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"Coming here, you will discover yourself, discovering others"
Romanian Prader-Willi Association

ASOCIACIÓN MADRILEÑA
PARA EL SÍNDROME DE
PRADER-WILLI



SEXUAL BEHAVIOR IN ADOLESCENTS AND ADULTS WITH PRADER-WILLI SYNDROME

Barbara Y. Whitman, Ph.D., Saint Louis University Department of Pediatrics, St. Louis, MO. USA

INTRODUCTION: Since first described, immature genitalia, and endocrine deficiencies precluding normal growth and sexual maturation have been cardinal features of Prader-Willi syndrome (PWS [Hauffa, 2000]). Early and consistent data regarding these abnormalities has led to an assumption of universal infertility (Katcher et al., 1977; Bray, 1983; Butler, 1986; Eiholzer & Lee, 2006), despite normal to premature adrenarche (Schmidt et al, 2001; L'Allemand et al., 2002). Further, the combined impact of sex hormone deficiencies and cognitive/social deficits have led to a clinical assumption that sexual understanding, interest and activity rarely, if ever, exceeded that noted in non-affected pre-adolescents. Behaviorally, except for the rare female who has exchanged sex for food, or aggressive sexual behavior among males treated with testosterone replacement, most clinicians have viewed affected individuals as essentially "asexual." While many affected youngsters talk about dating, getting married and having babies, this has been seen as learned socio-cultural behavior, not sexual, an understanding in part supported by earlier data (Greenswag, 1987). Three coalescing factors demand a reassessment of these previously held beliefs: (1) recent reports of at least three successful pregnancies; (2) the author's experience with three previously sexually abused adults, two females and one male, who now demonstrate indiscriminate and predatory like sexual behavior; and (3) an apparent "cross-over" effect of growth hormone replacement therapy (GHRT) on sexual maturation. This presentation reports initial survey data from parents and community-based residential providers regarding sexual behavior in adolescents and adults with PWS, the relation of this behavior to supplemental hormone therapy or psychotropic medications, and the sexual policies and sex education training programs of group homes.

METHODS: The study is surveying parents and direct care providers of adolescents and adults with PWS using two "informant" questionnaires: (1) the Sexual Behavior Questionnaire and (2) the Aberrant Behavior Checklist. In addition, group homes are being asked to provide copies of their policies regarding client's sexuality and sexual relationships. For those adults in group home/supported living care, information is being sought from both parents and care-staff.

RESULTS: At the time of this writing, the survey process has just begun. Results will be summarized and distributed at the time of the presentation.

DISCUSSION: Multiple factors demand a better understanding of "normal" or "baseline" sexual behavior in those with PWS including: (1) improved strategies for managing the obesity resulting in many adults living into their 50's and 60's; (2) the use of growth and sex hormone replacement therapy in both sexes; (3) the impact of increased estrogenization from selective serotonin reuptake inhibitors used as behavior management adjuncts; (4) the recently reported pregnancies; and (5) a shift in adult living from institutions to a "normalized" community integration model combined with concurrent "disabilities rights" legislation and advocacy groups actively promoting the sexual activity rights of cognitively handicapped adults. The results will be critical for designing and delivering the appropriate sex education services for this population, an effort that currently is hampered by the limited empirical data regarding the nature and frequency of sexual behaviors in this population.