



Identifying Issues Related to Sexual Health in Adults with 22q11.2DS

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Background: Risky sexual behaviour is an issue in adults with 22q11.2 deletion syndrome (22q11.2DS) with potentially serious consequences. Having basic sexual knowledge is known to increase the chance of having healthy and positive sexual experiences. We investigated the use of a tool that identifies deficits in sexual knowledge and assessed whether such knowledge deficits were associated with risky sexual behaviours in adults with 22q11.2DS. **Methods:** In an initial sample of 45 adults with 22q11.2DS we assessed knowledge using a semi-structured interview, the Tool for the Assessment of Levels of Knowledge Sexuality and Consent (TALK-SC). A separate questionnaire was used to assess knowledge about genetics, technology use, sexual history, and sexual behaviours. We used univariate analysis to investigate whether basic characteristics (i.e., sex, psychotic diagnosis, intellectual disability (ID)) were associated with deficits in sexual knowledge, and used these basic characteristics as predictors in a multivariate regression analysis with sexual knowledge as outcome. We tested whether risky sexual behaviours were associated with deficits in sexual knowledge. **Results:** The median age at assessment was 24 (range 17-64) years, 21 (47%) patients were male, 11 (24%) had a psychotic illness and 26 (58%) had ID. 14 (31%) passed all five sections of the TALK-SC. Of the 25 adults who reported sexual activity, 16 (64%) reported engaging in a form of risky sexual behaviour. ID ($p=0.04$), but not sex or psychotic disorder, was significantly associated with deficits in sexual knowledge. In this initial 22q11.2DS cohort, risky sexual behaviour was not significantly associated with deficits in sexual knowledge, sex, psychotic diagnosis or ID. **Conclusions:** The results indicate that many adults with 22q11.2DS have sexual knowledge deficits and are vulnerable to high risk sexual behaviours. While deficits in sexual knowledge were associated with ID, there were no significant predictors of risky sexual behaviours. Larger sample sizes and more sophisticated assessments of risky sexual behaviours will be essential to extend these initial findings. Meanwhile, the results can begin to inform best practices for clinicians and family members. These include repeated education, e.g., at times of transition, and assessing the need for psychosexual counselling and related clinical interventions for adults with 22q11.2DS.