

Improving the Sexual Health of Young People With Mobility Impairments: Challenges and Recommendations

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ABSTRACT

Introduction: This mixed-method study (a) describes challenges to providing sexual health services to youth with mobility impairments from the perspective of health care

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providers and experts and (b) describes and compares sexual health-related experiences of youth with mobility impairments.

Method: Secondary data analysis of My Path, a study focused on the transition to adulthood for youth with mobility impairments. Using an exploratory sequential design, qualitative data ($n = 10$) were analyzed using systematic content analysis followed by quantitative analysis of survey data ($N = 337$).

Results: Challenges included not talking about sex, managing sexual development, adaptation and instruction, parent roles, and safety. Survey data showed that youth with mobility impairments are diverse in their experiences with sexual behavior and sources of sexual health information. Although connected with primary care providers, few received information about sexual health.

Discussion: Interventions to improve youths' well-being should include comprehensive care and education that promotes and supports healthy sexual development. *J Pediatr Health Care.* (2017) ■, ■-■.

KEY WORDS

Adolescent, mobility impairment, sexual health

INTRODUCTION

Adolescence is an important developmental period characterized by individuation, strong peer influence, separation from parents, physical sexual development, and the beginning of intimate relationships (Wiegerink, Roebroek, Bender, Stam, & Cohen-Kettenis, 2011). In particular, sexual maturation, including the initiation of sexual activity, is a complex developmental task tied closely to emotional and physical development,

as well as cultural and social contextual influences (Wiegerink et al., 2011). For adolescents with physical mobility impairments, challenges associated with sexual development and intimacy may be exacerbated by additional functional challenges, such as wheelchair use, urinary and fecal incontinence, spasticity, and/or neurologic problems (Cardenas, Toposki, White, McLaughlin, & Walker 2008; Verhoef et al., 2005; Wiegerink et al., 2011). Physical disabilities may also limit the sexual experiences of adolescents with mobility impairments. For young men, mobility impairments can be associated with a range of sexual function. However, females with mobility impairments generally retain normal fertility (Cardenas et al., 2008; Murphy & Young, 2005).

Adolescents with mobility impairments may also experience social barriers to the developmental tasks associated with adolescence, especially related to sexual maturation and intimacy. Some studies suggest that social barriers create bigger challenges to the healthy sexual development compared with function limitations for adolescents with mobility impairments (Murphy & Young, 2005). Youth with mobility impairments often experience social stigma about sexuality related to their disability, especially from a heterosexual perspective that emphasizes penile–vagina penetrative sex and excludes the sexuality of persons with disabilities (Esmail, Darry, Walter, and Knupp, 2010; Murphy & Young, 2005). From this perspective, adolescents with physical disabilities are often viewed as childlike and asexual (Esmail et al., 2010; Murphy & Young, 2005; Tepper, 2000). Young people may also experience social barriers such as disclosing complications of mobility-impairing conditions that could affect sexual relationships (e.g., incontinence; Heller et al., 2016).

Despite potential physical and social limitations related to sexual development, limited available research shows that youth with physical and mobility impairments are interested in sexual relationships and do engage in sexual behavior (Heller et al., 2016). Similar to their nondisabled peers, 54% to 78% of youth with physical disabilities report kissing in a sexual way, 65% have masturbated, and 54% report having had sex (Verhoef et al., 2005; Wiegerink et al., 2011). However, only 16% of youth with physical disabilities report using contraception

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(Murphy & Young, 2005). Experiences of sexual behavior among youth with physical disabilities also vary by gender. For young men, there is a significant correlation between mobility and sexual activity, but the relationship is not present for young women (Decter et al., 1997). In one study among youth with physical disabilities, young women were 2.4 times more likely to have had sex compared with young men (Verhoef et al., 2005).

The literature is clear that youth with physical disabilities report experience with sexual activity with far less information about sexual health including basic information about sex, birth control, and sexually transmitted infections (Cardenas et al., 2008; Esmail et al., 2010; Porat, Heruti, Navon-Porat, & Hardoff, 2012; Sawyer & Roberts, 1999; Verhoef et al., 2005). Although youth with physical disabilities have the same sexual health needs as their nondisabled peers, few youth with physical disabilities receive formal information or instruction from health professionals. In one study among youth with spina bifida, only 39% of youth reported ever discussing sexual health with their health care provider (Sawyer & Roberts, 1999). Other barriers to providing sexual and reproductive health services to youth with physical disabilities may include negative provider attitudes, lack of provider skills or knowledge, and poor coordination between health care services (Porat et al., 2012). However, 63% of youth with physical disabilities reported that they would like to talk with their health care providers, and 100% said they would discuss sexual health with their health care providers if provider initiated (Sawyer & Roberts, 1999). Youth report a desire to learn about the impact of their diagnosis on sexuality, fertility, treatment options, medical devices, and how to handle sexual problems with partners (Wiegerink et al., 2011).

Many young people get information about sexuality through informal social interactions, such as peers and media. However, youth with physical disabilities may not be able to directly benefit from these sources of information about sexuality. Some data suggest that youth with physical disabilities have fewer social experiences compared with nondisabled peers and often require the presence of adult caregivers, limiting their opportunity for peer exchange of information about sexuality, as well as sexual experimentation (Murphy & Young, 2005; Wiegerink et al., 2011). In addition, youth with physical disabilities may be able to receive some information about sexuality from the media; however, that information is unlikely to include information specifically relevant to their experience of sexuality with a physical disability (Esmail et al., 2010). Similarly, school-based sexuality education is not tailored to the needs of youth with disabilities (Porat et al., 2012). Only 8% of youth reported receiving spina bifida–specific sexuality education, and 84% of youth reported receiving no sexuality education at all (Sawyer & Roberts, 1999).

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