

## Correction to: Sexuality and Reproductive Health in Young People with Disability: A Systematic Review of Issues and Challenges

Mathew P. Manoj<sup>1</sup> · M. K. Suja<sup>1</sup>

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This paper that originally published in the December 2017 issue contains judgmental non-professional terminology that does not reflect the standards of the field and of this journal. The journal and its Editor-in-Chief regret that this version gained acceptance and publication as such. A corrected version follows below.

**Abstract** This paper conducts a systematic survey of the problems and challenges faced by young people with disabilities (YPWD) in their sexual lives and in procreation. Some of the challenges, such as relationship difficulties, faced by YPWD are due to inadequate and inaccurate sex education and guidance. To address the challenges faced by YPWD, a noticeable change needs to occur in society, life partners, people in the domestic circle, and significant others. Without accurate information about the real difficulties faced by individuals with disabilities in India, it is not possible to provide pragmatic education and individualized guidance related to sexuality.

**Keywords** Young people with disabilities · Disability · Reproductive health · Sex education · Sexuality · Sexual victimization · India

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✉ Mathew P. Manoj  
phdatamrita@gmail.com

M. K. Suja  
mk\_suja@cb.amrita.edu

<sup>1</sup> Department of Social Work, Amrita Vishwa Vidyapeetham, Amrita University, Coimbatore, Tamil Nadu, India

## Introduction

Adolescence is a decisive period between childhood and adulthood. During this period, many noticeable behavioral and emotional changes can be seen among young people [1]. People with disabilities can face many life challenges, and they have the right to pursue their dreams [2]. However, in some instances, the basic needs and rights of people with disabilities and their social acceptance are not well met. Often, individuals with more severe cognitive and physical disabilities have less opportunity for academic degree achievement, lower rates of sustained full-time competitive employment, and fewer opportunity choices and access for relationships. Furthermore, they can be subjected to social and economic discrimination [3]. Economic instability and difficulty maintaining financial independence can add to life stress and life challenge.

Having a sexual and reproductive life is one of the fundamental rights of all human beings [3]. Even today, many people receive little or no knowledge regarding sex education from school, family, healthcare agencies, or society. Though young people with disabilities (YPWD) have sexual feelings and emotions, there are fewer opportunities to communicate sex education [4]. In some cultures, due to inadequate sex education, YPWD have decreased chance to express their sexual feelings and emotions in what some may consider a productive manner [5]. Physical limitations and social attitudes influence YPWD's ability to express sexual feelings and emotions [1]. Limitations in accessing education and information regarding sexual and reproductive health, combined with attitudes and misconceptions of YPWD, can lead to numerous health and psychological issues. Research historically has mentioned that, for some, YPWD may not be viewed as sexually attractive or having sexual prowess and face problems related to their appearance [6]. Increased awareness and enlightenment, in countries such as the USA, have improved respect for the individual through education about myths and stereotypes, with an increased focus on "ability" and "person contribution."

Some partners of individuals with disabilities report lower levels of sexual satisfaction. In some situations, the feelings of YPWD may be ignored by their family members and healthcare providers. YPWD may fail to express their sexual feelings, emotions, and difficulties if they are not approached with love and openness by their healthcare providers [3]. Even today, especially for those with more severe cognitive impairment, there is a greater risk of being abused, raped, or used for sexual activities due to YPWD's lack of knowledge/awareness and training to resist unwanted sexual contact. Adolescence is a critical stage of development. Without proper guidance and education, YPWD may engage in behaviors without being fully informed about possible consequences, such as unprotected sexual activity which could increase the possibility of contracting sexually transmitted diseases such as HIV/AIDS [7]. Lack of specialized and individualized education and lack of organizations and service providers to address problems can increase, for example, the risk for depression and sexual abuse. There is a clear need for investigation of the challenges and problems faced by YPWD across all disabilities regarding sexual and reproductive health issues and to find solutions to combat mental health and health distress and complications.

## Methods

A systematic review utilized a mixed approach of qualitative and quantitative methods [8, 9]. For this systematic review, we collected papers from various databases and analyzed the

qualitative and quantitative work. The method used in this paper is not restricted to either qualitative or quantitative.

## Search Strategy and Data Extraction

Online databases (PubMed, Springer, Elsevier, Scopus, and Google Scholar) were searched for qualitative and quantitative peer-reviewed papers. While collecting the data, the following criteria were used:

1. Studies related to people with physical/mental disabilities,
2. Studies related to people with physical disabilities and any of the following areas: sexual victimization, sexual violence, sexual activity and reproduction, sex education, sexual negotiation with life partner, and sexually transmitted diseases,
3. Studies which use any research methods/techniques to analyze data,
4. Papers/reports/theses in English.

The authors extracted information regarding sexual and reproductive issues faced by YPWD, factors and barriers experienced by them, and the solutions and suggestions proposed in the study. The authors also collected limitations of each study for future research considerations.

## Data Analysis

The authors organized the collected data into four different themes and analyzed and reviewed the themes in terms of issues related to sexual and reproductive health aspects, causes of sexuality and reproductive health challenges, study findings, solutions and suggestions from the review, category (age and place) of people surveyed in the study, and limitations of the study.

## Results

### Background

In this paper, we compiled a literature review of sexual and reproductive health issues faced by YPWD and solutions and suggestions from different views. The study of sexual and reproductive health issues of YPWD is from the social workers' point of view. Most of the study or analysis in this field is published in disability studies or interdisciplinary journals [10] but does not access direct care providers or YPWD or their families and caregivers. People with disabilities can face many challenges, especially during youth as they enter adulthood. Adolescence is a risky period for people with disabilities because it is a time of expanding independence and responsibility. During this time, many YPWD also experience restrictions in education, employment, and economic opportunities. There are misconceptions in some societies and for some individuals regarding people with disabilities [11, 12]:

1. People with physical and mental disabilities are like children and require total assistance.

2. People with disabilities are asexual, have dangerous sexual behavior, or have uncontrollable sexual feelings and emotions.

Many people with severe disabilities require additional structured support, such as a 24/7 care setting, while others may be able to work utilizing personal strengths and/or compensatory strategies to be fully independent. There is a misconception within some families and in some societies that people with disabilities do not have sexual feelings or emotions, which creates barriers to access to optimal education, knowledge, and opportunities for self-exploration and actualization. Family members and other caretakers may ignore the abilities, expressions, and problems of people with disabilities and assume that they just need food and clothes for a good quality of life. A sexual life is a normal psychological part of human growth, and it is essential to being human, just as sleeping and drinking. Sexuality does impact one's behavior, psychological, physical, and social well-being. Due to myths, some people with disabilities may face barriers to being viewed as socially acceptable partners [13, 14]. They may feel shy or lack confidence to either share or discuss privately their concerns or questions with others [15, 16].

To understand and enjoy sexual activity, all people should have access to factual evidence-based sex education, information, and guidance at a developmentally appropriate age. The complexity of choosing a mate or life partner can be difficult for anyone. Without the personally identified "best" person who is supportive, for example, there can be a breakdown of the relationship ending in divorce [17]. Since the number of people with identified disability is increasing, it is essential to initiate steps to address comprehensively individualized needs.

## Reproductive and Sexual Health in YPWD

Review revealed that limited information is available about the sexual behavior of YPWD across the spectrum of disability and culture. People with disabilities experience more barriers in sexual life and relationships compared to their peers without disability [13]. YPWD require authentic self-confidence to satisfy their sexual needs [18]. Kassa et al. [1] analyzed the sexual and reproductive health status and related factors of YPWD. They conducted a cross-sectional survey in 2012 in Ethiopia among 426 YPWD aged between 10 and 24 years. Their findings indicate that YPWD are sexually active despite a possible misconception from those misinformed that they are asexual and do not have sexual feelings or emotions. Their findings indicate that most YPWD start sexual relationships between 15 and 19 years. Researchers in Ethiopia emphasized the dire need for a social attitudinal change toward the sexual behavior of people with disabilities. They also recommended clear and in-depth research needs as related to sexual and reproductive health-related issues of YPWD. Though their findings are impressive, they are not without limitations. Their study focused only on YPWD living in the capital and did not include YPWD that live in suburban or rural areas of the country.

Kattari [10] used a meta-synthesis approach by analyzing 15 qualitative studies to explore sexual and reproductive health issues of people with disabilities. They found that there are internal and external factors affecting sexual and reproductive health of people with disabilities.

Internal factors include personal knowledge, attitudes, and psychological behavior. Inaccurate knowledge in sexual and reproductive health leads to lack of confidence and lower life satisfaction. External factors affecting the sexual and reproductive health issues of

people with disabilities are education, life partner choice, finance, transportation, fitness, and health service availability. They concluded that internal and external factors contribute to YPWD's difficulty in maintaining a sustained relationship or married life. Their suggestions include:

1. The ability to get accurate information regarding sexual and reproductive issues.
2. Increased accessibility of healthcare service providers.
3. Increased service providers who are willing to understand and discuss more about individual needs and issues, along with the ability to have a more comfortable mutual dialogue.

Kassa et al. [11] conducted a cross-sectional survey in 2012 regarding the sexual and reproductive health issues in YPWD. They collected data using trained interviewers among people aged between 10 and 24 years in Ethiopia. Their study showed that YPWD lack fact-based sexual and reproductive health knowledge, such as sexually transmitted infections like HIV and protection methods. Their study indicates that there is a very urgent need to conduct sex education programs to increase awareness of potential negative health consequences.

Sellwood et al. [19] conducted a systematic review of the experiences of people with profound physical and communication disabilities in developing sexual, social, and intimate relationships. They analyzed and classified data into six categories: social participation, social networks, relationships and sexuality, access to sexual healthcare and support services, body language and image, and sexual activities and dating. Socialization is a key component of a healthy life. The self-esteem of the person plays an important role in maintaining a sexual and healthy relationship. They underline the importance of sex education and the availability of healthcare service providers to ensure resources and support are given as needed. Their work recommended the need to investigate romantic and sexual life related issues. A limitation of their review is that the papers collected were mostly related to Western culture. Their findings may have similarity or lack of similarity to problems faced by people with disabilities in other cultures.

Incedere and Kucuk [20] conducted a cross-sectional study to identify the factors that influence the sexual life of people with the disability of psychiatric illness. They reviewed a sample of 200 people with psychiatric disorders in a university hospital in Turkey. Many people with profound psychiatric disorders face serious sexual and reproductive health-related issues. Their focus was on the type of diseases and treatment directly affecting an individual's sexual life. They concluded that premature marriage and the increasing rate of divorce are adversely affecting the family life of these individuals. Significant portions of people with mental disorders are not aware of sexually transmitted diseases in Turkey. The study strongly recommends sex education and counseling to increase awareness of the dangers of sexually transmitted diseases and unprotected sex. The parents were also aware of the significant need for sex education. Care and attention must be given to people with mental health issues during the period of pregnancy, delivery, and child rearing. They also recommend free access to healthcare professionals and counseling to express their sexual and health concerns. A periodic medical checkup is also suggested. Many participants did not provide responses to the questionnaire, highlighting a need for modification to make the questionnaire more accessible and easier to understand and follow.

Neufeld et al. [12] addressed the sexual needs of people with disabilities. Their findings indicate that the healthcare service providers ensure caring, attentive, and

affectionate care in their approach to YPWD. This is to ensure a life of increased happiness and enjoyment. They also underline the importance of sex education, aimed at learning the basics of a sex life, human growth and anatomy, sexually transmitted diseases, birth control, pregnancy, parenthood, and sexual harassment and abuse.

### **Negotiations with a Life Partner**

Kattari [10] analyzed YPWD's negotiations with a life partner regarding sexuality-related issues. They conducted a study among adults aged between 25 and 50 in a metro city of the southwest United States. Their study emphasized that understanding one's partner is the root of lasting sexual happiness. Some people with disabilities may require additional education and support to optimize these negotiations with a life partner. Their study suggests that one way to support their needs is to give in-depth sex education. Limitations of this study include a smaller sample size and limited age range (excluded people less than 25 years old).

### **Sexual Violation**

People with various disabilities (e.g., severe traumatic brain injury) may be at higher risk of becoming a victim of sexual violence. Sexual violence is categorized in two types: abusive sexual contact, such as kissing/touching and penetration including forced sex, and verbal/abusive non-contact sexual activities, such as exposure to the sexual act, exhibitionism, and harassment [21]. Both types of sexual violence adversely affect the victim mentally, socially, and physically since some may not be able to physically resist. Victims are often subjected to harassment [22].

Alriksson-Schmidt et al. [23] conducted an investigation to find whether adolescent females with disabilities in the USA experience more sexual violation compared to their peers without disability. They applied logistical regression analysis between physical disability and sexual violence in US high school students. They used data from the US National Youth Risk Behavior (2005) survey. The findings indicate that YPWD spend most of their time in schools. Education professionals have a vital role in preventing abuse against people with disability. The survey contained a limited number of variables.

Mueller-Johnson et al. [24] conducted a study and considered three factors:

1. Whether boys and girls with disabilities are at risk of sexual contact and non-contact victimization,
2. Whether YPWD are exposed to higher risks in their domestic circle,
3. Whether being a YPWD is a significant predictor of sexual victimization while taking the other factors (e.g., child maltreatment and harsh parenting) into account.

They conducted the study among adolescents in Switzerland. Their findings suggest that physical disability was a significant predictor of contact and non-contact sexual victimization for boys, but not for girls. Children with disabilities have been thought to be at an increased risk for victimization than those without. However, not all types and all levels of severity of disabilities may be equally connected to victimization.

## Sexually Transmitted Diseases

Unsafe and unplanned sexual behavior can lead to sexually transmitted diseases or unwanted pregnancies [25]. One situation where sexual victimization could occur may be an inpatient psychiatric ward, where one might be exposed to sexual harassment, and having unwanted sexual contact and decreased ability to protect oneself physically [26, 27].

Maart and Jelsma [7] conducted a study to compare the sexual behavior of adolescents with disabilities with those without disabilities, utilizing a cross-sectional sample of people with disabilities in Cape Town, South Africa. A quarter of the adolescents with disabilities were sexually active. They also found that some people with disabilities are at a higher risk of having sexually transmitted diseases since they may not have basic knowledge about sex and sexually transmitted diseases. The parents and other caretakers may assume that YPWD do not require sex education. The limitation of this work is that it focused exclusively on people with physical disability.

McCabe and Holmes [28] conducted a critical ethnographical study to explore the experiences of nurses providing sex education to adolescents with physical disabilities. Their findings highlight a need to build a relationship among nurses, patients, and family members to support the sexual lives of YPWD.

## Analysis and Discussion

The focus of this review is exclusively on the sexual and reproductive health issues and challenges that YPWD face. It also focused on a lack of education that undermines the sexual happiness of YPWD, a frequently ignored population. The opportunity to have a satisfying domestic sexual life is a fundamental right of each and every individual irrespective of gender and physical status.

There are many factors that can influence:

1. Accurate sex education,
2. Support and guidance from family members,
3. Awareness about body development and growth,
4. Awareness about reproduction, pregnancy, birth control, and parenting,
5. The attitude of society toward them—accept them as having the same needs, emotions, and rights,
6. Availability and accessibility of healthcare services,
7. Support and care from life partner,
8. Training and counseling to encourage and build confidence,
9. Awareness about sexually transmitted diseases and abuse,
10. Awareness about the impact of risky sexual behavior.

The attitude of society and its approach play a vital role in the sexual lives of YPWD. A positive and caring approach from society plays a decisive role in determining the sexual happiness of YPWD. Steps must be initiated to ensure a life of sexual harmony for YPWD and to bring them into the mainstream of social life [29]. Parents play a critical role in molding the behavior and attitude of youth and developing in them a feeling of reassurance. To ensure a lasting marital and sexual relationship, a supportive partner on equal

footing is needed to avoid a feeling of inferiority [30], leading to more complete psychological development. In fact, the maximum development of one's talents activates one's creativity, generating a feeling of esteem and pride. Familiarity and training with modern electronic devices may help YPWD from feeling inferior and make them an integral part of social life [31–33].

Since YPWD almost everywhere are found to be unsupported by comprehensive sex education, they are not aware of the dangers of risky sexual behavior. As a result, they are at a higher risk to contract sexually transmitted diseases. YPWD may be unable to resist unwanted sexual advances and can become victims of sexual violence. To prevent such negative experiences, family members of YPWD and social activists must initiate steps accordingly. Establishing positive relationships develops a stable and steady balance of mind, leading to a life of harmony. The review found that though sincere attempts were made to improve the quality of relationships, they are still not free from imperfections. The main imperfection was that most of the researchers focused on YPWD who reside in urban areas, overlooking significant numbers of YPWD in rural areas. Focusing on the development of one particular subsection of a population and ignoring the other parts is troublesome. Due care and attention must be given to YPWD both in the city and rural areas.

## Limitations

Sexuality of YPWD is reviewed in this paper. We analyzed different themes including: sexual violence, sexually transmitted diseases, negotiation with life partner, and sexual and reproductive issues of YPWD. Most of the papers discussed represent the countries of Ethiopia, USA, Switzerland, and South Africa. The papers discussed focus mainly on people from cities. Future directions should broaden the study to people from other parts of the world and also from rural areas. Studies on YPWD living in different conditions and cultural and labor levels should be included in future research. The spectrum of disability across and within conditions requires further delineation and examination to tailor strategic and meaningful education and support as needed.

## Conclusion

There is an abundance of research in the field of disability management. However, meager information is available about the sexual life and reproductive health of people with disabilities. Although researchers initiated the beginning steps, the research may not accurately reflect the experiences of YPWD living in rural areas. Most of the literature focused on the need for sex education, healthcare service providers, the role of parents, and awareness about abuse and risky sexual behavior.

Due to some misconceptions, the form of disability within the context of society, YPWD can often be sidelined from the social mainstream. As a result of inadequate and inaccurate sex education and lack of care and attention from family, society, and healthcare service providers, some YPWD can be subjected to physical harassment and abuse, which has been found to cause adjustment difficulties. There is a need for in-depth research to improve the quality of service with respect to sexual and reproductive health. There is a requirement to increase awareness for YPWD about social media and other communication modalities. Further study is required to understand how modern communication techniques



will help YPWD to improve their quality of life. Further study is also needed to explore new research methodologies to collect social activities and social media data for information collection.

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