Arch Sex Behav (2011) 40:1101–1102
DOI 10.1007/s10508-011-9823-4

LETTER TO THE EDITOR

Androgen Insensitivity Syndrome with Male Sex-of-Living

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Published online: 2 August 2011
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Recent articles (Kulshreshtha et al., 2009; Meyer-Bahlburg, 2009, 2010; Nourizadeh & Hashemzadeh, 2008; T'Sjoen et al., 2011) regarding male gender identity in complete androgen insensitivity syndrome (CAIS) prompt me to report my own similar history of male upbringing in spite of Quigley grade 5 (i.e., close to CAIS in phenotype, but with slight clitoral enlargement and partial labial fusion) (Quigley et al., 1995), partial androgen insensitivity syndrome (PAIS), and change to female sex-of-living in early adulthood.

I am also seeking to clarify some minor points. Meyer-Bahlburg (2009) and Zucker (1999) have both written that there had been a previous case of CAIS with male upbringing reported by Money (1991). I know that this patient actually had partial AIS because I am his cousin. He (my cousin) was also described by Money and Ogunro (1974). Another minor point: Crawford et al. (1970) reported my age at mastectomy as 14 and Money (1991) reported it as 15. I was actually still age 13 at that time.

I would like to offer my thoughts based on first-hand experience of a situation similar to that of the patients in the aforementioned articles with CAIS living as males. An underlying, unquestioned assumption in much writing on changes of sex-of-living is that "gender identity" is an imperative, overriding psychological force. My own pediatric endocrinologist (J. D. Crawford, M.D. of Massachusetts General Hospital) told me when I was age 21 that gender identity was "an unshakable conviction." However, he never asked me whether I experienced it that way.

My actual inner experience was of gender identity as an ordinary, malleable conviction, vulnerable to changes in perception of facts. As a child, I had been told that medical authorities had concluded that I was male. However, later, as a young adult, I revised this to the belief that I was actually a person with AIS who should more appropriately be living as female. Perhaps those interested in the psychology of gender identity should pause to question the belief that "gender identity" always exists as a profound, unalterable psychological force or drive. Some seem to be using as their model for gender identity the compulsion of transsexuals to live as their target gender, no matter what the impediments. If transsexuals did not have such a need, they would not be transsexuals, but it is a great leap to assume that all other persons' experience of gender identity is of the same nature.

Perhaps what clinicians perceive as "core gender identity" is sometimes not a deep and integral component of a patient's psychological makeup, but instead a somewhat superficial reaction and adaptation to the social and medical predicament the patient perceives himself/herself to be in. The apparent male gender identity of the patients in the Kulshreshtha et al. and T'Sjoen et al. articles might be partly, or even wholly, explicable as the product of the patients' having been told they were, in some sense, "really" male, than having their reactions reinforced by counselors. The authors seek an explanation in chromosomes or genetics or brain differentiation, but perhaps what they are seeing is not much more than their own ideas being recycled back to them.

A person's actions may be controlled, not only through overt or inchoate coercion, but also through their being misinformed or under-informed. A child's apparent "gender identity" may consist of his or her perception of an immutable reality. Children know that, in the ordinary course of events, people do not choose their own sex. They may perceive the word of an authority like a physician, not merely as one human being's opinion, but as a simple statement of an unchangeable fact.

My own history indicates that clinicians are not extremely perceptive about intersex children's gender identity and can even be complexly wrong about it. Records from when I was

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age 13 stated that I was "…expending a great deal of energy in attempting to maintain a facade of maleness when, indeed, he did not seriously believe himself to be male…" but then, only a few days later, "…He is firmly fixed in the male gender role…" What kept me fixed in that role was not, however, a strong desire to be male, but being uninformed and inhibited in communication. I ultimately changed my sex-of-living to female, not due to gender dysphoria, but to avoid continuing as a social and sexual invalid. That happened only after I obtained fuller information, from medical textbooks at a college library.

In my own childhood, I would have been better served by a pragmatic approach to my gender assignment that emphasized providing information and informed decision making based on what was possible, not a fatalistic approach giving primacy to "gender identity."

Norris and Keetel (1962) described a young person assigned to the wrong sex at birth making a relatively smooth gender transition during the teenage years. The decision was evidently made for pragmatic reasons, not primarily due to gender dysphoria. This case suggests that gender identity is sometimes potentially malleable even in late childhood. Even the late John Money, who originated the concept of gender identity, recognized that a change in sex-of-living for intersex persons can sometimes be practical after early childhood (Money, 1969).

One more point: Meyer-Bahlburg (2005) wrote that a change in sex-of-living from female to male in intersex persons is more often observed than one from male to female. This is not the same, however, as saying that a person living as female is at greater risk of perceiving themselves as "misassigned" than one living as male. Among those born with any of the more common causes of ambiguous genitalia, a female sex-of-rearing is more frequent, and thus there is a larger population of persons potentially seeking to change from female to male than in the other direction. The dynamics of gender change are also different between those two situations, in that cross-gendered behavior is more highly stigmatized among those reared male; also in that discordance between gonadal and chromosomal sex and sex-of-rearing is more common among those reared female. What appears to be a direct causal link between genetic sex and gender identity may actually be mediated through a social mechanism whereby perception of karyotype becomes the ultimate arbiter of "true" sex. Money and Ehrhardt (1972, pp. 153–154) made a similar point.

Acknowledgment Elements of the medical history of Ms. Cadet were verified in a personal communication to the Editor by Lynne L. Levitsky, M.D., Chief of the Pediatric Endocrine Unit at Massachusetts General Hospital for Children in Boston, Massachusetts, dated February 21, 2011.

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