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Sexual Behaviors in Autism: Problems of Definition and Management

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Surveys of sexual behavior in autism suggest a variety of behavioral expression. However, the course of sexual development in autism is unplotted, leaving questions about the normalcy of specific behaviors. Even less is known about deviations of sexual development and the incidence of paraphilias in this population. We explore the problems of definition of sexual behaviors and describe a case report that highlights the difficulties of management. An application of a testosterone-suppressing medication and its effect on sexual behavior are reported. After failure of behavioral and educational programs, leuprolide, an injectable antiandrogen, resulted in suppression of behaviors and retention of the participants' community placement. Follow-up for almost 3 years shows no abnormal physical effects. Dosage has been tapered over that period to a low but effective dose. Directions for research are discussed.

KEY WORDS: Sexual behavior in autism; leuprolide; antiandrogen; masturbation.

INTRODUCTION

Autism is a disorder of development affecting broad areas of psychological and behavioral functioning. While new scientific technologies have been applied to better understand causative mechanisms, important areas of behavior remain largely unstudied. One such domain is the sexual development of individuals with autism (Ford, 1987; Mesibov, 1983; Ousley & Mesibov, 1991; Ruble & Dalrymple, 1993). With limitations in our understanding, sexual expression in individuals with autism may easily be mistaken as deviant. Such attributions may jeopardize goals for community integration consistent with normalization (Wolfensburger, 1972) and the least restrictive environment (Individuals with Disability Education Act, P.L. 101-476, U.S. Department of Education, 1990). Misunderstanding of behavior, poor social skills, restrictive community standards for sexual expression, and fear based on stigma and ignorance may significantly influence program participation and caretaker and administrative decision-making.

The cause of public displays of sexual behavior in autism, whether deviant such as fetishes, or socially inappropriate such as touching private parts, has been speculated. Dalldorf (1983) has proposed that persistent masturbation may be emphasized in some individuals with autism because of a lack of alternative outlets for sexual tension and a predisposition for self-stimulatory behavior. However, socially unacceptable sexual behaviors may be related to core features of autism. The impairment in social awareness and reciprocal interaction, typically necessary for the learning and understanding of appropriate sexual interaction, is profound in autism leading to errors in social judgment (Ruble, 1992). In particular, difficulty learning adaptive social behaviors in an unstructured fashion (Ferra & Hill, 1980; Lord, 1984), recognizing subtle affective cues (Hobson, 1986), communicating accurately and competently with others (Wetherby, 1986), taking the perspectives of other individuals (Baron-Cohen, Leslie, & Frith, 1985), and considering their own and others' viewpoints (Baron-Cohen *et al.*, 1985; Howlin, 1986)

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may confound sexual development and contribute to inappropriate sexual behaviors (Griffiths, Quinsey, & Hingsburger, 1989). Further, sexuality is often an area children learn about through nonformalized socialization opportunities (Cavanagh Johnson & Ross Felmeth, 1993) and adolescents with autism are most likely excluded from social cliques (Adams & Sheslow, 1983) where such training takes place. Alternatively, inappropriate sexual behaviors might correlate with degree of mental retardation. Discriminant analysis, however, correctly classified only 59% of persons who reportedly displayed inappropriate sexual behavior when cognitive and verbal levels were used as predictor variables. This finding suggests that deficits other than cognitive or verbal played a role in whether or not parents reported that the person displayed inappropriate sexual behaviors (Ruble, 1992).

A small body of literature is available describing sexual behavior in individuals with autism. Wing (1972) suggested that young children with autism show masturbatory behaviors more frequently than other children. In a recent survey of 89 individuals with autism, ages 16 to 59 years, 68% were reported to masturbate, which rarely occurred outside the group home, while sexual stimulation generally was derived from readily available objects. About 25% of the subjects were aroused by looking at people. Little sexual interest was shown in casual acquaintances, staff, or residents, or in individuals participating in activities in the group home. No individuals with autistic disorder were reportedly attracted to or aroused by children (van Bourgondien, Reichle, & Palmer, 1997). In adolescents, Dalldorf (1983) reported that masturbation is a common behavior, especially in boys, but is not more common in adolescents with mental retardation or autism. Over 50% of the parents in Ruble and Dalrymple's study (1993) reported that their child, whose age ranged from 9 to 39 years, exhibited inappropriate sexual behaviors. The range of inappropriate sexual behaviors included touching private parts in public, removing clothes in public, masturbating in public, touching the opposite sex inappropriately, and presenting other behaviors such as discussing inappropriate subjects, looking up shorts or down shirts, and touching parents inappropriately. This typology of behaviors is not out of keeping with behaviors found in normally developing children (see Table I for a brief description); however, with increased socialization, normally developing children learn to become discrete and selective in the display of behaviors at a very young age (see Gil, 1993).

Table I. Normal Sexual Development in Childhood

Age	Behavior
Infancy (birth to 1 year)	Discovery of pleasure areas
	Rubbing of genitals for pleasure; self-stimulation
	Physical closeness with primary caregivers, holding, clinging, cuddling, nursing, dressing, playing
	Adjustment of self-stimulation to conform to external reactions from others
	Responding to others by touching, kissing, and hugging
Early childhood (2 to 5 years)	Interest in one's body and its function
	Increased curiosity about differences between boys/girls, men/women
	Labeling/naming of body parts, sensual feelings, and body functions
	Intense interest in physical sensation, including genital self-stimulation
	Body exhibitionism
	Questions about how babies are made and delivered
	Jokes about sex and genitalia and bodily function
	Fascination with "obscene" words
	Modeling of parental interactions of expressing affection; continued responding to others with hugs, kisses, and cuddling
	Possible jealousy of intimacy shared by parents
	Beginnings of peer sexuality explorations, including genital examination
	Opportunity for parent–child communication about sexuality development
Middle to late childhood (6 to 12 years)	Continued self-stimulation in private
	Continued sexual play and exploration between same and opposite sex peers (secretive and hidden from adults)
	Peer discussion regarding sexual behavior
	Intense interest in children of opposite sex; "boyfriends, girlfriends" often established
	Increased need for personal privacy
	Opportunity for parent–child communication about sexuality development
	Onset of puberty (late childhood); making the shift into adolescent sexuality development

Given the limitations of our understanding of autism and sexuality, designating a sexual behavior as unacceptable, inappropriate, or deviant is difficult. More important, do these designations require different interventions?

Although their work does not address autism specifically, Hingsburger, Griffiths, and Quinsey (1991) offer insight into the differentiation of inappropriate sexual behavior from deviant sexual behavior. These authors suggest that inappropriate sexual expression may result from default as the only allowable expression of sexuality in an environmental context that does not support appropriate sexual knowledge and relationships in individuals with autism. Deviant behavior, however, has causes, although not clear in any population, that are similar to deviant behavior found in the nondevelopmentally delayed population. Hingsburger *et al.* suggest multiple hypotheses to clarify the etiology of sexual misbehavior in the developmentally delayed population, and offer a detailed explanation for each hypothesis and a corresponding intervention. The differential diagnosis of sexual misbehavior, deviant or inappropriate, is critical so that individuals are not improperly treated.

Prior to the 1970s, the treatment of public displays of sexual behavior was managed by institutionalization (Griffiths *et al.,* 1989) and the differentiation of inappropriate sexual behavior from deviant sexual behavior was moot. Griffiths *et al.* observed that since the 1970s, treatment approaches have included the suppression of inappropriate behavior through the teaching and reinforcement of alternative or incompatible behaviors. Further success was obtained if treatment approaches included the development of sociosexual skills and coping strategies. Alternatively, treatment options have included aversion therapies such as electric shock, satiation, and covert sensitization. While behavioral therapies have been studied more extensively, Griffiths *et al.* reported that short-term results are maintained only for persons who remain under legal and clinical supervision; however, effectiveness has not been shown for persons with developmental disabilities. Furthermore, ethical issues exist with the use of aversives for persons with developmental disabilities.

Another treatment option has been hormonal therapies (e.g., Blumer & Migeon, 1975; Money, 1968; Rich & Ovsiew, 1994). Hormonal therapy has been deemed controversial because of possible side effects, the perception of suppression rather than the teaching of sexual expression, and the limitations of efficacy.

This article examines these issues and highlights the need for intervention alternatives. A case study presents the usefulness of a unique medication treatment when other treatments were unsuccessful. Recommendations to guide future intervention and research efforts are provided.

CASE REPORT

This is a white male, the firstborn child, whose pregnancy was complicated by mother's use of phenytoin secondary to seizures from head trauma. Delivery was complicated by toxemia, placenta previa, and Caesarean section. At delivery, the child was noted to have bilateral cleft lip, which was repaired uneventfully during the first year of life. Delays in development were noted within the first year of life. The participant walked at 19 months and began speaking at 2 years. Social behaviors were diminished and he did not relate actively to people or imitate the usual social conventions of young children, and seemed to be more interested in inanimate objects than people. At age 3, eye contact was noted to be fleeting and speech was perseverative. Both extreme and nonresponsive reactions to sensory stimuli were noted. He was easily upset over small changes in his daily routine. In middle childhood, he regularly insisted on talking about the mating and territorial behavior of birds leading to emotional upset. Either continuing or terminating the conversation resulted in temper tantrums. Cognitive testing at the age of 3 placed him in the low-average range. He received a formal diagnosis of autism at age 6.

He had regular pediatric care with no unusual illness during childhood. Medical treatments for temper tantrums included valproic acid and diazepam with little beneficial effects. He was enrolled in special education at the age of 4. In his elementary school years, psychotherapeutic efforts included individual play psychotherapy and, later, behavior modification approaches for angry outbursts, all with limited success.

This participant presented for psychiatric evaluation about the age of 16 when he complained of visual hallucinations which often escalated into very agitated behavior. He was treated initially as an outpatient with low-dose haloperidol but, within 1 month of developing visual hallucinations, he was admitted to a psychiatric hospital for catatonia including negativism, anorexia, posturing, catalepsy, and muteness. Treatment with moderate doses of haloperidol resulted in rapid improvement. Blood laboratory tests were normal but magnetic resonance imaging of the brain showed enlargement of the lateral and third ventricles. Some 4 years later, despite continued neuroleptic treatment, auditory hallucinations were noted which resulted

in agitated behavior and the content of the "voices" was very threatening. Other symptoms included strongly held morbid beliefs about certain movie and television plots that required repeated confrontation and reality testing. A comorbid diagnosis of undifferentiated schizophrenia was made.

Since age 18, this young man has lived in a group home and attended a local high school through age 21. He participated in a number of community activities including a supervised community job, outings to restaurants and shopping malls, and recreational activities. At age 21, while on 50 mg of loxapine succinate, a moderately potent neuroleptic, masturbation began. He showed considerable interest in young children, asking questions about their clothing and their activities. In addition to sexual arousal by small children, he subsequently became sexually excited by adolescents and young men with instances of masturbation in the presence of his young adult roommate and a male relative. He sometimes took objects belonging to these individuals which were incorporated into solitary sexual activity. Further, a brief romantic interest developed in a young adult female who held an adjunctive therapy position at his community job site. Public masturbation was now a major concern of his parents and caretakers (Fig. 1). A number of simple behavioral programs were developed to confine masturbation to his room. He was given food and recreational rewards for exercising the necessary judgment to eliminate public masturbation. He was generally redirectable. Appropriate contact with the female therapist was encouraged. Sexual excitation in the presence of young children continued.

A consultation was arranged with a university department of human sexuality to clarify issues of possible pedophilic proclivities and for ongoing assistance in developing treatment interventions. The evaluation provided no new information or treatment directions.

The staff organized and implemented a program of sexual education which included identifying sexual feelings, clarifying objects that precipitated those feelings, and specifying the need for privacy in engaging in masturbation. Female staff were reluctant to participate in this program as the patient became sexually aroused by the discussion and the task was relegated to male staff. After multiple programs failed, a simple contingency-based, behaviorally reinforced program with evidence of success was adopted. Key words such as "safe masturbation" became a concept around which sexual themes and behavioral expectations were focused.

However, at age 24, following persistent public masturbation elicited by young children, community activities were gradually eliminated from his outings. In one situation, he slipped out of his home and approached a group of elementary school children awaiting a school bus. The bus driver interrupted what was perceived as predatory behavior and the police were summoned. He was taken into custody, but not charged, and then released.

Neuroleptic medication, that was started to treat catatonic symptoms and other psychotic symptoms, pre-

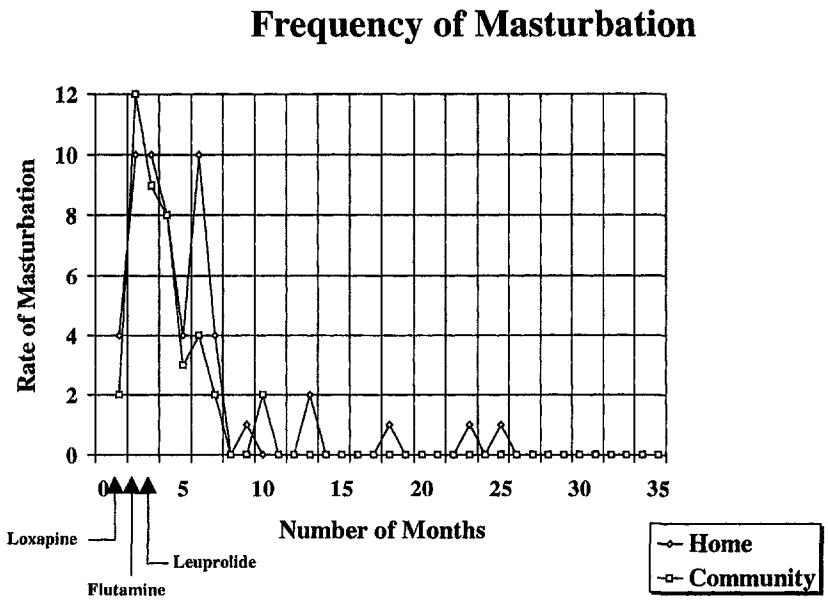

Fig. 1. Rate of monthly masturbation in the home and community after treatment.

ceded onset of public masturbation and did not affect these behaviors. After 12 episodes of public masturbation during the previous month, the patient was seen by an academic pediatric urologist. During the visit, he became sexually excited by a picture of the urologist's young son seated on a horse. The participant, who was aware of growing restrictions in community activities due to public sexual behavior, was informed of the range of possible medical treatments to decrease masturbation and requested flutamine. This treatment was considered among many with the approval of his conservator. Flutamine, an acetanilid, nonsteroidal, orally active antiandrogen, was started. A daily dose of 750 mg/day was reached with suppression of public masturbation for 2 weeks after which the rate returned to episodes every other day.

Response to flutamine was considered ineffective and discontinued and leuprolide was begun. Leuprolide acetate depot was administered as an injection at a dose of 7.5 mg/month. The following month, there was a dramatic decrease in libido with no episodes of public masturbation in the week prior to his office visit. Subsequently, all community privileges were restored. Slowly the dose of leuprolide was decreased and the patient is now maintained at 1.87 mg/month. At this dose, there is regular masturbatory activity at approximately 2 times per week with no episodes of public masturbation or sexual excitement due to contact with children. The participant has been on leuprolide for over 36 months (see Fig. 1).

RESULTS

Treatment with leuprolide was considered successful. Leuprolide is a synthetic nonpeptide analog of human gonadotropin-releasing hormone. Leuprolide acts as a potent inhibitor of gonadotropin secretion when given continuously. Chronic administration results in suppression of testicular sterogenesis. Flutamine, an antiandrogenic medication that exerts its effect by inhibiting androgen uptake and/or by inhibiting nuclear binding of androgen in target tissues was not helpful.

Follow-up for 3 years demonstrated this individual no longer exhibited public masturbatory behaviors (see Fig. 1). While inappropriate sexual behaviors subsided, aggressive, destructive and at times psychotic symptoms continued and at times worsened as measured by daily detailed counts of episodes of property destruction, physical assault of staff, and report of auditory hallucinations.

DISCUSSION

Effect of Hormonal Treatment

This young man's community placement was preserved due to hormonal treatment with leuprolide depot. The medication was extremely effective in reducing sexual behaviors. While sexual behavior decreased, other problematic behaviors did not, suggesting that sexual behaviors did not correlate with aggressive behaviors, as questioned by Elgar (1985).

Etiology of Unacceptable Sexual Behavior

For the case presented, physical maturation, onset of puberty, and the development of secondary sexual characteristics were delayed. With the onset of sexual activity, multiple stimuli become sexually exciting. Sexual objects were as conventional as a preference for a young woman therapist and as deviant as sexual predatory behaviors towards young children.

The etiology of the patient's more deviant sexual behavior is unclear. He was not subject to the list of putative causal mechanisms described by Griffiths *et al.* (1989), such as childhood sexual victimization, restrictive and punitive early experiences, or early conditioning to deviant stimuli. However, like most developmentally delayed individuals there were missed opportunities for rich and complex social experiences. His family's personal resources provided multiple social and educational experiences; however, this child's restricted social contacts were more often self-induced. Other etiologies that have been proposed, and may be applicable in the case reported, include reduced exposure to erotic material during puberty, the unavailability of a suitable sexual partner, and significant deficits in social skills. These are circumstances encountered by most individuals with autism. It is not clear whether this young man's sexual development is out of keeping with other individuals with autism. Like many individuals with autism, he experienced delayed puberty onset. We may have had a chance to observe a period of indiscriminate sexual exploration prior to narrowing of sexual objects choice. We must also consider the psychosexual influence of comorbid psychiatric disorder. A longitudinal study of sexual behaviors in persons with autism may clarify the developmental course of sexual object choices and the onset and persistence of deviance.

The decision to use hormonal therapy in this case was in some ways a consequence of default. The practical implementation of sound behavioral programs in a community setting were fraught with obstacles. Female

staff would not participate. Rewards and redirection were unsuccessful. Consultation with a university department specializing in sexual development and treatment of deviance was not helpful. Psychotropic medications, although modifying psychotic symptoms to some extent, failed to modify sexual behavior. Finally, medication to modify sexual impulses directly was undertaken with considerable modification of behavior.

The case presented suggests that there may be multiple causes of inappropriate sexual behaviors. Our knowledge about the inner life of individuals with autism with regard to sexual desires is scarce. This lack of information may be due to the nature of autism, as this disability often restricts self-report as a source of information about most areas of emotional interest. This limitation is especially true for the individual with more impaired social/cognitive skills. Often our knowledge base (e.g., theory of mind studies) derives from individuals who can respond to the cognitive demands of questionnaires, interviews, and structured tasks; however, problems of generalizability to individuals across the autism spectrum may result. Finally, it is often the emergence of sexual behaviors that organize efforts to modify, control, or eliminate these behaviors rather than generate helpful data for better informed programs.

We propose a plan of prevention of socially unacceptable sexual behaviors. To accomplish this it is necessary to improve the range and depth of social experiences so that healthy sexual development of children with autism may proceed. Because of the pervasive social difficulties and restricted range of communication, we must go beyond the efforts that are usually devised for children with mental retardation. Children with autism require intensive social and sexual education interventions starting at a very young age. These efforts may best be accomplished through structured teaching approaches (Schopler, Mesibov, & Hearsey, 1995). Education must include programs supported by the child's usual social contacts such as teachers, family, peers, and others such as adults in the community.

Ethical Issues

There are many unanswered clinical, ethical, and legal dilemmas for treatment of sexual deviance in individuals with a developmental disability. Should a formal process to assess competence to consent for sexually modifying behaviors be established? How should assent in a child or consent in an adult be obtained? How best can the treatments be described to the affected individual? If effective, how should they be periodically reevaluated? What are the risks to placement if the behaviors reemerge? Does sexual development proceed when sexual feelings have been suppressed? Is the "right" to a community placement more important than the right to sexual expression? How do we systematically evaluate sexual behavior in the cognitively handicapped so as to accurately diagnose deviance and inappropriateness? Should there be legal mandates for assessment of sexual behavior in the developmentally delayed and how should a balance between safeguards for community and individual protection be achieved? In addition, should an individual be deprived of his or her preferred object of sexual pleasure if it is nonnormative, and do sociocultural biases judge sexual behaviors in individuals with autism differently than the majority? These are some of the difficult questions that await a better informed discussion.

We recognize that "sexuality" when applied to persons with autism has often been narrowly defined, focusing on behaviors (Johnson, 1987). Such stringent behavioral definitions diminish the element of psychological and emotional intimacy that accompany sexual expression; the narrower behavioral definition may simplify this complex phenomenon. Simple descriptions may do little to inform a public with low tolerance for inappropriate sexual behaviors. Moreover, simple description may be consistent with the lack of professional expertise in this area.

The lack of perception of the contextual appropriateness of sexual behaviors in individuals with autism raises enormous concerns for parents. Parental worries about indiscreet sexual behaviors in individuals with autism has been reported. Results from a survey conducted by DeMeyer (1979) indicated that parents of children with autism were concerned about their male children exhibiting inappropriate sexual behavior in public. More recently, Ruble and Dalrymple (1993) confirmed the continued parental concern regarding the display of sexual behavior of their children with autism. Over 75% of survey respondents reported worry that common behaviors would be mistakenly thought of as sexual. These concerns of parents about the misperceived malevolence of their child's sexual behaviors may be heightened by the trend toward community placement. Individuals with autism are at great risk for negative consequences and punishment with any display of sexual behavior. Our clinical practice includes cases of loss of privileges to ride a public bus, loss of a job, and placement in an out-of-state residential setting due to sexually inappropriate behavior that was confused with sexual deviance. Current societal trends to legislate and codify a variety of behaviors apparently

responding to well-publicized cases of stalking, sexual harassment, and infection with deadly sexually transmitted diseases further contribute to parental and caregiver fears about sexual expression in individuals with autism.

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