HHS Public Access

Author manuscript

Int J Transgend. Author manuscript; available in PMC 2016 October 15.

Published in final edited form as:

Int J Transgend. 2015 ; 16(2): 97–102. doi:10.1080/15532739.2015.1075929.

The Role of Assent in the Treatment of Transgender Adolescents

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Keywords

transgender; adolescent; assent; consent; developmental delay; autism

Introduction

There is evolving evidence that individuals with certain forms of developmental disabilities may have higher prevalence of gender noncomformity than individuals without developmental disabilities (Bedard, Zhang, & Zucker, 2010; de Vries, Noens, Cohen-Kettenis, van Berckelaer-Onnes, & Doreleijers, 2010; Gallucci, Hackerman, & Schmidt, 2005; Landén & Rasmussen, 1997; Robinow, 2009; Strang et al., 2014). Gender Dysphoria (GD) is a diagnosis formalized by the Diagnostic and Statistical Manual of Mental Health Disorders, 5th edition, used to describe incongruence between the gender assigned at birth and the experienced or desired gender. GD is only diagnosed when this incongruence is accompanied by clinically significant distress or impairment in social, school, or other important areas of functioning (American Psychiatric Association, 2013). Because adolescence is a period marked by robust cognitive, social, and emotional changes, many in the field recommend that those with suspected gender dysphoria and/or gender incongruence have a careful evaluation prior to consideration of a medical intervention (e.g., Tishelman, Kaufman, Edwards-Leeper, Mandel, Shumer & Spack). The Endocrine Society and the World Professional Association of Transgender Health (WPATH) recommend treatment with medications which suppress puberty, and also with cross-sex hormones, in carefully assessed adolescents presenting in gender clinics as transgender (Coleman et al., 2012; Hembree et al., 2009).

In this paper we illustrate some of the general complexities that can occur in this field through the use of a case composite report, based on our clinical experience at a gender clinic associated with a large pediatric hospital in the United States. We describe an adolescent with co-occurring gender dysphoria and developmental challenges, and then discuss issues of patient assent and prescribing medical therapy in this patient population.

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Financial Disclosure: The authors have no financial relationships relevant to this article to disclose.

Conflict of Interest: The authors have no conflicts of interest to disclose.

Case Composite Report

Psychological Evaluation

The patient's and family's initial on-site interaction with our clinic consisted of a comprehensive psychological evaluation. The goals of the evaluation, conducted by a licensed clinical psychologist, are to independently evaluate the child's gender status and identity, understand the child and family's needs, and provide information relevant to the possible initiation of medical treatment. Within this context, the evaluation provides information regarding a youth's mental health status, developmental concerns, and family and social support (see Tishelman et al, in press, for more detail). The evaluation consisted of a clinical interview with the patient and father, along with standardized measures addressing behavioral issues, anxiety, depression, and an autism and ADHD screening. These included the Child Behavior Checklist and Youth Self Report (Achenback & Rescorla, 2001), the Children's Depression Inventory 2 (Kovacs, 1992), and the Piers-Harris Children's Self-Concept Scale (Piers & Herzberg, 2002)). In addition, a number of measures were used to assess gender identity, including the Utrecht Gender Dysphoria Scale (Cohen-Kettenis & VanGoozen, 1997) and the Recalled Childhood Gender Identity/Gender Role Questionnaire (Zucker et al., 2006); relevant documents were reviewed (e.g., prior neuropsychological assessment data), and collateral informants were contacted with prior family authorization (e.g., psychotherapist; school counselor).

Referral Information

John was a 14 year-old natal male of African descent when he was referred to our clinic for a psychological evaluation, to assist in determining whether medical intervention would be beneficial. He was referred to as John, and with male pronouns, at the time of referral and had not transitioned to living as a female. John and his family expressed interest in pursuing puberty-blocking medication. His father, John's primary caretaker, stated at the outset of the evaluation that John wanted to be a girl.

Background Information

John was adopted from foster care when he was two-years old. Little is known of his early years, and he was placed into foster care after being found abandoned at a fast food restaurant at 18 months of age. His current family consisted of another, older adopted male, and his father. His adoptive mother was deceased.

According to his father, John's development was delayed, with his receptive and expressive language posing particular challenges. By the time he presented in our clinic he had been tested multiple times throughout his life. The most recent neuropsychological evaluation, conducted about 1 year prior to the evaluation, noted that his nonverbal skills were in the low average range, but that he has significant cognitive challenges related to verbal processing, expression and comprehension. Other important areas of concern for John included severe behavioral dysregulation, with a history of tantrums at school and at home, and verbal aggression. He was in a regular 8th grade classroom, at school, with a 1:1 aide at his side throughout the day, and received a range of other academic services tailored to his needs. John's father reported that he was always “different” with regard to gender. He stated

that as a toddler and preschooler he liked to play with dolls and with girls, was always disinterested in sports and other activities stereotypically often associated with boys, and very early on insisted on wearing female underwear. At approximately age 12, John started to experiment with wearing make-up. His father reported that he was very accepting, noting that they had a number of close friends and relatives who were “gay.”

Given John's disruptive behavior at school, and his atypical presentation, John was often ostracized and bullied by boys at school. This had been a chronic problem, although his father had strongly advocated on his behalf. John did have some female friends at school and a couple of male and female youth in his neighborhood who were accepting of him. At about the age of 11, John started saying that he did not like boys, and did not want to be a boy. According to his father, starting at the age of 12, John started saying that he was a girl and not a real boy. His father took him to a psychotherapist with experience working with gender variant youth, where John and his family were in therapy for several months prior to the coming to our clinic. When contacted, John's therapist, Dr. Smith, stated that John's father was devoted to John, and wanted to act on his behalf, whatever that path might be. Dr. Smith also stated that he felt that John believed he was a girl, but that he was not sure that John had a grasp of what that entailed in a deeper sense.

John presented as happy to be at the evaluation. It was notably difficult for him to participate in the evaluation, however. He was observed not to comprehend some basic words, such as “sad’ and “angry,” and was unaware of typical terms for many body parts. He had a propensity to answer yes-no questions, even if he did not actually comprehend what was being asked. He often asked if his father could answer in his stead and stated that he was bored. Nevertheless, based on the confluence of information obtained, he appeared to meet DSM-5 criteria for gender dysphoria (American Psychiatric Association, 2013). In our clinic's multidisciplinary conference, we discussed whether the patient would be eligible to receive hormonal suppression as outline by The Endocrine Society's clinical practice guidelines (Hembree et al., 2009) and the World Professional Association for Transgender Health (WPATH) standards of care for treatment of transgender adolescents (Coleman et al., 2012). According to The Endocrine Society guidelines, patients are eligible for pubertal suppression only if they meet several readiness criteria. For example, patients must meet criteria for gender dysphoria, be at least Tanner stage 2, and have adequate psychologic and social support, all criteria met by our patient. However, they must also have “knowledge and understanding of the expected outcomes of GnRH analog treatment [the medication which blocks production of pubertal hormones], cross-sex hormone treatment, and sex reassignment surgery, as well as the medical and social risks and benefits of sex reassignment (Hembree et al., 2009). During the initial psychological assessment the patient had not demonstrated this level of understanding.

Similarly, the WPATH Standards of Care suggests that the adolescent give informed consent, in addition to consent of the parents, as a minimum criterion prior to receiving puberty suppressing medication (Coleman et al., 2012). The American Academy of Pediatrics (AAP) Committee on Bioethics recognizes that children and adolescents are not capable of providing fully informed consent, but that decision-making involving older children and

adolescents “should include, to the greatest extent feasible, the assent of the patient”. The AAP describes assent as including the following:

1. Helping the patient achieve a developmentally appropriate awareness of the nature of his or her condition.
2. Telling the patient what he or she can expect with tests and treatment(s).
3. Making a clinical assessment of the patient's understanding of the situation and the factors influencing how he or she is responding (including whether there is inappropriate pressure to accept testing or therapy) (AAP, 1995).

Cameron & Murphy (2006) evaluate the process of obtaining consent in a research study with participants at four levels of comprehension ability. In their discussion, they present a number of implications of their work, and suggest that the consent process may be more time consuming, that it may need to be individualized, and that adapted procedures may be warranted. Others also explore such questions (e.g., Lewis & Porter, 2004; Lloyd, 2012), suggesting that in many cases great care must be taken, and approaches may need to be adapted to ensure no undue coercion. In addition, literature discussing pediatric assent for research emphasizes that ability to understand all nuances of the research is not required for assent (Roth-Cline & Nelson, 2013). Creative methods of informing children about risks and benefits, such as with pictures, may improve understanding and aid in obtaining assent (Adcock, Hogan, Elci, & Mills, 2012).

The clinical team turned to our hospital's Ethics Committee for further guidance. After careful consideration of the issues, the Committee and the clinical team developed an individualized strategy for understanding the patient's comprehension of the proposed intervention, and for obtaining assent, involving developmentally appropriate verbal and visual approaches. In this case, the endocrinologist created drawings demonstrating anatomy and typical male and female pubertal changes and referred to these drawings when guiding the patient through the risks and benefits of pubertal suppression. The patient was able to convey comprehension through spontaneous generation of questions indicative of his concerns (“The [GnRH analog] medication will stop my mustache from getting bigger?” and “The medication won’t make me develop breasts yet?”. He used verbal and nonverbal communication (pointing to the visual depictions) to express a desire to avoid further progression of male puberty, and desire to eventually progress through a female puberty. The patient was prescribed GnRH agonist therapy to suppress puberty; the potential use of cross-sex hormones will be discussed in future visits, and a careful assent procedure will need to be developed in the event that cross-sex hormones are considered. Such an assent procedure would need to include understanding of the irreversible changes resulting in estrogen therapy and implications regarding impaired fertility. In the interim, John was encouraged to further explore his gender preferences, with the flexibility of a time frame that relieved the burden of immediate decisions, through the use of puberty suppressors.

Discussion

Cases similar to the one described may become more common as providers continue to adopt The Endocrine Society's and WPATH's guidelines for treatment of transgender

adolescents. While our patient was not diagnosed with autism, there is evolving evidence that patients presenting to gender clinics have higher than expected rates of autism and autism spectrum disorder. In a study from the Netherlands the prevalence of autism spectrum disorder in children and adolescents presenting for evaluation of gender dysphoria was 7.8%, much higher than the prevalence in the Dutch pediatric population (de Vries et al., 2010). Another study from a pediatric neuropsychology program in the US demonstrated greater prevalence of gender variance in patients with autism spectrum disorder and attention deficit hyperactivity disorder than in non-referred controls (Strang et al., 2014). A small descriptive study of adults with developmental disabilities found 4 of 32 participants to have gender dysphoria (Bedard et al., 2010).

There may be clinical situations where patients with carefully diagnosed gender dysphoria, who otherwise meet eligibility and readiness criteria, are not able to provide meaningful consent due to cognitive or verbal disability. In other medical conditions, such as cancer or diabetes, medical interventions would never be withheld from these patients provided parents or guardians are available to make proxy medical decisions. This comparison requires acknowledgement that treatment of gender dysphoria with pubertal suppression and cross sex hormones continues to remain controversial, is the subject of continued research, and requires careful individualized assessment, whereas the decision to treat of cancer or diabetes with medical interventions is typically not controversial. However, as clinicians continue to prescribe hormonal interventions for gender dysphoria, they must also be prepared to prescribe these interventions in situations where patients are not able to demonstrate clear “knowledge and understanding” of the interventions. Nevertheless, the psychological evaluation would need to be carefully constructed to provide a thorough comprehension of the client's gender issues, to the extent possible.

One of the complications of working with individuals with developmental differences is that they may have a harder time understanding the spectrum of gender and sexuality options. In particular, some individuals with non-conforming gender presentations may simply be atypical males or females, and others may not fit precisely into a binary model of gender. We are hopeful that John, as well as others in similar circumstances, will use the period of time afforded by puberty-blockers, to explore their own identities in a way that will be authentic and comfortable for them.

A fresh look at the issue of consent and assent, as relevant to the care of transgender adolescents is recommended. For instance, the AAP Committee of Bioethics on notes that pediatricians “should not necessarily treat children as rational, autonomous decision makers.” They should, instead, “give serious consideration to each patient's developing capacities for participating in decision-making, including rationality and autonomy”. In addition to specifying the essential elements of assent, as noted above, they clarify some of the problems with relying solely on parental or guardian judgment or “proxy consent”, including that the medical provider has the legal and ethical duty to render competent care based on a youth's need. This obligation can transcend and exist separately from a guardian's wishes and opinions (AAP, 1995). It is therefore imperative, especially in issues involving fundamental aspects of identity, to represent the adolescent's voice and will to the extent possible. The committee also notes that as children develop, they should be given increased

responsibility for personal health care, and be involved in an interactive process with parents and providers (AAP, 1995). We believe that this standard applies to children with developmental differences as well, as highlighted by our case composite, utilizing a flexible model based on the unique conglomeration of factors associated with every adolescent and family.

Thus, we suggest providers assess for developmental differences prior to initiation of pubertal suppression or cross sex hormones. Explanation of medical treatment options, risks and benefits of treatment, and the assent or consent process should be individualized whenever feasible for each patient based on their level of understanding, and a comprehension of their abilities. Youth who are eager for treatment should not have it withheld based on developmental differences, unless it is not possible to make a determination of treatment needs. Any other approach would present significant risk of discriminating against gender dysphoric adolescents with developmental disabilities, and potentially lead to emotional harm to youth who are already vulnerable.

Acknowledgments

Funding Sources: Dr. Shumer is supported by NIH grant 1T32HD075727-01

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