

Intersex Mental Health and Social Support Options in Pediatric Endocrinology Training Programs

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ABSTRACT. The birth of a child with an intersex condition is often an emotionally stressful event for parents. Preparation and ongoing support

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Journal of Homosexuality, Vol. 54(3) 2008

Available online at <http://jh.haworthpress.com>

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doi:10.1080/00918360801982074

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systems could be beneficial to both parents and children and would alleviate some of the shame and isolation associated with intersex conditions. To assess the extent to which psychological support is available, a short e-mail survey on this topic was sent to the directors of 50 pediatric endocrinology fellowship training programs (PEFTPs), who are most likely to evaluate and treat intersex children and their parents. Of the 29 PEFTPs that responded, 69% offer psychological support and 58% have a mental health specialist on staff. However, only 19% of patients or families receive emotional support during diagnosis and only 15% receive support after diagnosis. We found two barriers that prevent patients and families from receiving psychological help from their intersex care team. First, there is a lack of training for mental health professionals regarding the needs of intersex patients and families. Second, some families refuse help even though it is offered. This study reveals that further research is needed to overcome these two barriers regarding mental health treatment of intersex patients and families.

KEYWORDS. Intersex, genital development, psychosocial support, endocrinology, pediatrics, genital surgery, patient centered care, corrective treatment

BACKGROUND

Increasingly studies show that the current approach to intersex treatment needs to be reconsidered. We now have evidence that clitorectomies and clitoral reduction can reduce orgasmic function and sexual response in women (Minto, Liao, Woodhouse, Ransley, & Creighton, 2003). We also know that infant gender assignments based on physical characteristics and surgical limitations aren't always maintained in adulthood (Reiner & Gearhart, 2004).

The birth of a child with an intersex condition is almost always an unexpected occurrence. Approximately one out of every 1,500 children is born with atypical genital or reproductive anatomy that raises the question of cosmetic "correction" (Blackless, Charuvastra, Derryck, Fausto-Sterling, Lauzanne, & Lee, 2000). Whereas these data are derived from birth records, the true estimate for intersex occurrence is probably higher when including children who are not diagnosed until adolescence or later in life.

As is the case when any child is born with an unforeseen condition, health care workers and parents are often ill-prepared to handle the psychological consequences (Starke, Wiklund, & Moller, 2002). Parents grieve the loss of their anticipated "normal" child and must redefine their concept of well-being while trying to make informed decisions about their child's treatment.

In addition, as an intersex child matures, he or she is likely to experience psychological stress, regardless of medical condition or sex of rearing. Confusion about gender roles and interventions related to the condition can be overwhelming. Considerable first-person reports from adults with intersex conditions express significant emotional distress as a result of their treatment. These include, but are not limited to, surgeries at a young age, surgery without informed consent, and lack of disclosure from parents and health care providers who keep diagnoses and details of treatment secret. With limited follow-up data available from providers we must rely on anecdotal evidence from intersex adults regarding treatment outcomes (Gorman & Cole, 2004; Preves, 2003; Long, 2002; Moreno, 2001; Coventry, 2000; Dreger, 2009; Grovemann, 1998; Kessler, 1998).

Traditional protocols for treatment of children born with intersex conditions are also being questioned by ethicists and physicians (Frader et al., 2004). Once health risks have been ruled out or addressed, additional treatment is based on cosmetic concerns and perceived needs. Quality of life is making its way into the debate and expands the need to integrate mental health services into treatment teams. There is no consensus about the medical management of intersex patients (British Association of Paediatric Surgeons Working Party on the Surgical Management of Children Born with Ambiguous Genitalia, 2001) (Gruppuso & Lee, 1999). However, much of the literature stresses the importance of providing psychological support, not only for parents during the critical stage of diagnosis, but also for people living with intersex conditions. Adults with intersex recommend psychological support before, during, and after treatment, and periodically throughout their lives (Leidolf, 2006). However, current protocols are being challenged for broader outcomes by providers as well as patients. "Outcome itself must be defined from the perspective of the patient" (Berenbaum, 2003).

There are no published training guidelines for mental health professionals, and it is unknown how many treatment teams include mental health professionals. Most intersex infants are referred to a pediatric endocrinologist for care, ideally through a tertiary care center where a team of physicians specializing in intersex treatment is available (American Academy of Pediatrics, Committee on Genetics, 2000). The purpose of this study, therefore, is to ascertain the extent to which pediatric endocrinology fellowship training programs (PEFTPs) include adequate patient and parent counseling by a certified mental health professional as a part of their treatment regimen because Endocrinologists are most likely to work with intersex families.

METHODS

A list of the fifty pediatric endocrinology fellowship programs in the United States and Canada was obtained from the *Journal of Pediatrics* January 2001, volume 138, number 1. E-mail and U.S. mail addresses for the listed directors were obtained from a directory of the Lawson Wilkins Pediatric Endocrine Society. A pilot survey about intersex patient treatment was sent via e-mail, followed by a focused survey about mental health and social support. The focused survey was mailed to all subjects who did not respond via e-mail. Total response rate was (58%). The focused survey was composed of questions regarding:

1. The approximate number of intersex infants and ages of intersex patients diagnosed and followed by the institution.
2. The presence of certified mental health specialists affiliated with the institution that provides psychological support to intersex patients and parents.
3. The approximate number of patients and parents who receive psychological support and at what times during the course of diagnosis and treatment the support is provided.
4. The types of psychological and social support that are offered.
5. Any comments the director had about mental health and social support options for intersex patients and families.

RESULTS

Geographically, the respondents represented institutions in Canada (10%) and the United States (90%). The U.S. respondents were from the Northeast (24%), the Midwest (21%), the Southwest (3%), the West Coast (14%), Southern states (14%), and the Mid-Atlantic states (14%). In total, the responding PEFTPs see approximately 700 intersex patients annually. We should note that not all institutions include the same syndromes in their definition of intersex conditions. Twenty-seven percent of these patients are infants, and were represented by answers regarding psychological support for the parents. Responding programs serve one to thirty intersex infants (median seven) and one to one hundred intersex patients each year (median thirty). The age range of the patients is birth to fifty-years old. Of the 59% of PEFTPs that were able to state an age range in the pilot survey, 35% of their patients were 18 years old or younger.

We found that 69% of PEFTPs offer mental health services to patients and families, and 59% of PEFTPs have certified mental health professionals on staff. The type of psychological support offered includes child psychologists, psychiatrists, and social workers, as well as website resources, patient advocacy groups, and support groups. Seven percent of practices refer their patients or families elsewhere, and 3% offer support through the Internet. While the numbers given appear to support the idea that mental health services are available, the comments physicians made express the manner in which mental health professionals are integrated in the treatment process or not. Those comments include:

- “We have access to a psychologist who helps with these cases but doesn’t have training in intersex other than what our pediatric endocrinologist has given her.”
- “To my knowledge, none of our social workers have actually counseled and intersex patient (they work primarily with our diabetics). The lack of availability of qualified mental health services for these patients is a tremendous problem. We have had a great deal of frustration identifying anyone in our system with expertise/interest in this area. I usually refer my patients to...a clinical psychologist in group practice elsewhere in the city.”
- “Several involved—no one with particular expertise.”
- “I know this sounds awful, but we don’t have anybody to refer the patients (or parents) to, and we are very worried about a mental health person doing more harm than good. There have been several instances in the last five years when we felt that psychological support and care was absolutely essential. In these cases, I found an experienced person who was willing to meet with us (the endocrinologist involved) to go over the case and discuss the goals of therapy.”
- Response to “Does your group include one or more certified mental health specialists?”: “I answer no with great regret.”
- “In our area, counselors who are not first interested in health insurance information are hard to come by. And there are only a couple of people who will take on a challenging patient who might require a major time investment. There are a lot of people who will offer opinions authoritatively without knowing what they’re talking about—which really scares me.”

Providers also expressed some frustration with the availability of mental health services by stating:

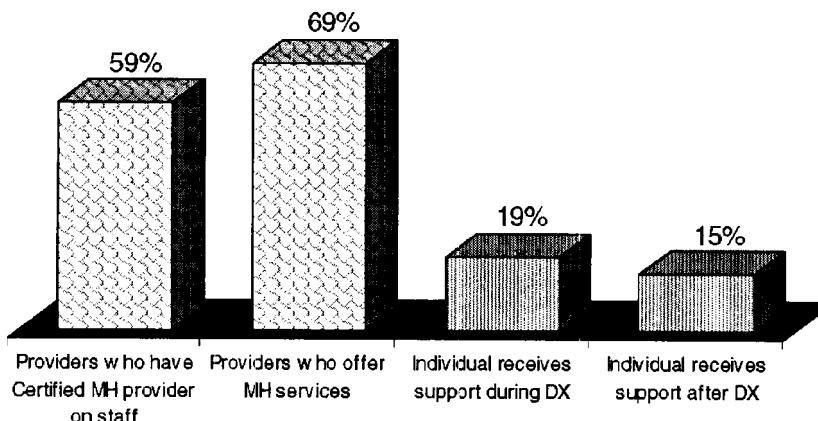
- “Psychological support for our families is needed but unavailable. We don’t have the resources to hire our own psychologist with special training in intersex cases. We have to rely on the psychologists or psychiatrists hired by the hospital. They unfortunately are also overwhelmed with their own needs and face budget cuts. When hiring a new person, our needs are low on their list. We have to hope that any new hires just happen to have training in intersex counseling.”
- “We work in a county hospital with limited resources. It’s a depressing, deplorable state of affairs.”

Of the 69% of PEFTPs that offer psychological support, 19% of patients or families receive emotional support during diagnosis and 15% receive support after diagnosis. This disparity between the number of programs offering support and the number of individuals receiving support could be explained by how emotional support is offered:

- “I think our psychological evaluation and support here is not adequate for patient needs. Only most obvious problem ones seem to get support. Yet probably the need is universal for all patients with this sort of condition.”
- “Whenever I am asked.”
- “Each family is offered, but some don’t take it.”
- “All are offered. Parents of CAH girls tend not to inquire about further follow up, however more do if surgery was done early.”
- “Usually the pediatric endocrinologist is the primary person for discussing the case with parents. Other specialists involved are genetics, surgery, urology, OB/GYN as needed.” It wasn’t specified whether the pediatric endocrinologist had mental health training.
- “It’s offered to all, but not generally chosen. Strange isn’t it.”
- One practice has a psychologist on staff, but emotional support is described as, “None, other than provided by pediatric endocrinologist.”
- “Very rarely given. We physicians try to provide as needed.”
- “Patients tend to seek specialists who live close to them.”
- “We seek help from MH professional when needed.”
- “Use counselors in Department of Medical Genetics.”

A number of physicians stated that psychological support was “given as needed,” but none specified who determines the need for support.

FIGURE 1. Mental Health Support Services Provided by PEFTPS in the Study.



DISCUSSION AND RECOMMENDATIONS

Although 69% of the responding PEFTPs offer mental health support and 59% have a mental health specialist on staff, only 19% of families receive support during diagnosis and 15% of patients receive support after diagnosis. Why then, when mental health support is available, is it not often received by patients or parents? The discrepancy between these numbers needs to be examined. At times, support is offered "as needed," but it is unclear who determines the need. Other times, psychological support is offered, but it is unclear why families and patients choose not to use those services.

This study helps to raise some important questions about medical treatment and medical care in regard to intersex and distinctions between treatment and care. Are treatment outcomes designed to treat people or anatomy? Is treatment meant to correct intersex or to teach people how to live with intersex conditions? There is no question that atypical anatomy can contribute to psychosocial and psychosexual trauma but it is not clear whether the distress is caused by atypical anatomy or the social reaction to atypical anatomy. With mental health providers minimally integrated into treatment teams, we need to examine the viability of expecting psychological outcomes via medical means. Management of intersex is focused on medical intervention or

correction, while mental health and social support systems are essential for patient centered care.

The anatomy involved with intersex conditions make this an extremely sensitive issue to address. In addition, the time between normalizing genital or reproductive anatomy and cognitive awareness of one's genital or reproductive anatomy make it harder to confirm consequences on the quality of life. Even though quality of life outcomes are difficult to measure, there is ample first-person data to support the need to reevaluate the approach to intersex patient care (Human Rights Commission of the City & County of San Francisco, 2005). Other factors we should consider are:

1. The growing number of support groups and patient advocacy groups that support the idea that corrective treatment is not the only answer. Many adults seek support after the very treatment that was meant to secure their psychosocial and psychosexual development.
2. Prenatal counseling should include the possibility of having a child with an intersex condition with the same support, education, and guidance that accompanies the birth of any child. Intersex conditions (1:1,500) are more common than Cystic Fibrosis (1:2,800) but many expectant parents have never heard the word intersex.
3. Medical providers state that their former patients are “lost to follow-up” at the same time patient advocacy groups rally to update the current treatment protocols. Adults with lived experience state that current protocols interfere with their quality of life, while Medical providers have limited data that support the need for the current protocols.
4. Medicine and society do not create the same sense of emergency for other physical features that we hold for atypical genital or reproductive anatomy.
5. With the lack of follow-up research available, providers need to use the resources that are available. Adults with intersex possess a wealth of information and can contribute to de-stigmatizing intersex and making it a manageable condition rather than a shameful one that requires correction.
6. We need to take a closer look at what is being taught about intersex in medical schools and how to expand that knowledge to include first-hand feedback from adults with lived intersex experience, as well as mental health providers.

As we have learned from this study, families and people with intersex conditions do not use the mental health services provided with intersex treatment. We are left to wonder why 69% of these providers offer support but only 15–19% of patients are receiving support. The barriers to mental health support could result from the lack of access individuals and families have to mental health support, the lack of intersex training available to providers, and the lack of support for parents dealing with the anxiety and stigma associated with intersex conditions. However, we have sufficient first-hand knowledge from adults with intersex that mental health is an essential component of total patient care. We have learned from other marginalized populations such as LGBT, immigrants, and people with disabilities to name a few, that medical and mental health providers must incorporate the lived experience of their patients in those populations into their understanding of treatment and care. Because conditions of atypical genital development are associated with stigma and social emergency (APA, 2000) providers must use caution to determine the difference between a medical or psychosocial problem when they determine the need for corrective treatment and care.

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