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Knowledge among Caregivers on Reproductive Health Issues for Individual with Special Needs in Dhaka City

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Abstract: *This study explores the level of knowledge among caregivers on reproductive health issues concerning individuals with special needs in Dhaka city. Despite being educationally qualified, many caregivers including parents, special educators, and attendants-were found to have only average understanding of key reproductive health topics such as menstruation, puberty, sex education, wet dreams, and hygiene practices. The research, conducted at a special education institute with 157 participants, revealed significant knowledge gaps, misconceptions, and limited awareness about available reproductive health services. A large number of caregivers lacked specialized training, making it difficult to support children especially those with autism or intellectual disabilities who often struggle to express their needs. The findings stress the need for regular training, awareness programs, and accessible health services to equip caregivers with the necessary tools to ensure a healthier, safer, and more supportive environment for individuals with special needs.*

Keywords*: Reproductive Health, Special Needs, Intellectual Disabilities, Menstruation, Autism.*

1.1 Introduction

Reproductive health is an important part of life for everyone but when it comes to individuals with special needs, it's often overlooked. Society tends to see people with intellectual disabilities as asexual, assuming they don't need reproductive health education or care (Haight-Liotta, 1996). As a result, many of their real concerns like managing menstruation, understanding puberty, or learning about healthy relationships go unnoticed or unaddressed (McCarron & Service, 2002). Women with intellectual disabilities, in particular, may struggle to express pain or discomfort during their menstrual cycle, and often rely heavily on caregivers to advocate for them (Walsh, 2002).

Unfortunately, many caregivers are not equipped with enough knowledge to support these needs (Lin et al., 2011). Issues like menstrual hygiene, puberty, or even how to teach basic sex education are often areas of uncertainty. Barriers such as stigma, lack of training, and poor access to services make it even harder (Gans et al., 1993). In Bangladesh, there's very little research on this topic. This study aims to understand how much caregivers in Dhaka know about reproductive health for individuals with special needs and how we can do better to support them.

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1.2 Caregiver

Caregivers are fundamental to the development, daily support, and wellbeing of individuals with special needs, particularly in the context of reproductive health. They often act as the primary source of guidance and support, especially for individuals who may not be able to communicate their needs effectively (Walsh, 2002). According to Lin et al. (2011), caregivers especially those working closely with individuals with intellectual disabilities (ID) need a strong understanding of reproductive health topics, yet studies reveal significant knowledge gaps in areas like menstruation and sex education.

In many instances, caregivers are not adequately trained to manage reproductive health challenges. Although some may be familiar with topics such as menopause or general health services, their understanding of menstrual care, sex education, and even basic reproductive physiology remains limited (Lin et al., 2011). Furthermore, cultural and social taboos make these discussions even more difficult, leaving caregivers unprepared to handle the emotional, physical, and psychological needs of the individuals they support (Haight-Liotta, 1996).

Gans et al. (1993) identify major barriers that caregivers often face when trying to access proper health care for individuals with disabilities: transportation issues, inaccessible medical facilities, unhelpful attitudes among service providers, limited caregiver education, and insufficient health insurance coverage. When these barriers are compounded by a caregiver's limited knowledge, the quality of reproductive health care for individuals with special needs can suffer.

In Bangladesh, caregivers often rely on their personal judgment and experience rather than formal training or institutional support. The lack of structured education for caregivers on reproductive health means that many feel unsure or ill-equipped to address sensitive issues like puberty, wet dreams, or masturbation (Lin et al., 2011; Koller, 2000).

1.3 Reproductive Health Issues

Reproductive health, as defined by the World Health Organization (WHO, as cited in Lin et al., 2011), encompasses the full range of physical, emotional, and social well-being in all matters relating to the reproductive system. It includes the capacity to have a satisfying and safe sex life, the ability to reproduce, and the freedom to decide when and how often to do so. For individuals with intellectual disabilities, reproductive health is equally essential, yet largely ignored in many societies.

Lin et al. (2011) report that while many caregivers are aware of sex education and reproductive health services, they lack a comprehensive understanding of menstruation and puberty, especially when it comes to women with ID. In Taiwan, for example, only 64% of caregivers were aware of menstrual discomfort, and many were unsure how to assist in expressing related symptoms (Lin et al., 2011). Similarly, in a Canadian study, 31.7% of parents sought gynecological advice even before their daughters with developmental disabilities reached menarche, expressing anxiety over future challenges (Kirkham et al., 2013).

According to Dizon et al. (2005), these misconceptions may stem from a lack of discussion and societal discomfort surrounding such topics.

Gans et al. (1993) stress that access to reproductive health care for individuals with disabilities is hindered not by the disabilities themselves, but by systemic ignorance and poor service delivery. This includes limited support from healthcare providers and a lack of tailored resources for caregivers. Moreover, even when caregivers are educated, their reproductive health knowledge is often disconnected from practical caregiving experiences (Lin et al., 2011).

1.4 Individual with Special Needs

Special needs individuals include those with a wide range of disabilities intellectual, physical, developmental, emotional, or behavioral that make learning or daily activities more difficult. These individuals often require unique and ongoing support, especially when navigating complex topics like reproductive health. Unfortunately, societal views often portray people with disabilities as non-sexual, leading to the dangerous assumption that they do not need reproductive education or services (Haight-Liotta, 1996).

Women with ID face even greater challenges in this regard. According to McCarron & Service (2002), many cannot adequately express reproductive discomfort or understand what is happening to their bodies. This leaves them vulnerable to anxiety, fear, or even abuse situations where the caregiver's role becomes critical. Yet, caregivers often lack proper tools and knowledge, especially concerning how to handle menstruation or identify early signs of reproductive health issues (Lin et al., 2011).

Goldstein (1988) and Yaacob et al. (2012) observe that although individuals with special needs such as those with Down syndrome experience menstruation, puberty, and sexual feelings like anyone else, their caregivers are often underprepared. Many parents express fear or depression when anticipating their child's first menstruation and often have no prior discussions with health professionals. More than 90% of caregivers in Yaacob's study welcomed guidance in the form of pamphlets or seminars, indicating a strong demand for support.

Moreover, misconceptions about sexuality in individuals with developmental disabilities persist. Ruble & Dalrymple (1993) and Koller (2000) both note that caregivers often view the sexuality of people with disabilities as problematic or inappropriate. This stigma results in poor education and emotional support for special needs individuals, leaving them more susceptible to abuse, confusion, and isolation.

1.5 Institute of Special Education

Special education institutions are meant to provide a supportive environment tailored to the educational and developmental needs of children with disabilities. In Bangladesh, such institutions are also where many special needs individuals receive a significant portion of their social interaction and daily care. As such, these institutes play a central role in the sexual and reproductive health education of these children but the quality and scope of such education vary widely.

Lin et al. (2011) found that in structured settings such as disability institutions, caregivers who received training were more likely to support reproductive health behaviors among women with ID. These behaviors included monitoring menstrual cycles, offering sex education, and helping individuals express discomfort or distress. Still, many institutions do not have formal policies or training programs in place to support caregivers in these areas.

Institutes often fail to incorporate reproductive health into the curriculum or care plans due to cultural sensitivity or administrative oversight. According to Norjaudah et al. (2012), many caregivers in educational settings also avoid discussing menstruation or sex education unless there is a medical or behavioral crisis. This reactive approach does little to empower special needs individuals with the tools they need for safe, independent living.

1.6 Statement of the Problem

Menstrual and reproductive health issues in women with intellectual disabilities are often overlooked, especially in individuals with conditions like autism, Down syndrome, or cerebral palsy. Topics such as menstrual hygiene, masturbation, wet dreams, and sex education are rarely discussed, even though they're important for healthy development. Caregivers often face real challenges, like managing hygiene or understanding emotional and physical changes, and they worry about things like sexual desire and the risk of abuse. Although reproductive health is a key part of women's public health, it hasn't received enough attention when it comes to those with intellectual disabilities. In Bangladesh, there's very limited research on this subject especially for children with special needs. Compared to other countries, there's a clear knowledge gap. That's why this study aims to explore how much parents and caregivers in our country actually know about reproductive health for individuals with special needs.

1.7 Objectives of the Research

- To assess the level of knowledge among caregivers on reproductive health issues for individual with special needs.

2. Review of Literature

Reproductive health is a vital part of human life, yet for individuals with disabilities-particularly intellectual disabilities it remains largely overlooked. One of the main reasons is the persistent societal belief that persons with disabilities are asexual or do not require reproductive health education and services (Haight-Liotta, 1996). This misperception has contributed to a general lack of awareness and preparedness among caregivers, families, and even healthcare professionals.

Caregivers play a critical role in supporting individuals with intellectual disabilities, especially in navigating physical and emotional changes during adolescence and adulthood. However, studies show that caregivers often feel unequipped to handle reproductive health concerns due to limited knowledge and training. Lin et al. (2011) found that while many caregivers in institutional settings were aware of reproductive health concepts like sex education or menopause, they lacked deeper understanding in practical areas particularly menstruation, masturbation, and emotional changes. This

knowledge gap can leave individuals with disabilities vulnerable to discomfort, confusion, and even health risks.

The emotional burden on caregivers is also highlighted in the literature. Kirkham et al. (2013) reported that many parents, especially mothers of daughters with developmental disabilities, visited gynecologists even before menarche. This proactive but anxious behavior often stemmed from fears about how their child would react or cope with menstruation. Similarly, Norjaudah et al. (2012) found that over half the caregivers of individuals with Down syndrome in Malaysia felt emotionally distressed when thinking about their daughters' first menstrual experience. Many were worried about their daughters' safety, the risk of exploitation, and how they would manage hygiene independently. Despite these concerns, most had never received any guidance or training and were eager for support materials like brochures or educational talks.

Reinforcing the importance of education, Gans et al. (1993) outlined systemic barriers to health care access for people with disabilities. These include transportation difficulties, inaccessible health facilities, negative attitudes among providers, and crucially inadequate knowledge and support for caregivers. These barriers are not just physical but institutional, reflecting a broader neglect of reproductive health in disability care policies.

The review also draws attention to the broader social myths and discomfort surrounding sexuality and disability. According to Koller (2000) and Ruble & Dalrymple (1993), caregivers and even professionals often perceive sexuality in individuals with intellectual or developmental disabilities as inappropriate or problematic. These misconceptions result in limited or no education on healthy sexuality, creating an environment where individuals cannot ask questions, express their needs, or understand boundaries.

Despite the challenges, the literature offers hope. Most caregivers, as seen in multiple studies, are eager to learn. With the right support training programs, school-based resources, and awareness campaigns they can become empowered advocates for the reproductive well-being of those in their care.

3. Methodology

This study used a descriptive cross-sectional design to understand how much caregivers know about reproductive health issues in individuals with special needs. Conducted over four months in 2017, data was collected from 157 caregivers at a special education institute in Dhaka through a semi-structured, interviewer-administered Bangla questionnaire. Participants included parents, special educators, and attendants. Although the calculated sample size was 288, only 157 responses were obtained. Simple random sampling was used to select the institute, and responses were analyzed using SPSS. Ethical approval was secured, and participants gave informed consent before participating in the research.

3.1 Participants

The study population were the caregivers (parents, special educator, class attendants, personal care taker) of children with special needs who take care of the children at home and or at school.

Table 1: Sex of Respondent

Gender	Frequency (n)	Percentage (%)
Female	104	66.2%
Male	53	33.8%
Total	**157**	**100%**

3.2 Study Area

The study area was the institutes of special education for special needs individuals in Dhaka city those who had more than 200 students.

3.3 Sampling Technique

First, the researcher prepared a list of institutes in Dhaka city that have more than 200 students. Four institutes were identified: Proyash Institute of Special Education, Alokito Shishu, Autism Welfare Foundation, and Beautiful Mind. One institute was then selected using a simple random sampling procedure. After selection, data were collected from caregivers who met the inclusion criteria until the desired sample size was achieved.

3.4 Data Collection and Procedure

A pre-tested, interviewer administered, semi-structured questionnaire in Bangla was used for data collection. According to specific objectives, the variables was identified. After necessary corrections and thorough checking of the English questionnaire, it was translated into Bangla. The questionnaire was then pretested on respondents with a similar background who were not included in the study sample. The questionnaire was finalized after necessary modifications. After finalization of research instrument, the respondents received questionnaire and they return the answer sheet after fulfilling it. Purpose and procedure of the study was elaborately explained to each of the respondent.

3.5 Data Analysis

Data was analyzed by the software named Statistical Package for Social Science (SPSS) version 16.0. A five-point liker scale (Excellent, Good, Average, Poor, very poor) was used to explore the overall knowledge on reproductive health of the participants.

4. Results

Study found that minimum age of the participants was 17 years and maximum age was 57 years where 25.5% participants were between 33 to 37 years. Two third of the participants were female that is 66%. Most of them that are 73% of total respondents have completed their graduation. The mean experience of working with special needs individual's was 7.12 years. and 51.6% respondents were special educator or teacher in relation with special needs individuals.

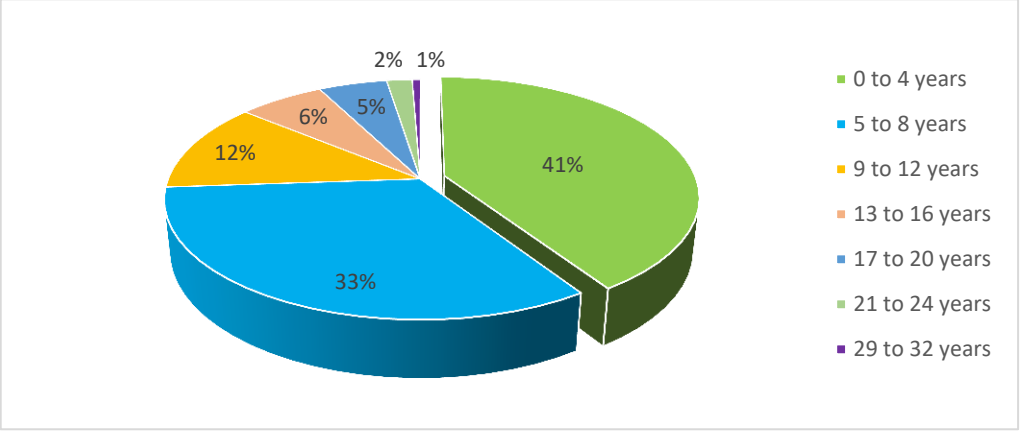

Figure 1: Working Experience with Special Needs Individuals

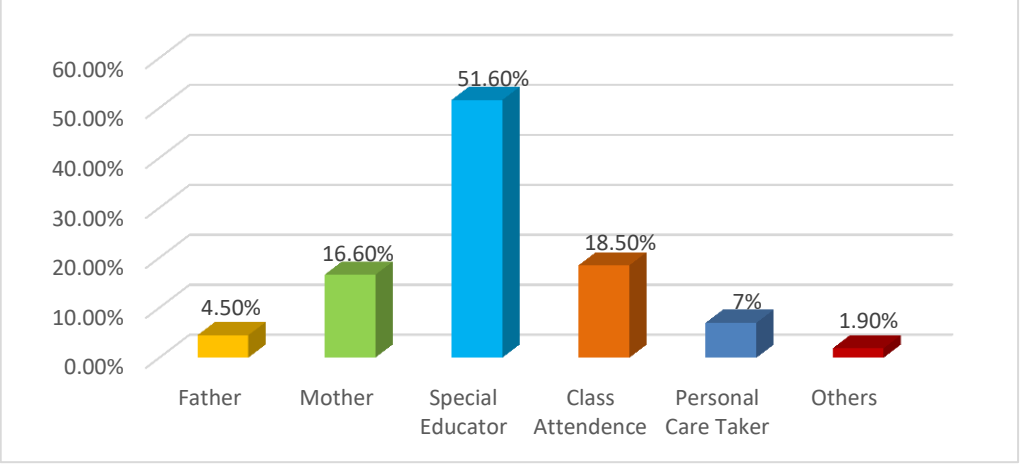

Figure 2: Relation with Special Needs Individuals

40% of total participants have no training to manage special needs individuals and 37.6% manage Autism. 52.6% respondent thinks that reproductive health is sexual health. 40% respondent's opinion was that there is variation between normal and special needs individuals in case of reproductive health. 81.5% indicates lower abdominal pain as premenstrual symptoms.

Table 2: Distribution of Respondent by Knowledge on Reproductive Health Related Events

Option	Frequency	Percentage
Reproductive Health Is (n= 157)		
Women's Health	7	4.5%

Sexual Health	81	52.6%
Health during delivery	41	26.6%
Others	25	16.2%
Reproductive Age for Male (n= 157)		
Puberty to death	34	21.7%
12 to 60 years	19	12.1%
18 to 80 years	18	11.5%
Others	72	45.9%
Reproductive Age for Female (n= 157)		
Puberty to Menopause	27	17.2%
13 to 45 years	37	23.6%
16 to 50 years	22	14%
Others	63	40.1%

92.4% thought some changes occur during menstruation where 96.2% gave opinion that maintaining menstrual hygiene is very important. 17.2% thought that wet dream is a disease and 58% thought wet dream is only a male issue.

Table 3: Distribution of Respondents by Knowledge on Wet Dream

Wet dream a disease (n= 157)		
Option	**Frequency**	**Percentage**
Disease	27	17.2%
Not disease	127	80.9%
Don’t know	03	1.9%
Effects of Wet dream on health (n= 157)		
Harmful	74	47.1%
Not harmful	58	36.9%
Don’t know	25	15.9%
Wet dream only a male issue (n= 157)		
Yes	91	58%
No	42	26.8%
Don’t know	24	15.3%

93.6% respondent's opinion was sex education is very important where 69.4% respondent's opinion was that there is no religious barrier of sex education. 82.8% thought reproductive health service for special needs individual is not available.

Table 4: Distribution of Respondent by Knowledge on Availability and Place of Reproductive Health Services for a Special Needs Individual

Availability of Reproductive Health Services (n= 157)		
Options	**Frequency**	**Percentage**
Available	18	11.5%
Not available	130	82.8%
Not answered	9	5.7%
Where to go for Reproductive health services (n= 157)		
Doctor	39	24.8%
Specialist Doctor	20	12.7%
Hospital	81	51.6%
Family planning center	11	7%
Community clinic	30	19.1%
Others	11	7%
Not answered	12	7.6%

52.9% have overall average knowledge and 25.5% have overall good knowledge on reproductive health.

5. Discussions

This study assessed the level of knowledge among caregivers on reproductive health issues for individuals with special needs in Dhaka city. The majority of respondents demonstrated average knowledge (52.9%), with only 8.9% having excellent knowledge. This finding indicates a substantial knowledge gap, particularly in understanding specific reproductive health events, sex education, and available services for individuals with disabilities.

The observed knowledge gap is consistent with the findings of Lin et al. (2011), who reported that caregivers in Taiwan were generally familiar with broader topics such as sex education and menopause, but lacked adequate understanding of menstruation-related issues among women with intellectual disabilities. Similarly, in the current study, while 96.2% of respondents recognized the importance of menstrual hygiene, a significant proportion had misconceptions about menstrual physiology, with 19.1% unaware of the uterus as the source of menstrual blood.

The present study found that over 80% of caregivers did not believe reproductive health services for special needs individuals were readily available, which aligns with WHO/UNFPA (2009) observations that persons with disabilities often face barriers to reproductive health care due to inaccessible services and societal attitudes. However, the proportion in our study reporting unavailability was higher than in the study by Patage et al. (2015) in rural India, where limited but some localized services were acknowledged. This difference may reflect variations in service delivery systems and urban–rural disparities.

A notable finding is that 93.6% of respondents considered sex education necessary, echoing Kassa et al. (2016) who found strong support for sexual and reproductive health education among young people with disabilities in Ethiopia. However, misconceptions persisted-15.3% equated sex education solely with awareness about sex, and over a quarter did not know the correct definition. This suggests that while caregivers support the idea, content-specific training is lacking.

Knowledge about sexual health problems such as wet dreams and masturbation was mixed. While most respondents correctly identified that these are not diseases, many still perceived them as harmful-similar to the misconceptions highlighted by Ruble and Dalrymple (1993) regarding sexual awareness among persons with autism. Cultural and religious attitudes in Bangladesh may further reinforce these misconceptions, as suggested by the 24.2% of participants who perceived religious barriers to sex education.

When comparing our findings to Norjaudah et al. (2012) in Malaysia, a contrast emerges: in their study, higher educational attainment among caregivers was significantly associated with better knowledge of menstrual care. In the present study, despite more than half of participants holding postgraduate degrees, detailed knowledge in specific areas (e.g., age of menarche, reproductive age limits) remained incomplete. This indicates that formal education alone may not ensure adequate reproductive health literacy without targeted caregiver training.

Overall, the study's findings reinforce existing literature indicating that caregiver awareness is partial and often focused on general rather than specific reproductive health issues. Misconceptions, service inaccessibility, and cultural barriers persist, necessitating structured education programs, caregiver-focused workshops, and integration of reproductive health modules into special education curricula.

Among all the respondent the mean working experience with special needs individuals was 7.12 years and most of the respondent 51.6% (n= 81) was special educator where most of them spend 4 to 8 hour duration with special needs individuals but surprisingly 40% (n=63) participants have no training on management of special needs individuals with different types of disabilities.

According to Lin et al. among 1152 respondents most of them were female which is 89.8% and two third of them were processed college or higher degrees. The average working experience of the participants was 6.62 years and most of them are first line worker such as special educator which was 47.4% and living assistant was 19.8% (Lin et al., 2005).

In this study, 40.1% of respondents believed that there is a variation between typically developing individuals and individuals with special needs in relation to reproductive health. Among them, 28.4% stated that the reason for this variation is that individuals with special needs are unable to express their needs. However, according to Patage et al. (2015), differently abled individuals have the same reproductive and sexual needs as typically developing individuals.

Regarding menstruation, one-third of respondents (32.2%) reported that they believe menstruation begins between the ages of 10 and 12 years, and about half stated that menstruation usually lasts 3 to 5 days. Most participants (80.3%) believed that menstrual blood originates from the uterus, and 73.9% attributed it to normal hormonal events.

Yaacob et al. (2012) reported that 55% of their study participants had attained menarche, with a mean age of 12.18 years. Girls in Malaysia typically attain menarche between the ages of 11 and 13 years. Additionally, 77.3% had regular menstrual cycles, and 59% experienced abdominal discomfort during menstruation. In comparison, in the present study, 81.5% of respondents stated that their child complained of lower abdominal pain during menstruation, and 21.7% reported vomiting tendencies, based on multiple responses.

Most respondents (78.3%) identified AIDS as a sexually transmitted disease (STD), while 37.6% mentioned gonorrhea. In reality, there are more than 20 types of STDs. Among all respondents, 93.6% agreed that sex education is essential for parents and caregivers of individuals with special needs, and 69.4% stated that there is no religious barrier to sex education, whereas 24.2% disagreed.

Kassa et al. (2016) conducted a cross-sectional study in Ethiopia on the sexual and reproductive health (SRH) of young people with disabilities (YPWD), focusing on their knowledge, attitudes, and practices. They found that only 64.6% of YPWD were aware of SRH services. Radio and television were cited as the main sources of information by 62.2% of participants, and 77.9% reported never having discussed SRH topics with their parents.

6. Limitations

According to sample size calculation the calculated sample was 288 but the study was conducted with 157 samples. Respondents were taken from a selected institute so possible selection bias could not be ruled out. There are a few literatures about reproductive health related issues of special needs individuals in the perspective of Bangladesh so it is difficult to compare the study with the other research.

Large scale study should conduct to find out knowledge among the caregivers about reproductive health issues of individuals with special needs which will generalize the actual scenario of Bangladesh. Regular training session should arrange to train or educate every caregiver specially parents about reproductive health. To establish a medical center in every special needs institute for better management and strong referral.

7. Conclusion

In general from the findings of this study we can conclude that caregivers of special needs individuals have average knowledge on reproductive health related events though most of the participants were educationally qualified enough. In this study more than two third of the respondent completed graduation. More than half of the participants worked as special educator other than that more than one third of participants has no special training to manage special needs child which is very important. More than one third of the participants manage autistic so it was very much difficult for them to understand their reproductive health related issues as they can't express properly. Place and accessibility is not convenient to the caregivers to get reproductive health related services for the individuals with special needs. Taking reproductive health care should not concerning issue only for the parents or caregivers, institutional authority can take initiatives to arrange training or workshop to educate caregivers about reproductive health care as well as health camp by expert health professionals.

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