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**Relationships, sexuality and parenting: The experience of five young women
with 22q11.2 deletion syndrome (22q11DS). An interpretative
phenomenological study.**

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Structured Abstract

Introduction Many people with intellectual disability (ID) experience problems with maintaining social relationships, have smaller social networks and experience feelings of social disconnectedness. A large majority do not enjoy intimate relationships, marry or have children. When adults with ID fulfil parenting roles, many experience significant barriers including stigma. It is clear that there is value in relationships for adults with ID and that there are some unique challenges associated. 22q11.2 deletion syndrome (22q11DS) is a genetic condition associated with developmental disabilities and has an incidence of approximately 1 in 4000 newborns. More than 90% of people with 22q11DS have developmental difficulties, with approximately half having an ID. There is a paucity of research available from the experiences of individuals with 22q11DS. This study aims to explore how young women with 22q11DS experience relationships, sexuality and parenting. The perception of parental and service provider's attitudes on relationships, sexuality and parenting among the women will also be explored, to understand the quality of support experienced.

Method Using Interpretative Phenomenological Analysis, this study explored the experiences and perceptions of five women with 22q11DS, regarding relationships, sexuality and parenting. Semi-structured interviews were conducted to elicit the themes.

Results Four Superordinate themes were evident within the women's dialogues, including several subthemes: (i) Limitations of 22q11DS (Engagement in social comparison/responsibility); (ii) Acceptance/ normality (Social competence / to be a good parent); (iii) Support (From Mum); and (iv) Individuation (Readiness for adulthood/ with parental agreement).

The women interviewed offered insights into how they experienced their limitations associated with 22q11DS, commonly reporting difficulties with learning and social skills problems. Participants engaged with their disability/ limitations through processes of social comparison; noting their individual strengths through comparisons with those with more serious disabilities; and identifying their own limitations through comparisons with typically developing peers. With regard to childbearing, the women tended to overestimate the risks of heritability; and reflected themes of responsibility, expressed as a commitment to meeting the individual needs of any children who may be affected by the deletion.

Participants ascribed value to normality, with social competence identified as a mechanism for achieving this. The women offered their experience of relationships with typically developing peers as evidence for their own perceived social competence. Being a good parent was also an important aspect for the women who expressed intentions for parenting; and parenting values were often derived from the behaviours and values of parents and extended family. Being a good parent was also viewed as a possible mechanism for ensuring acceptance from others.

Support from family, especially mothers, was perceived positively by the women interviewed. Supports provided by mothers ranged from practical assistance with daily living, through to provision of emotional support and friendship.

Themes of individuation from family and aspirations for independence were also contained in the women's dialogues. The women communicated their understanding of relationships, sexuality and parenting; and in doing so believed this inferred a readiness and competence for adulthood.

However, the expressed knowledge of adulthood had often not been derived through direct personal experiences. There was a perception that parents were supportive of the longer-term plans for adult roles held by the women with 22q11DS, inclusive of marriage and parenthood; however, the perceptions had developed often without having these explicit conversations with family.

Conclusions This study has begun to explore how women with 22q11DS experience their relationships, sexuality and parenting. The women with 22q11DS in this study had positive perceptions of support and faced their futures with optimism and confidence regarding their abilities. They expressed a desire for normalisation and a strong sense of self-determination, in a context of perceived family support. Consideration and further understanding of the unique experiences of women with 22q11DS, including the acknowledgement of expressed desires and concerns regarding relationships, sexuality and parenting, will invariably assist young women with the deletion to achieve fuller and meaningful life roles for themselves and their future families.

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