Disorders of Sex Development among Sudanese Children:


A newborn with ambiguous genitalia is considered as a medical and psychosocial emergency as two major issues need to be immediately addressed; the relationship of sexual ambiguity to a possible life-threatening disease and the sex of rearing. Children as well as their families who have had the wrong sex assigned to them in infancy could face considerable social and psychological problems. Diagnosis and management of these disorders needs understanding of the basic pathophysiology, expert clinical judgement, specialized diagnostic facilities, medications and skilful surgery among others. Management needs a multidisciplinary team including pediatricians, paediatric endocrinologist, surgeons, geneticists, psychologists in addition to the family and subject understanding religious leaders. As is the situation in many developing countries these teams and investigative facilities were not available in Sudan and therefore many cases were either missed, or managed on guess basis. This is compounded by the fact that most deliveries take place at home and sex assignment was left to the discretion of the midwife. In this cross-sectional descriptive study we review our 5 years experience of the University of Khartoum Paediatric Endocrinology unit which started in January 2006 at Gaffar Ibn Oaf Children’s Hospital and Suba University Hospital. During this period about 120 cases, the biggest series in the region, were seen. The commonest cause was congenital adrenal hyperplasia followed by XY disorders of sex development particularly androgen insensitivity syndromes and true hermaphrodites. Investigative facilities were available however some tests had to be sent abroad and the cost was prohibitive. The mean cost of investigating one case was over 800 SDG excluding laparoscopy and others. These cases were managed by a multidisciplinary team. Availability of laparoscopy helped us in reducing the cost of many dynamic tests and we believe this is a cost effective tool in developing countries. In many cases we had to do sex reassignment even at an older age. Guidelines for managing these cases
in Sudan including the religious opinion will be discussed with emphasis on the importance of intra and interinstitutional cooperation.