luteinizing hormone
- LHRH: luteinizing hormone releasing hormone
- SSRI: selective serotonin reuptake inhibitor

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