

RESEARCH ARTICLE

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Caregiver awareness of reproductive health issues for women with intellectual disabilities

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Abstract

Background: Limited attention has been paid to the issue of reproductive health as it affects women with intellectual disabilities, despite reproductive health being a vital issue in public health policy for women in the general population. This paper describes caregiver awareness of reproductive health issues relative to women with intellectual disabilities who are being cared for in welfare institutions in Taiwan.

Methods: The study employed a cross-sectional, questionnaire-based study which recruited 1,152 caregivers (response rate = 71.87%) from 32 registered disability welfare institutions in Taiwan. We classified their understanding/awareness of reproductive health issues into four domains: menstrual (1) and menopause (2) issues, sex education (3), and reproductive health services (4). Each domain had five associated yes/no questions and the total score for the four domains was out of a maximum of 20. Data were analyzed using SPSS 15.0 software.

Results: We found that most of the caregivers were familiar with matters concerning sex education, menopause, and reproductive health services, but they lacked adequate understanding of issues associated with menstruation in women with ID. Many aspects of reproductive health such as "menstrual pain", "age at menarche", "masturbation", "diet during perimenopause", and "publicly available reproductive health services" were issues in which caregivers lacked adequate knowledge and required further instruction. Logistic regression analysis revealed that female caregivers with a university degree, and those who had experience assisting with reproductive health care were more inclined to have higher reproductive health awareness scores than their counterparts.

Conclusions: This study highlights that service providers should offer appropriate reproductive health education to institutional caregivers, and that more attention be focused on the personal experiences and concerns of intellectually disabled women in future research.

Background

There is general consensus in the healthcare community concerning the need for defined policies and services aimed specifically at reproductive health for individuals with intellectual disabilities (ID). It is likely that such undertakings would be supported by society as a whole. Previous studies have shown that the sexuality of people with ID has often been stereotyped, with this group typically characterized as being childlike and asexual, invariably leading to a denial of their socio-sexual maturity and needs. Rodgers suggested that women with ID should have more control over the non-medical

aspects of menstrual management, so that their individual needs can be met [1]. Generally, people with ID have conservative attitudes towards sexual intercourse and homosexuality, but they may become involved in personal intimate contact with persons with whom they are familiar [2]. Schupf and colleagues encountered a variety of reproductive health issues, such as the age-adjusted likelihood of menopause being twice as high in women with Down syndrome as in women with other forms of ID [3], and despite the ban on involuntary sterilization, it appears that many parents and caregivers of persons with ID still support sterilization as a form of contraception, especially for persons with severe ID [2]. Servais [4] reviewed previous scientific studies that assessed the expectations and support needs of persons with ID in terms of sexual health, and pointed out that

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