

Assessment of psychosocial wellbeing of parents & Quality of life (QoL) of Children with 46, XY Disorders of Sex Development (46,XY DSDs) attending Endocrine clinics at Lady Ridgeway Hospital for Children (LRH)

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Introduction:

46, XY DSDs have lifelong implications for the parents and patients. Documented literature is scarce in relation to this in Sri Lankan setting

Specific Objectives:

1. To assess the psychosocial well being of parents of children with 46,XY DSDs
2. To assess the Quality of Life of children with 46,XY DSDs aged more than 12 years

Methods:

A Descriptive cross-sectional study carried out at endocrine clinics at LRH over a period of 1 year. Informed written consent of both parents were taken. Ethics approvals were obtained from the Sri Lanka College of Paediatricians and LRH. Approval for use of all Questionnaires obtained from the original authors.

	Specific objective 1	Specific objective 2
Study sample	Both parents of 51 children with 46,XY DSDs -102 who were able to read and understand the questionnaires Children with 46, XY DSDs were diagnosed according to DSD consensus statement	A sub group – 21 children (12 -16 years) Able to read and understand the questionnaires Exclusion criteria of children < 12 years of age (unavailability of validated questionnaire) Chronic co-morbidities having an impact on the QoL
Study tools	<ul style="list-style-type: none"> Validated Sinhala version of General-Health-Questionnaire-30 (GHQ-30) and translated Tamil Questionnaires A judgementally-validated Sinhalese questionnaire and its Tamil translation 	<ul style="list-style-type: none"> Validated Sinhala version and a translated Tamil version of PaedQL TM version 4.0 generic core- Parent copy and Child Copy. Domains assessed were: Physical, emotional, social and school functioning

Results:

- The median (IQR) age of the cohort was 60 (6 to 147) months. There were 42 boys and 9 girls. Consanguinity was positive in 8 (16%) of children. Figure 1 shows the education level of the parents. Table 1 shows the probable clinical diagnosis.

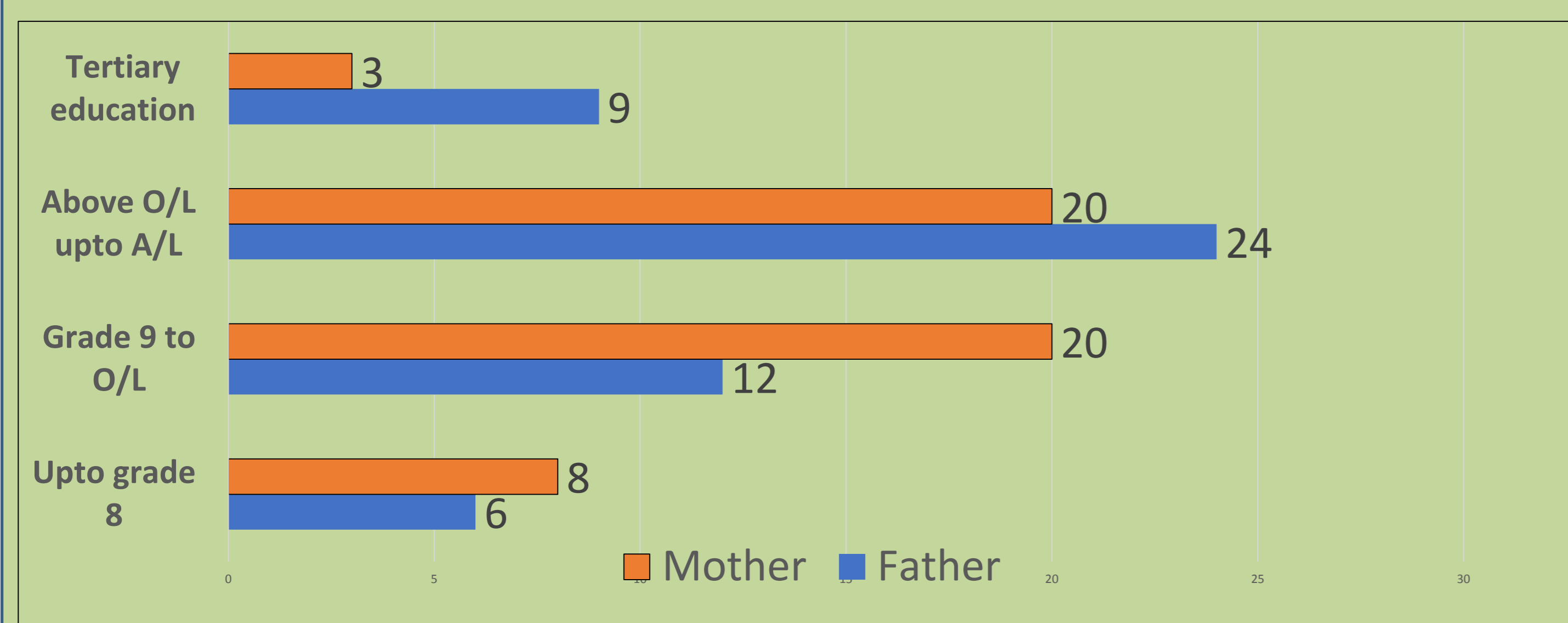


Figure 1: Education level of parents

Diagnosis	Frequency (%)
Partial Gonadal Dysgenesis	3 (5.9)
Testosterone Biosynthetic Defects	6 (11.8)
Partial Androgen Insensitivity Syndrome	24 (47.1)
Complete Androgen Insensitivity Syndrome	7 (13.7)
3 beta Nonclassic Congenital Adrenal Hyperplasia	3 (5.9)
3 beta Classic Congenital Adrenal Hyperplasia	6 (11.8)
Ovotesticular DSD	2 (3.9)

Table 1: Probable clinical diagnosis

- 28 (53%) mothers and 23 (45%) fathers had psycho-social morbidity when assessed with GHQ-30 with a cut-off score of 6. Patients' age was negatively correlated with GHQ-scores of both parents ($p < 0.05$). Median psycho-social well-being scores were 44.0 (40.0-52.0) and 50.8 (44.0-56.0) for mothers and fathers. They were positively correlated ($p < 0.001$).
- The median scores of PaedQL were 75 (60.8-78.3) and 73.3 (58.3-80.8) respectively for parental and child components. Scores of parental-component of QoL were negatively associated with age of the child ($p < 0.01$), but non-significantly with the education level of parents and family income ($p > 0.05$).
- Other encountered difficulties before school admission: 4 of patients had to change their sex in the birth certificate subsequently, 2 of them were rejected by the school.
- Other encountered difficulties among school-aged children (> 5 years): 17 children (65.4%) were not drinking water in school, 15 (57.7%) did not use wash-rooms and 17 (65.4%) did not participate in sports due to fear of exposure.

Conclusions:

46, XY DSDs are conditions associated with significant psycho-social morbidity in parents and psychological distress in the affected children in Sri Lanka