

Exploring Fathers' Roles and Experiences with Dissemination of Sexual Health Information to their Children with Down syndrome

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Objective: Sexual exploration and education is an essential part of human development during adolescence and young adulthood. While typically developing children may inherently understand the social nuances of peer-peer relationship building, children with intellectual disability (ID) such as Down syndrome often require more direct instruction. Previous studies on this subject have primarily included only mothers' perspectives and while mothers have historically been the primary caregivers, the roles for fathers in the household have been expanding. This exploratory case study aimed to identify the modes and methods some fathers use to explain sexual health information to their children with Down syndrome. Goals were to better understand when and how this dialogue is initiated, the resources fathers utilize to inform these conversations, and the concerns, challenges and experiential advice fathers wish to share with other fathers.

Methods: Semi-structured interviews were conducted with two fathers of children with Down syndrome. Purposive recruitment of fathers of teens and young adults with Down syndrome was completed through the informal social networks of individuals working at the Massachusetts Down syndrome Congress (MDSC) who also had children with Down syndrome. Participants were asked open-ended questions about their experiences talking to their children about sexual health. Interviews were audio-recorded, transcribed verbatim, coded, and analyzed using modified grounded theory techniques.

Results: Personal phone interviews were conducted with two fathers of children with Down syndrome who were both 16 years old; one a boy and the other a girl. Participants reported using specific strategies to discuss sexual health content with their children including repetition, contextualization, and role-play. To inform their conversations fathers utilized community organization workshops and print resources, their co-parent, and personal reflections of adolescence. Throughout both interviews salient themes emerged regarding the conflict of safety versus access to sexual exploration and intrafamilial communication.

Conclusions: This pilot study is the first to directly address fathers' experiences discussing sexual health information with their children. This research highlights the complex relationships some fathers have with the sexual health information dissemination process, and broadens the dialogue on parent-child gender dyads to be more inclusive of families with children with developmental disabilities.