
Gender outcome

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Gender outcome and sexual functioning in Indonesian patients with a disorder of sex development (DSD)

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Background: In Indonesia, comprehensive treatment for individuals with DSD became available recently. Consequently, many affected individuals had been living untreated or received treatment late in life and have been raised in an ambiguous body and gender. Objective: To investigate gender identity, gender role behaviour, and sexual functioning in patients with DSD. Patients were compared to healthy controls matched for gender, age, and socio-economic background. Methods: Subjects: Cross sectional study comparing 116 patients aged 6-41 years and 116 healthy matched control subjects. Materials: Gender identity and gender role behaviour was measured using Indonesian versions of GII and GIQC for children; Activities and Gender Questionnaires for adolescents/adults. Sexual functioning was measured only in adults using Indonesian versions of FSFI, FSFS-R and MSHQ. Statistical analysis: Principal Component Analysis and Cronbach's alpha were applied in measuring construct validity and internal consistency. Differences between patients and controls were compared using Mann-Whitney U-test. Results: Social gender role change was reported in 20/116 (17%) patients: 4/60 (7%) children; 2/23 (9%) adolescents and 14/33 (42%) adults. All changed from female to male. Patients living as girls reported more often long-term gender-related problems (i.e. affective gender confusion and cross-gender role behaviour) than their matched controls did. 14/18 (78%) adult women and 7/21 (33%) adult men never had sexual/romantic relationships. Taboo, fear of ostracism, and infertility were the reported as main reasons for delay or refusal in entering a romantic relationship. Women experienced great distress due to infertility. Discussion: Particularly women are disadvantaged since gender identity problems largely occur among patients assigned female at birth, and infertility causes distress in a collective-driven society that expects procreation. Conclusion: Many untreated or late-treated patients experience gender identity problems. Counselling and education on DSD is prerequisite to promote social acceptance of DSD. Follow-up is needed to compare late-treated with early-treated patients.

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