



## EXPLORING MENSTRUAL HEALTH ISSUES IN TEENAGE GIRLS WITH INTELLECTUAL DISABILITIES: A QUALITATIVE APPROACH

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### Abstract

*Menstruation is a challenge for teens with intellectual disability is a complex phenomenon as they are a vulnerable group. Teens with intellectual disabilities face unique menstrual health challenges often experiencing difficulties with self-care, hygiene practices and understanding the menstrual process itself. A sample size of 5 participants. This data was collected from the mother/father/sister of girls in Pakistan. We conducted interviews over the phones and asked them a series of questions. We applied thematic analysis to examine the qualitative data. We focus was on teen with ID in Pakistan. We aimed to explore the strategies that can be effective in supporting teens with ID. The study focuses on identifying ways to improve their mental well-being and enhance their overall quality of life. Proposing supportive interventions tailored to their development and psychological needs.*

**Key words:** Menstrual health, Intellectual disability, Hygiene, Self-care challenges,

### Introduction

After reaching adolescence, all girls experience the natural and significant biological process of menstruation. It signifies the start of a girl's reproductive years and often occurs between the ages of 13 and 19. Menstruation is a normal part of life, but it can cause emotional stress, physical discomfort, and difficulties with personal cleanliness, particularly in the early adolescent years. Most girls are better able to comprehend and cope with these changes when they get menstruation education from their parents, teachers, or health programs. However, the menstrual cycle is more challenging for girls with intellectual disabilities (Chandra-Mouli & Patel, 2017).

Achieving menstrual health entails making sure that all women and girls are aware of the menstrual cycle and have access to resources—such as water, sanitary facilities, and hygiene facilities—that are safe, efficient, and reasonably priced. Research indicates that many girls in low- and middle-

income countries (LMICs) do not have optimal menstrual health, which has a detrimental impact on their educational possibilities, social participation, psychological and physical well-being, and career prospects. According to additional research, girls with intellectual disabilities in LMICs—especially those who are totally dependent on their caregivers—face even more obstacles in obtaining menstruation health (Paul B. Tchounwou).

Parents and other caregivers may frequently experience discomfort as well. According to studies, girls with special needs frequently view their periods as a burden for both them and their caretakers. They were worried about hygiene and pain during the cycle. Additionally, it results in coping with menstrual flow, lack of privacy, and shame. Girls are said to experience worry and bewilderment because of inadequate information. Regardless of management, few ID girls come forward to ask for assistance, even though the menstrual cycle has a substantial influence on them and their caregivers. Most of them said that their daughter's menstrual issues affected their day-to-day activities. (Schwartz, Peter E.).

Menstrual health involves not only hygiene but also their privacy and recognition of their periods, which makes this problem particularly crucial. When it comes to menstruation care, hygiene, and sanitation products, girls with intellectual disabilities are among the most neglected populations in society because they are frequently excluded from health programs and conversations. Their needs are frequently disregarded, and their voices are seldom heard. There are several issues with menstrual health, particularly for girls with ID. We ought to attempt to develop some coping mechanisms for all these difficulties. These girls will be able to lead healthier, more comfortable lives and feel valued and included in society as a result (UNICEF, 2019).

### **Statement of problem**

Teens with intellectual disabilities' menstrual health has received little attention and research. These young girls now face numerous difficulties because of this neglect, such as inadequate education and limited access to menstrual supplies. This not just puts the girls at danger for mental and physical health problems in addition to causing them to feel confused and uncomfortable. The stigma associated with disability and menstruation is sustained by a lack of assistance and knowledge about this subject, which exacerbates the challenges these vulnerable people confront. To improve the menstrual health of teenagers with intellectual disabilities, we must actively and compassionately address this issue.

### **Purpose of Study**

Understanding the issues teenage girls with intellectual disabilities encounter during their menstrual cycle is the aim of this study. This study made recommendations on the challenges they face and how caregivers, educators, and parents can help them more effectively. The study also aims to improve menstrual health education and care for intellectual disability girls, so they can manage their menses safely, comfortably, and with confidence.

### **Significance of study**

The primary goal of this study is to investigate the menstrual patterns of girls with special needs and to assess the impact of menstruation on these girls and their caretakers. It also aims to increase

awareness of menstruation management. It also explains how tough it is for parents to handle their daughters. It also investigated menstrual education programs that emphasized MHM skills among preadolescents with intellectual disabilities.

## Objectives

- 1) To understand the difficulties experienced by teens with intellectual disabilities during menstruation, including self-care, hygiene, and emotional responses, as reported by their caregivers.
- 2) To examine the impact of menstruation on the daily lives and well-being of these teens and the burden on their parents, teachers, and caregivers.
- 3) To identify coping mechanisms, such as routines and visual aids, used by caregivers to manage menstrual health.
- 4) To assess awareness levels of menstrual management and education needs among caregivers of teens with intellectual disabilities.

## Interview questions

1. Can you describe your experience managing your daughter's menstrual health?
2. How do you help her cope with these challenges?
3. What kind of support do you think would be helpful for you and your daughter?
4. What advice would you give to other parents in similar situations?
5. How does your daughter respond to menstruation? Does she experience any emotional or behavioral changes?

## Literature Review

Recent studies highlight significant challenges in menstrual health for adolescents with intellectual disabilities (ID), spanning three major domains: acquisition of menstrual hygiene skills, emotional and behavioral ramifications, and structural/cultural support systems. In skill acquisition, structured interventions prove effective; for instance, Aktas and Oncu (2023) found in a randomized controlled trial that both professional-led and caregiver-led eight-week chaining programs using dolls and modeling significantly improved proficiency, though professionals excelled in complex tasks like pad placement. Similarly, Tsuda et al. (2024) reported gains in napkin changing via dolls, task analysis, and peer involvement, albeit with lingering gaps for those with high support needs three months post-intervention. Early instruction, starting 2-3 years before menarche (ages 9-10) with repeated reinforcement for fine motor and multi-step tasks, combined with caregiver support, emerges as optimal. Emotionally, communication gaps exacerbate behavioral disturbances, such as screaming, self-harm, and volatility, particularly when teens cannot verbalize pain or mood changes (Iranian study cited). Cultural stigma intensifies this; in Nepal, menstrual traditions limit autonomy and heighten abuse risks for those with ID, hearing, or mobility impairments, while in India, families often resort to seclusion, sterilization, or suppression, undermining rights. Structurally, schools and public health lag: Randall's (2024) review notes inconsistent U.S. accommodations

(only 31 states mandate sexual health education), leading to stigma, absenteeism, and low self-efficacy. Caregivers in Iran report shame and lack training, though peer-led programs in Turkey boost hygiene and empowerment via school-parent collaboration. Synthesis reveals reliable short-term skill gains but gaps in self-agency, self-esteem (only one study in Randall, 2024), long-term retention (most follow-ups  $\leq 3$  months), and cultural sensitivity. Future research should prioritize psychological empowerment, scalable long-term tracking, and intersectional approaches. Recommendations include early tailored education with visual aids and reviews; caregiver training for complex routines; peer/school programs with buddy systems; psychosocial support for self-esteem and communication; and policy reforms mandating accessible curricula and funding. In conclusion, holistic strategies—early education, cultural adaptation, caregiver empowerment, peer integration, and sustained follow-up—can enhance menstrual health, autonomy, and quality of life by balancing technical skills.

### Theoretical framework

Health Belief Model: Perceived susceptibility, severity, benefits, and barriers.



### Methodology

This study used qualitative research design, conducting in-depth interviews of 5 caregivers of teens with intellectual disabilities in Pakistan. The participants were recruited from special schools and autistic center. The interviews were transcribed by using thematic analysis.

### Participants

The study included 5 caregivers of teens with intellectual disabilities, comprising mothers, fathers and sisters. They tell us insights challenges faced by girls. They share their experiences and management during menstrual days.

### Participants characteristics

Table 1

*Demographic Characteristics of Participants*

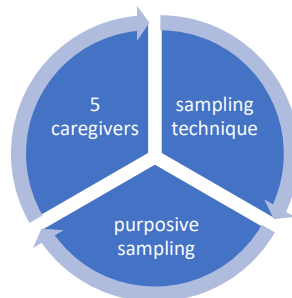
Participant	Relationship with Teens	Age	Profession	Marital Status
Woman	Mother	35	Housewife	Married
Woman	Mother	28	Doctor	Married
Woman	Mother	36	Government Teacher	Married
Man	Father	40	Clerk	Widower
Girl	Sister	23	Student	Single

### Recognition of intellectual disability girls

By using CPM (colored progressive matrix) test and portage guide test we identify that following girls fall under intellectual disability. These tests are mainly used to check the intellectual level of a person.

### Sampling

This study selected 5 caregivers of teens. Purposive sampling was done to collect the sampling of desired participants.



### Care giver responses

#### 1) Mother of a 15-year-old daughter with down syndrome

**Q#1** her mother responded that firstly it is very difficult for me and for her. She started getting her periods, and it hard for her to understand what's happening. She gets anxious to see blood.

**Q#2** firstly she took a deep breath and then said I have tried to explain it to her in simple terms. It is not easy I always developed a routine to help her to feel more comfortable. Sometimes I feel that there are more resources available to help me to support her.

**Q#3** she felt amazed and replied, I need guidance on how to support our children and help them develop good habits. She also says that mother's education on disabled child is more important.

**Q#5** She gets anxious and irritable before her period. We've learned to recognize the signs and try to calm her down.



## 2) Mother of 16 years old daughter with cerebral palsy

**Q#1** firstly her mother introduced herself that she is also a child specialist and daughter is with cerebral palsy. She said she had to develop a routine that works for her taking into account her physical limitation and sensory needs. We use sanitary products that is easy to use. I'll try my best to learn her hygiene.

**Q#2** firstly she took a pause and said we developed a strategy to help her cope with anxiety and stress related to menstruation. Provide her with a calm environment and regulate her emotions.

**Q#4** I would advise parents to be patient and flexible. It's essential to prioritize your child comfort because every child is different. We take care of their emotional well-being. Parents should try different approaches to finding what environment is best for their children.

**Q#5** The biggest challenge is dealing with the emotional changes she experiences. She can get upset and conscious.

## 3) Mother of a 19-year-old daughter with autism

**Q#1** she replied I am a government teacher, and I keep a maid for her. I guide my maid. So, it is very difficult journey for us. We must navigate through trial and error to find what works for her. She's had difficulty understanding her body changes.

**Q#2** she replied we use visual schedules, social stories and provide reassurance when she's anxious. I tried my best to make my daughter feel comfortable during the days. Moreover, I also admitted her to an autistic center. Her therapist also helped me to managing in menstrual days.

**Q#3** The biggest challenge is getting her to communicate her needs effectively. She can't always tell us when she's uncomfortable or in pain. **Q#5** She experiences a lot of physical discomfort during her period, so we've learned to recognize the signs and try to make her more comfortable.

## 4) father of child with level intellectual disability

**Q#1** he firstly told us that her mother passed away at the time of her birth. So as a father I must learn how to communicate with her about menstrual and hygiene. I use simple language and visual aids to help her. Sometimes she gets frustrated and I need to be patient and supportive.

**Q#2** when she is her on periods, she got frustrated. So, I provide calming strategies and make sure she knows it's okay to feel overwhelmed. Moreover, he replied support groups or workshops could provide valuable insights and strategies for parents facing similar challenges.

**Q#3** We use a combination of medication and behavioral strategies to manage her menstrual cycle.

**Q#5** She experiences a lot of physical discomfort during her period, so we've learned to recognize the signs and try to make her more comfortable.

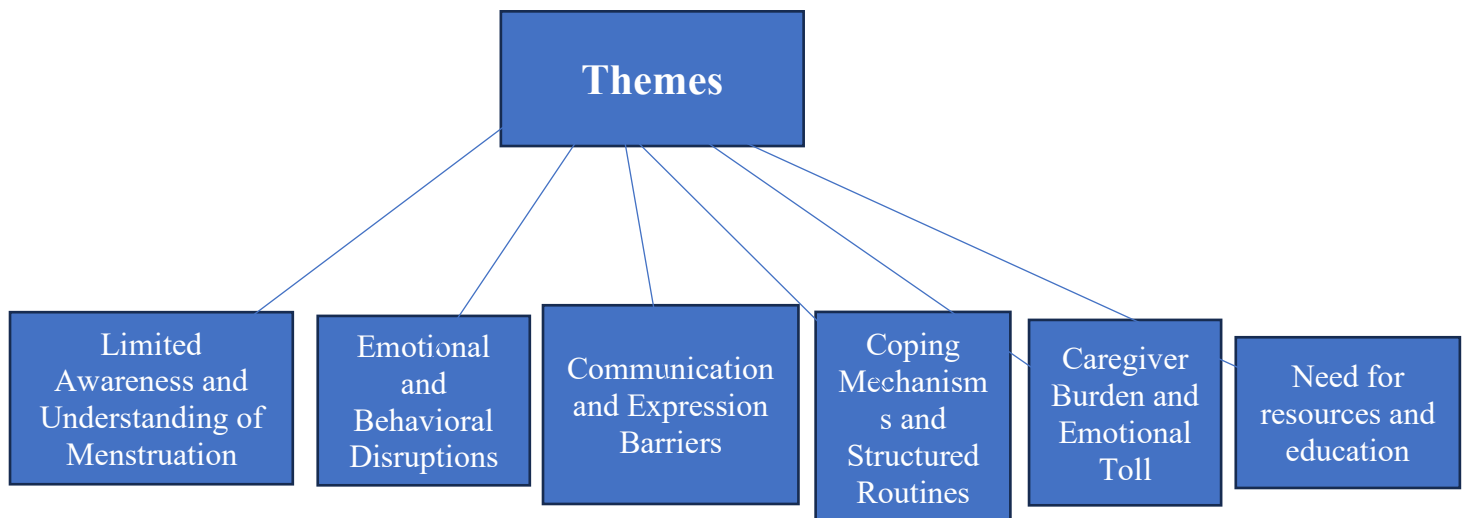
### 5) Sister of 18 years old with ADHA

**Q#1** she told us her father and mother had been divorced. Her father got 2nd marriage and mother passed away. So, I take responsibility for her. She tells us the biggest challenges are managing her impulsivity during her menstrual cycle. Sometimes, she forgot to change her sanitary pads. So, I used reminders and checklists to help her to stay organized.

**Q#2** she took a pause for few seconds and then replied I recognize the signs of premenstrual syndrome. Then I try my best to manage her emotions and behaviors. I develop strategies to learn her hygiene routine and try my best to manage her frustration during these days.

**Q#3** I think more resources and guidance will be helpful. Support groups or online forums could provide valuable insights and strategies for parents facing challenges. Also established a structured routine can help individuals with ADHA manage their menstrual health and reduce stress.

### Themes



### Themes and Subthemes from Caregiver Interviews on Menstrual Health of Teens with Intellectual Disabilities

Theme name	Description	Quotation
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Limited Awareness and Understanding of Menstruation	Teens have little knowledge about menstruation, leading to confusion and fear	“She gets anxious to see blood... she doesn’t understand what’s happening.”
Emotional and Behavioral Disruptions	Mood swings, irritability, anxiety, and distress during menstrual cycle.	“She gets really anxious and irritable before her period.”
Communication and Expression Barriers	Difficulty expressing pain, discomfort, or emotional needs. “She can’t always tell us when she’s uncomfortable or in pain.”	“She can’t always tell us when she’s uncomfortable or in pain.”
Coping Mechanisms and Structured Routines	Use of routines, visual aids, and strategies to manage menstruation.	“We use visual schedules and social stories to prepare her.”
Caregiver Burden and Emotional Toll	Emotional, physical, and psychological strain on caregivers.	“It’s a very difficult journey... we had to find what works
Need for resources and education	Lack of proper guidance, training, and support systems for caregivers.	“Support groups or workshops would really help us.”

### 1. Limited Awareness and Understanding of Menstruation:

Most caregivers shared that the adolescents had very little understanding of menstruation, which often led to fear and confusion during their first period. One mother of a 15-year-old with Down syndrome explained,

*“She gets anxious to see blood... she doesn’t understand what’s happening.”* This lack of awareness made it difficult for teens to recognize bodily changes or maintain proper hygiene.

### 2. Emotional and Behavioral Disruptions:

Caregivers often noticed emotional instability such as irritability, mood swings, and distress during the menstrual cycle. These reactions were often heightened by the adolescents limited ability to manage or express their feelings. As one mother of a 15-year-old with Down syndrome shared, *“She gets really anxious and irritable before her period.”* Another caregiver, the mother of a 16-year-old with cerebral palsy, explained, *“The biggest challenge is handling her emotional changes.”*

### 3. Communication and Expression Barriers:

Many teens struggled to express their physical discomfort, menstrual pain, or emotional needs, leaving caregivers to rely on non-verbal cues or changes in behavior to understand what was wrong. As one mother of a 19-year-old with autism shared, *“She can’t always tell us when she’s uncomfortable or in pain.”* Similarly, a father of a 16-year-old with an intellectual disability explained, *“I have to learn how to talk to her about menstrual hygiene in a way she understands.”*

#### **4. Coping Mechanisms and Structured Routines:**

Caregivers developed adaptive routines and strategies—such as using visual schedules, social stories, and consistent hygiene practices—to help with menstrual management. Many noted that

Support from therapists and educators was especially helpful.

As one of mother of 19-year-old with autism shared, *“We use visual schedules and social stories to prepare her.”* Another mother of a 15-year-old with Down syndrome explained, *“I had to explain everything in simple terms and make a routine for her.”*

#### **5. Caregiver Burden and Emotional Toll:**

Caregivers described the emotional, physical, and practical challenges of supporting a teen with an intellectual disability during menstruation as exhausting and, at times, overwhelming. Many shared feelings of isolation, helplessness, and anxiety. One mother of a 19-year-old with autism reflected, *“It’s a very difficult journey... we had to find what works through trial and error.”* A father of a 16-year-old with an intellectual disability added, *“Sometimes I feel exhausted, but I have to be strong for her.”*

#### **Need for Resources, Education, and Support Systems:**

Caregivers stressed the urgent need for professional guidance, community support, and educational resources specifically designed for menstrual health in the context of disability. As one father of a 16-year-old with an intellectual disability shared, *“Support groups or workshops would really help us.”* Similarly, a mother of a 15-year-old with Down syndrome expressed,

*“I need guidance... mothers should be educated on how to support their daughters”*

#### **Step 1: Familiarization with the Data**

In the first step, we became familiar with the data by asking parents of teens with intellectual disabilities questions over the phone and writing down their responses. We read these notes several times and highlighted important points, repeated experiences, and emotional expressions. This helped us understand the menstrual health experience of these teens from the caregiver’s perspective.

#### **Step 2: Generating initial codes**

Using an open coding approach, key patterns were identified throughout the dataset. The initial codes pointed to several recurring themes, such as

- feelings of confusion and fear surrounding menstruation,
- a limited understanding of bodily changes,

- episodes of emotional distress and anxiety,
- difficulties in expressing needs and concerns,
- reliance on visual tools and structured daily routines,
- consistent involvement of therapists and educators,
- fatigue and emotional pressure experienced by caregivers,
- gaps in both resources and practical knowledge, and
- creative, adaptive methods for managing menstrual hygiene.

Together, these themes capture both the challenges faced and the strategies adopted by caregivers in supporting adolescents through menstrual health management.

### **Step 3: Searching for Themes**

Codes were then grouped into potential themes by identifying conceptual similarities and patterns across participants' accounts. This phase led to the development of preliminary themes that addressed core challenges, strategies, and systemic gaps in menstrual health care for teens with intellectual disabilities.

### **Step 4: Reviewing Themes**

The themes were then reviewed and fine-tuned by comparing them with the entire dataset to ensure they were consistent and made sense. Any themes that overlapped or repeated were merged. This step-by-step process helped create a thematic structure that genuinely represented the real-life experiences of caregivers.

### **Step 5: Defining and Naming Themes**

Each theme was clearly defined to capture the heart of caregivers' experiences and was given a suitable name. Direct quotes from participants were included to bring their voices into the study and add depth and authenticity to the findings.

### **Step 6: Producing the Report**

The final analysis revealed six main themes, each supported by quotes from participants to illustrate and bring their experiences to life.

## **Interpretations of study**

The study sheds light on the menstrual health challenges faced by teens with intellectual disabilities in Pakistan, such as low awareness, difficulties in managing menstruation, behavioral changes, limited access to resources, and the impact of stigma. To address these challenges, it recommends creating menstrual health programs tailored to their needs, providing training for caregivers and healthcare providers, and promoting greater awareness and inclusivity.

## **Findings from the Interviews**



The study identified several key themes highlighting the menstrual health challenges faced by teens with intellectual disabilities in Pakistan:

### **1. Lack of Awareness and Understanding**

Caregivers shared that many teens with intellectual disabilities had a limited understanding of menstruation in its causes, process, and management. This lack of knowledge often resulted in confusion, anxiety, and distress during their menstrual cycles.

### **2. Difficulty in Managing Menstruation**

Products, maintaining proper hygiene, and recognizing the signs of their menstrual cycles, making the process even more overwhelming. Managing menstruation was reported as a major challenge. Teens often struggled with using sanitary.

### **3. Behavioral Changes**

Some teens with intellectual disabilities experienced noticeable behavioral changes during menstruation, including increased irritability, anxiety, or even aggression. Caregivers shared that managing these emotional and behavioral shifts was often difficult and required patience and adaptability.

### **4. Limited Access to Resources**

Caregivers emphasized that limited access to menstrual health resources such as affordable sanitary products, proper education, and accessible healthcare services made menstrual management even more challenging for these teens.

### **5. Stigma and Social Isolation**

In Pakistani culture, menstruation is often surrounded by stigma, which can lead to social isolation and feelings of embarrassment for teens with intellectual disabilities. This lack of openness and acceptance further hindered their ability to seek support and manage menstruation confidently.

## **Conclusion**

The thematic analysis highlights the complex interplay of emotional, cognitive, and systemic factors in managing menstrual health among teens with intellectual disabilities. Caregivers are often under-equipped, under-supported, and emotionally burdened, despite their crucial role. These findings underscore the urgent need for targeted interventions, including caregiver training, inclusive menstrual education, accessible resources, and policy-level support to promote the dignity, hygiene, and health of this marginalized population.

## **Recommendation**



1. Healthcare professionals should provide tailored support and education: Adolescents with intellectual disabilities and their caregivers require individualized support and education on menstrual hygiene management.
2. Visual aids and routines can be effective coping strategies: Using visual aids and creating
3. routines can help adolescents with intellectual disabilities manage menstrual hygiene and reduce anxiety and distress.
4. Caregivers and healthcare professionals should be aware of vulnerability to abuse: Adolescents with intellectual disabilities are more vulnerable to sexual abuse and exploitation, and caregivers and healthcare professionals should take steps to protect these individuals.
5. Further research is needed: Additional research is needed to develop effective interventions for improving menstrual hygiene management in adolescents with intellectual disabilities.

### **Limitations of the Study**

This study provides valuable insights into the menstrual health challenges faced by teens with intellectual disabilities in Pakistan, but it has several limitations that should be acknowledged.

#### **Small sample size:**

With only 5 caregivers interviewed, the findings may not be generalizable to the broader population of teens with intellectual disabilities or their families in Pakistan. A larger, more diverse sample could strengthen the validity and representativeness of the results.

#### **Reliance on caregiver perspectives:**

Data was collected solely from mothers, fathers, and sisters, potentially introducing bias. Caregivers' reports might overlook the teens' direct experiences, emotions, or preferences, as the participants themselves could not provide input due to their disabilities.

#### **Lack of diversity in disabilities:**

The sample included specific conditions like Down syndrome, cerebral palsy, autism, intellectual disability, and ADHD, but did not cover the full spectrum of intellectual disabilities. Findings may not apply uniformly across all types or severities.

#### **Methodological constraints:**

Phone interviews limit depth compared to in-person observations or longitudinal tracking. Thematic analysis, while effective for qualitative data, is subjective and depends on researchers' interpretations without inter-coder reliability checks mentioned.

#### **Geographic and cultural narrowness:**

Focused exclusively on Pakistan (Gujrat, Punjab region), results may not transfer to other cultural, urban/rural, or socioeconomic contexts where menstrual taboos or resource access differ.

#### **Short-term focus:**

The study captures current experiences but lacks follow-up data on long-term outcomes of coping strategies, such as sustained hygiene improvements or emotional well-being. These limitations suggest opportunities for future research, such as larger-scale mixed-methods studies including teen self-reports (where feasible) and intervention trials.

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