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XY women with androgen insensitivity syndrome (AIS): a qualitative study (BL)

Alderson, J., 2000, G6s

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The purpose of this study was to provide an understanding of the psychological response to their conditions, of XY women affected by Androgen Insensitivity Syndrome (AIS). The aim was that this understanding would yield preliminary information regarding the patient group's requirements of psychosocial health care services.

A qualitative research methodology utilised Grounded Theory techniques to gather and analyse textual data derived from sixteen semi-structured interviews. Specific features of the application of these methods were theoretical sampling, the use of negative instances, and Glaser and Strauss' (1967) constant comparison procedures. In addition, a double-interview technique of data collection was used, based on the work of Hollway and Jefferson (1997). Participants of the main study were eight women who have a diagnosis of Complete or Partial AIS.

A model was constructed of women's psychological response to AIS. It is suggested that women with AIS experience psychological distress in relation to their condition. A central feature of this distress is Fear of Devaluation. Fear of Devaluation is a woman's concern that she might be considered to be of low worth in consequence of her condition or intersex state. Fear of Devaluation results from a woman's experience of certain consequences of AIS, including secrecy and withheld information, infertility, and medical intervention. The provision of full information about AIS, delivered sensitively and with support can foster positive adaptation to the condition, and reduction in Fear of Devaluation and AIS related distress.

The clinical implications of this model of AIS Distress are that a variable level of distress should be expected and psychosocial support should be offered to women and their families from initial investigations onward. Medical intervention should be provided in an atmosphere of openness and support. Psychosocial services should be utilised for appropriate preparation for procedures, and specialist psychological therapies should be available when necessary.

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