Ethical concerns regarding intersex

Sir,

We read with great interest, the editorial on intersex published in Indian Journal of Endocrinology and Metabolism.[1] Intersex, also known as disorders of sex development or hermaphroditism, forms an array of conditions characterized by an incompatibility between the development of chromosomal and anatomic sex. They are relatively common, with a prevalence rate as high as 2%.[2] They are divided into four categories, namely 46 XX, 46 XY, true gonadal intersex and undetermined intersex, and include disorders such as congenital adrenal hypoplasia and androgen insensitivity syndrome. Diagnosis usually involves appropriate history taking, physical exam, and investigations such as karyotyping, serum hormone levels, and ultrasound. Symptoms, some of which may not be apparent at birth, include enlarged clitoris, micropenis, or hypospadias. Treatment usually involves hormonal therapy and may require surgery. A host of complications have been found to be associated with intersex, including potential to develop malignancy.[3] Experts differ on the course of management for such patients, with some advocating early correction so that the patient may live a normal life devoid of ambiguity, while others maintaining that the treatment should be delayed as long as the patient remains healthy.

A cloud of ethical concerns hovers around intersex. The extent of controversy behind this phenomenon can be judged by the fact that the name "intersex" has attracted a whole lot of raised eyebrows in the past. This is particularly relevant to the subcontinental setups, where intersex conditions are met with a higher degree of criticism from social circles.

Gender assignment/reassignment for such patients has always been a hot topic of debate, as complications after such surgeries may prove fatal.[4] The "Consensus Statement on Management of Intersex Disorders" of 2006 laid down the guiding principles for the nomenclature, diagnosis and management of intersex disorders, and was aimed at eliminating the controversy around them.[5] However, it not go into sufficient detail to resolve all treatment dilemmas, and in any case, it did not end controversy but, instead, actually itself became the focus of controversy. Nevertheless, it was an essential step in elaborating management protocols for intersex conditions.

Majority of the cases remain undiagnosed. Such incidents result either from a lack of availability of proper diagnostic tools at an earlier stage, or from a disparity in the provision of healthcare in our setup. There is a dire need of the promotion of awareness regarding this topic, with the formulation of official guidelines for the ethical management of such cases, as literature provides limited and often conflicting evidence in this regard.

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