

Reproductive Endocrinology TRANSGENDER, DSD, AND TURNER SYNDROME

Understanding, Communication and Concerns Around Sexual Development Differences by Patients' Perspectives

LIA MESQUITA LOUSADA, MD¹, SORAHIA DOMENICE, PhD², Elaine Maria Frade Costa, PhD¹, Tania A. Bacheга, MD, PhD³, Rafael Loch Batista, MD, PhD⁴, Eveline Gadelha Pereira Fontenele, PhD⁵, Berenice Bilharinho Mendonca, MD⁶.

¹Hospital das Clinicas -FMUSP, São Paulo, Brazil, ²Disciplina de Endocrinologia e Metabologia, Laboratrio de Hormnios e Genetica Molecular/LIM42, So Paulo, Brazil, ³So Paulo University, Sao Paulo, Brazil, ⁴Universidade de So Paulo, Sao Paulo SP, Brazil, ⁵Universidade Federal do Ceara, Fortaleza, Brazil, ⁶University Sao Paulo Fac Medical, Sao Paulo, Brazil.

Introduction: The approach to Differences of Sexual Development (DSD) patients is complex. It involves discussion on karyotype, gonads, genital phenotypes, hormonal treatment, genitoplasty, sexual activity and fertility. A satisfactory understanding by the patients optimize the follow up and the acceptance of the condition. **Objective/Methods:** To analyze the understanding of DSD patients about their condition, the doubts and concerns, the barriers to communication and repercussion in gender, sexual orientation and relationships in a cohort of patients followed at a reference center, through a semi directed interview. **Results:** 57 patients were interviewed. The mean ages were 36.5y. Around 90% of all patients concluded at least the high school. Only 50% of all patients knew the condition's name and how they were affected by it. Still 92% knew the treatment. 63% of the patients presented doubts, mainly related to diagnosis. The median level of satisfaction about the condition understanding (on a scale from 1 to 5) was 4. Most of the patients were first informed by doctors (65%) or mothers (27%). The mean age of diagnostic disclosure was 13 y among patients with atypical genitalia. However, 67% of them preferred be first informed in childhood. Around communication, 60% of them reported no dialogue at home about the condition, 82% feel uncomfortable in talking to other people and 57% experienced negative comments related to DSD. Only four 46,XY DSD presented gender dysphoria: 3 with partial gonadal dysgenesis (who were admitted at the reference service after genitoplasty) and one 5- α -reductase 2 deficiency. About affective relationships, 42% of the patients were single and 70% had already experienced sexual activity. The mean age at first sexual activity was 22y. 72% considered that condition influences negatively on relationships because the stigma, the genitalia appearance, the insecurity in sexual intercourse and fertility. The concern related to stigma was higher among patients with atypical genitalia. The patients' self-evaluation (scale from 0 to 10) about their condition understanding improved after the interview: 6 to 8.9 (p<0.01). **Conclusion:** There is lack of knowledge about DSD among patients even treated in a referral center. The atypical genitalia arouses curiosity and stigma. Educational acts for patients, health team and community are needed to make DSD conditions popular, to improve the understanding and communication and to decrease the stigma.

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Understanding, Communication, Concerns and Repercussions of Sexual Development Differences by Mothers' Perspectives

LIA MESQUITA LOUSADA, MD¹, SORAHIA DOMENICE, PhD², Costa L. Elaine Maria Frade, PhD³, Tania A. Bacheга, MD, PhD⁴, Rafael Loch Batista, MD, PhD⁵, Eveline Gadelha Pereira Fontenele, PhD⁶, Debora Cabral Coutinho, MD⁷, Barroso L. Carina Marques Barroso, MD⁸, sandra regina geroldo, MD⁸, Berenice Bilharinho Mendonca, MD⁹.

¹Hospital das Clinicas -FMUSP, São Paulo, Brazil, ²Disciplina de Endocrinologia e Metabologia, Laboratrio de Hormnios e Genetica Molecular/LIM42, So Paulo, Brazil, ³Hospital das Clinicas -FMUSP, Fortaleza, Brazil, ⁴So Paulo University, Sao Paulo, Brazil, ⁵Universidade de So Paulo, Sao Paulo SP, Brazil, ⁶Universidade Federal do Ceara, Fortaleza, Brazil, ⁷HC-FMUSP, Sao Paulo, Brazil, ⁸Hospital Infantil Albert Sabin, Fortaleza, Brazil, ⁹University Sao Paulo Fac Medical, Sao Paulo, Brazil.

Introduction: Differences of sexual development (DSD) define congenital diseases in which an atypical development of chromosomal, gonadal or anatomical sex occurs. The approach involves complex themes: gender designation, genitoplasty, hormonal treatment and fertility. Mothers' understanding optimizes their children's assistance. **Objective/methods:** To analyze the mothers' understanding about the DSD condition, doubts, concerns, barriers to communication and repercussion in gender, sexual orientation and relationships in a cohort followed in reference centers in São Paulo (SP) and Ceará (CE), through an interview. **Results:** 112 mothers (72 from SP and 50 from CE) were interviewed. Mothers' mean age was 35 y. The satisfaction related to the understanding about their children's condition (on a scale from 1 to 5) was higher in the SP: medians of 4 (SP) and 3 (CE). Significant differences were evidenced between the numbers of mothers who knew the condition's name, 56.3% (SP) and 38.6% (CE); who knew why the children had been affected by it, 38.5% (SP) and 16.7% (CE); and who knew the drugs' function, 89.3% (SP) and 70.4% (CE). 70% to 83% of the mothers referred doubts, mainly related to the diagnosis and their feeling of guilt. Considering only children with atypical genitalia at birth (n:115), the difference was not diagnosed at hospital in 15% (4 from SP and 14 from CE). Pediatricians and obstetricians first communicated to mothers about the atypical genitalia in 73% of the reports. 70% (SP) and 41% (CE) of the mothers considered the first approach inappropriate. 89% of all mothers feel uncomfortable in talking to other people about the DSD condition and 68% experienced negative comments. Around 70% of mothers reported discomfort in exposing their children's genitalia and 64% considered genitoplasty as an urgency. 47% referred that the DSD may influence the gender identity, 65.4% referred it may prejudice relationships and 33.3% believed it may influence on sexual orientation. The concern related to stigma was higher than related to fertility, genitalia appearance, relationships, treatments, gender identity and sexuality. **Conclusion:** Most of the mothers of DSD children, even in reference centers, showed dissatisfaction and