

Social and ethical dilemmas associated with intersex conditionsHafiz Muhammad Aslam,¹ Asfandyar Sheikh,² Arsalan Ahmad Alvi,³ Muhammad Muzzamil Edhi⁴

Madam, intersex denotes a group of conditions characterised by an incompatibility between the development of chromosomal and anatomic sex. They are relatively common, with prevalence rate as high as 2%, and include disorders such as congenital adrenal hypoplasia and androgen insensitivity syndrome (AIS).¹ Diagnosis is based on the clinical features and investigations such as karyotyping, serum hormone levels and ultrasound. Treatment usually revolves around hormonal therapy and may require surgery. Complications associated with intersex include potential to develop malignancy.² Experts differ on the course of management for such patients, with some advocating early correction, while others maintain the delaying of the treatment as long as the patient remains healthy.

Intersex has always been a controversial topic for endocrinologists. Gender assignment/reassignment for such patients has always been a hot topic of debate, as complications after such surgeries may prove to be fatal for the patient.³ The "Consensus Statement on Management of Intersex Disorders" of 2006 marks an important event in the history of gender assignment and management of intersex conditions.⁴ It laid down the guiding principles for the nomenclature, diagnosis and management of intersex disorders, and was aimed at eliminating the controversy around them. However, it did not sufficiently resolve all treatment dilemmas and itself became the focus of controversy.

We recently encountered a patient in the Gynaecology

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ward of a local hospital, who presented with infertility for 4 years. She was married and was accompanied by her husband. Ultrasound showed a pair of testes in the lower abdomen, and further investigations confirmed diagnosis of AIS. The attending doctors were under a dilemma on whether to inform the husband or not, as doing so might lead to an immediate dissolution of marriage. The patient was operated on (after taking informed consent) and was discharged without fully explaining the diagnosis to the husband (after a general consensus). There is a contrast with the way this would have been handled in the west. The physicians' communication with a competent adult patient (the wife) would be confidential and not shared with other persons. The decision to disclose to the husband would be solely under the wife's discretion.

The above notion implies that appropriate and timely measures be taken in order to provide a standard of care comparable to the west. Guidelines should be setup for the ethical management of such conditions, as they may often prove to be devastating for the patient's life in the long run.

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