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.

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
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). 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. Treatment measures, including sexual education and the antiandrogen flutamide, had been ineffective, resulting in temporary police custody for public sexual behaviors toward other people. 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 al 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.

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. Short term side effects include injection site pain, abscess or local reaction, and growth suppression from loss of testosterone-mediated growth. 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. Other problem behaviors include undressing or touching body parts in public and sexual fetishism. Increased masturbation in autism may be a self-stimulatory behavior and related to sensory abnormalities. 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. Koller 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. 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. 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
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 Saith
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 health
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. 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.

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. 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.

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 colleagues 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. 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. 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

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ABBREVIATIONS

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


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