IS-1 The long term results in patients with congenital adrenal hyperplasia: anatomical, functional, cosmetic and psychosexual development

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BACKGROUND: Adrenal Androgen secretion is the cause for intersexual consequences in females with congenital adrenal hyperplasia (CAH). Analyzing the long term outcome of feminizing surgery is crucial to evaluate the effectiveness of therapies offered and to make necessary adjustments. AIM: To evaluate the results after feminizing surgery in patients with CAH from the pediatric intersex clinic. PATIENTS AND METHODS: Out of 163 patients of CAH being followed (1980-2004), fifty responded for review. The patients had undergone detailed evaluation and feminizing genitoplasty and hormonal therapy. Evaluation included filling a detailed proforma with questionnaires along with a physical examination and a structured interview in privacy. Assessment was performed for cosmesis (50), psychosocial adjustment (in 42 above 5 years) and functional outcome in 19 patients above 14 years. RESULTS: The mean age at clitoroplasty was 3.6 years (age 1-16 yr), and the mean age at the time of the study was 14.6 years (4-23 years), with a mean post-op follow up 6 year (6 mon-17 years). The cosmetic outcome was excellent in 37 patients, satisfactory in 10, atrophic in 2 and poor in 1. The clitoromegaly re-appeared in one due to non compliance to hormonal therapy for 3 years and required re-do surgery. The gender identity was female in 45, male in 4 and mixed in 1. The attitude to self and life was positive in 36 and negative in 6. The functional outcome was satisfactory in 11, unsatisfactory in 4 and undetermined in 4. Endocrine control was satisfactory in 36 and unsatisfactory in 14 requiring frequent monitoring and adjustments. CONCLUSIONS: Endocrine control and surgical treatment were complimentary to each other to achieve satisfactory results in majority of the patients with CAH in our setup.