

## INTELLECTUAL DISABILITIES AND SEXUAL HEALTH OF WOMEN: A REVIEW

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### Abstract

Women with intellectual disabilities (ID) have a number of personal and societal obstacles in their sexual life. They face double stigma and discrimination—one because of their disability and the other because they are females. They have low level of competencies that would allow them to better manage their sexuality; consequently, they have low level of control over their own health. In addition, families with disabled members may choose to ‘hide’ them due to the stigma associated with them. They obstruct access to sexual and reproductive health information and services, which is detrimental to their health and wellbeing. This aim of the study is to determine the issues and concerns related to sexual health that women with intellectual disabilities face. Our findings suggest that it is essential to offer women with Intellectual Disabilities, sexuality education in schools that is catered to their level of understanding in order to help them develop the skills necessary to form relationships, comprehend sexual and romantic relationships, and engage in safe sex when they choose this option. Families should give women with ID the chance to discuss their sexual needs and make their own decisions, along with the education and healthcare systems.

**Keywords:** Sexual health, intellectual disability, sexuality, discrimination

### Introduction

Sexuality has a complex role in our lives and can influence one’s quality of life. Although sexuality can be a source of wellbeing and happiness, it can also raise some ethical and social issues depending on the society (Matin et al., 2021). Sexual health is defined by the World Health Organization (WHO) as "the state of physical, emotional, mental and social well-being in relation to sexuality and requires a positive and respectful approach to sexuality and sexual relationships." The World Association for Sexual Health lists a number of variables that can affect sexual health, including attitudes, sexual behaviors, societal determinants, biological variables, and genetic disorders (Ivankovich et al., 2013).

A report Women Watch released by United Nations stated that women with disabilities of all ages often have difficulty with physical access to health services. Women with intellectual disabilities are particularly vulnerable, as they are more susceptible to gender discrimination, violence, poverty, dislocation and other forms of social deprivation (UN women 2011). Intellectual disability (ID) refers to a disability that is characterized by significant limitations both in cognitive functioning and in adaptive behavior (conceptual, social, and practical skills) that originate before age of 18 (Wilkinson and Cerreto 2008). In terms of their sexual lives,

people with ID encounter numerous personal and societal obstacles. These barriers can result in increased sexual violence and abuse of women with ID. Some of these barriers include limited sexual knowledge, poor education, unfavorable attitudes, lack of access to healthcare, lack of sexual experiences, and social isolation (Borawska-Charko et al., 2017). Lack of awareness of sexual health can also result in sexually offensive behaviors among people with ID (Servais, 2006). Lack of sexual health education contributes to increased prevalence of sexually transmitted infections among people with ID including an increased risk of HIV infection (O'Callagan and Murphy, 2007).

The literature has long focused on the sexuality of women with ID. However, the availability of sexual health services is an important and understudied topic in this population's medical research. We conducted a review of the literature on the sexual health problems faced by women with intellectual disabilities in order to fill in these gaps. We hope that the information presented in this review will be useful to researchers, policymakers, providers, self-advocates, and other parties involved in addressing the needs and barriers faced by women with ID.

### **Objectives**

The objective of this study is to provide a comprehensive overview of the challenges women with ID face regarding sexual health promotion.

### **Methodology**

The review process included identification of potentially relevant research articles searched on Medline, PubMed and Google Scholar. Our key words to search articles were combination of the words intellectual disability, sexual health, primary care, reproductive health, women's health, sex education, sexual health education, sexual abuse and sexuality. We excluded papers in languages other than English, a potential limitation of this review.

### **Review of Literature**

#### **Sexual abuse**

Both men and women in the community run the risk of being sexually exploited (Chavan et al., 2011). Numerous participants in the studies that were included in the review reported having unpleasant sexual experiences. Women with ID frequently reported experiencing sexual harassment from friends or coworkers. Being forcibly kissed, viewed or touched inappropriately, and raped were experiences reported by women with ID (Chou et al., 2015). Sexual abuse usually happened in public places like institutions, schools, public transportation, and workplaces (Rushbrooke et al., 2014). Vulnerability was one of the considerable concerns mentioned by women with ID or their caregivers (Eastgate et al., 2012). According to Schaafsma et al., (2017) research, women with ID may be more susceptible to various forms of physical and verbal abuse in public settings like schools and institutions. Sex was frequently a very unpleasant experience, according to a literature analysis on the sexual experiences of women with intellectual disabilities. Both women who were having sex and those who were not saw sex as having unavoidable bad outcomes with no pleasure. It was determined that women were frequently prone to abuse due to their gullibility and ignorance of sex and consensual relationships (McCarthy, 2014).

### **Shyness**

One of the major challenges that woman with ID encounter when trying to find a partner and establish an intimate relationship is the feeling of embarrassment. The attribute would affect sexual expression among women with ID. In some studies, participants were shy to discuss about topics like sexual intercourse and sterilization (Chou et al., 2015). In Löfgren and Martenson's (2012) study, one of the participant noted that she never talk to anyone about sexuality and this was a painful problem for her. In addition, some studies indicated that some parents and care givers are shy to provide sexual guidance for women with ID (Azzopardi-Lane and Callus, 2015).

### **Being controlled**

Compared to the general population, people with intellectual disabilities are more likely to have smaller social networks, fewer friends, and less social interaction. Living with parents or other caregivers, needing assistance with daily tasks, and having a disability may limit an individual's ability to form independent relationships, including romantic ones (Van et al., 2015). Women with ID who resided in institutions had to act in accordance with the rules of the facility. Women with ID in Kelly et al., (2009) study noted that their relationships with partners are managed by staff in the institutions and believed they were not trusted to have a healthy romantic relationship. Additionally, in a study by Bjornsdottir et al., (2017) which involved both male and female participants, women appeared to be more tightly controlled by families and staff for sexual activities, fertility, and sterilizations than men.

### **Lack of support to find an intimate partner**

Staff attitudes may have an impact on the independence and opportunity for friendship and relationship-building for persons with intellectual disabilities who depend on caregivers to help them with daily tasks. Their willingness to accept or assist persons with intellectual impairments in their sexual health and relationships may be impacted by their socially conservative values (Grieve et al., 2009). The participants in Stoffelen et al., (2013) study admitted they wanted a partner but had no idea where to look. They require assistance to look for a partner, but their caregivers were unable to give them the right kind of assistance. Participants in the study by Chou et al., (2015) stated that they secretly felt attracted to and had feelings for their male teachers or relatives. In addition, when women with ID did have partners, they had issues in ending an intimate relationship (Stoffelen et al., 2013).

### **Sociocultural barriers**

In institutions or group homes, some participants were forced to conceal their sexual experiences and their consensual sexual contact due to restrictive rules, animosity toward their sexuality, and a lack of privacy. Participants in the study by Berenert et al., (2013) had a poor opinion of sexual activity. They found some sexual acts to be physically painful, and some participants found having sexual relations frequently to be an unpleasant experience. In addition, they were worried about the sexual health problems of their partner. Women with ID were scared of the negative effects of sex, such as unintended pregnancy or STDs. Unwanted pregnancies in sexual intercourse between people with ID were one of the major concerns of families (Maia, 2016).

### **Knowledge and Education**

Lack of knowledge about sexuality can increase exposure to unsafe situations for women with ID (Leutar and Mihokovic, 2007). People with intellectual disabilities have lower levels of sexual knowledge compared with their peers from the general population (Baines et al., 2018). Kassa et al., (2017) reported that there was a lack of adequate knowledge, appropriate practice, and favorable attitude of young persons with disability regarding different reproductive health-related issues. In Eastgate et al., (2008) study, some participants with mild ID had correct information about menses and time of ovulation. Some women with ID did not know how to develop a sexual relationship with men (Frawley and Wilson, 2016). There is a widespread dearth of data on what constitutes successful sexuality education for individuals with ID (Swango -Wilson, 2011). Theoretically, women with ID will be better able to identify and report abuses committed against them if they are educated about fundamental reproductive physiology, communication about sexuality and intimacy, gender differences, and safer sex (Dukes and Mcguire, 2009). It has been suggested that decision-making abilities should be a part of successful sex education for persons with ID, as these adults may not have as many opportunity to practice decision making as their counterparts without disabilities do ((Aunos and Feldman, 2002) and should include practical and person-centered planning (Lumley and scotti, 2001).

One of the major reasons for limited knowledge of sexual health can be attributed to the lack of access to comprehensive sexuality education. Adults with ID may be ignorant of sexuality and sexual health, and they frequently lack formal and informal learning opportunities. Mothers of adolescents with intellectual disabilities talked about fewer sexual topics, started these discussions at a later age, and expressed more concerns about sexual vulnerability than mothers of other adolescents, according to a study that looked at how sexuality and sex education is viewed by mothers of adolescents with intellectual disabilities compared with mothers of adolescents from the general population. Families believed that withholding facts from their adolescent children was in their best interests in order to shield them from potential exploitation (Pownall et al., 2012). Additionally, adults with ID are more likely to get sexual information from questionable sources, such as television (Greenwood and Wilkinson, 2013).

### **Information and Communication**

One of the issues raised by women with ID in the studies included was a lack of information regarding sexuality. Additionally, their access to information on sexual health would be hindered by their lack of literacy and communication abilities like listening, eye contact, and empathy (Eastgate et al., 2011). Through their friends or family, they got their information at random (Kelly et al., 2009). Thompson et al., (2014) found that limited sexual health resources were one of the major barriers to access the needed information among women with ID. Women with ID found it difficult to discuss sexuality-related issues due to speech and cognitive impairments. Social interactions among ID women are impacted by cognitive difficulties. Some women with ID reported that they were not able to express their feelings and sexual needs (Lofgren-Martenson, 2012). Some participants in the included research stated

that women with poorer intellectual functioning had a lesser likelihood of establishing and maintaining an intimate connection (Aderemi, 2014).

### **Discussion**

The aim of this review study was to identify sexual health concerns experienced by women with ID worldwide. The study's findings showed that women with ID have sexual desires and require particular supports in order to engage in healthy sex. Participants in the included studies cited education as a major issue. To increase their understanding of sexual health, they must participate in programs that provide information regarding sexuality. Programs for sexuality education need to be modified to meet the needs of women with ID. Studies show that sex education interventions can have a positive impact on knowledge, self-protection, empowerment, and decision making for women with ID (Ballan and Freyer, 2017). It is significant to note that family members and caregivers can play a significant role in sexual health education. Women with ID frequently lack sexual knowledge, which can result in inappropriate behaviors and raise the risk of sexual abuse (Swango-Wilson, 2011). Some women with ID in the studies under consideration claimed that they were prohibited from taking part in sexual education in schools (Bjornsdottir et al., 2017). Finding an intimate partner is a notable issue mentioned by women with ID in the included studies. According to research women with ID are interested in having romantic connections, but have trouble in expressing their emotions. Lack of confidence, shyness, families' dissatisfaction, and lack of a meeting place were leading factors that affect their relationships. Studies reveal that parents have more conservative attitudes toward sexual activities in women with ID (Chen & MJJoSE, 2011). Cultural restrictions can sometimes make it more difficult for women with ID to access sexual care and increase their unmet sexual health needs (Lafferty et al., 2012). According to studies, parents are more conservative when it comes to the sexual behavior of women with ID (Cuskelly et al., 2004). Participating in supportive and educational programs can encourage positive ways to create wholesome relationships. Families must give women with ID more avenues for emotional expression. Families and policymakers should take into account and respect the thoughts and desires of women with ID. Additionally, researchers need to pay more attention to cultural barriers like prejudice and misunderstandings, particularly in nations with stricter religious laws.

### **Limitations**

The limitations of the study are that women with other disabilities, such as hearing loss, physical impairments, mental disorders, and vision loss, may have different concerns and needs that can be investigated in future studies. This study only addressed the sexual health concerns of women with ID. The concerns about men with ID's sexual health were not covered in our study.

### **Conclusion**

In general, participants with ID mentioned various concerns such as lack of sexual experience, negative experiences, lack of understanding, problem with finding a right partner, lack of access to information, sexual abuse, and limited knowledge of sexual behaviors. The findings

indicate that women with ID need to be provided with school-based sexuality education tailored to the level of understanding needed to attain the requisite knowledge to form relationships, understand sexual and romantic relationships, and practice safe sex when they choose this option. Families along with education and healthcare systems should provide opportunities for women with ID to talk about their sexual needs and make their own choices.

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