



## Challenges and Coping Strategies Adopted for Effective Menstrual Hygiene Management among Adolescents with Intellectual Disability and Their Caregivers: A Qualitative Study

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### ABSTRACT

**Background:** Menstruation is important for female life and reproductive health. The concern for parents or caretakers is how girls with intellectual disabilities (GWID) can have the capacity to handle menarche, menses, and sexual abuse. Therefore, this study explored the challenges and coping strategies adopted for effective menstrual hygiene management among intellectually disabled adolescents and their caregivers in Ghana. **Methods:** This is a cross-sectional qualitative study that involved three school caregivers, seven female intellectually disabled adolescents, and ten home-based caregivers. The study was carried out in the Asokore Mampong Municipality in the Ashanti Region of Ghana. Thematic content analysis was used to analyze the data. **Results:** The study revealed that both home-based and institution-based caregivers and intellectually disabled adolescents experience challenges in dealing with menstrual hygiene. These challenges include intellectually disabled adolescents destroying the unused pads and misusing them. Intellectually disabled adolescents complain of abdominal pain and discomfort during menstruation. **Conclusion:** Caregivers go through challenges when helping intellectually disabled adolescents manage menstruation, which was revealed by the study to be time-consuming. Addressing this issue can begin with training caregivers on the best measures to practice good menstrual hygiene among intellectually disabled adolescents. Motivation (monetary and any other form) should be given to caregivers especially institution-based caregivers to keep up with their work.

**Keywords:** Caregivers, intellectually disabled girls, adolescents, menstruation, menstrual hygiene management

### INTRODUCTION

Menstruation is a symbol of pubertal development that is important for the female's life and her reproductive health (Yaacob, et al.,2012). This stage of life is also experienced by adolescents with disabilities, particularly persons with intellectual disabilities (PWID) (Enoch, et al., 2020). Persons with intellectual disabilities (PWID) are characterized by significant limitations to both cognitive functioning and adaptive behaviour, which are not limited to conceptual issues but also social and practical skills, before attaining age 18 (Wilkinson, et

al., 2008). This implies that PWID, especially girls, may have difficulty with a range of cognitively based tasks, including language, literacy, social judgement, relationships, recreation, work tasks, and self-management (Tracy, et al., 2016).

Menstruation is a common experience, and menarche, the first menstruation, can bring about a lot of responses from these girls with intellectual disabilities (GWID) and their caretakers (Park, et al., 2016). Young girls and their parents or caretakers are sometimes faced with challenges assessing what constitutes a normal menstrual cycle, menstrual irregularities, and missed menses (AAo, 2006). Adolescent girls initially experience irregular cycles, but by the third year of menstruation, the majority of these girls would have their menstrual cycle from 21 to 34 days long (Quint, et al., 2016). It is estimated that about three in every four females of reproductive age experience premenstrual syndrome (PMS), which is usually one to two weeks before the onset of menses (Lobo, et al.,2010).

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However, the tempo and timing of maturation vary since early pubertal development may occur in girls with neurodevelopmental disabilities (Quint, et al., 2016). The early onsets of puberty among GWID may be associated with higher body mass index gain at a younger age, socioeconomic conditions, nutrition, and access to preventive health care (AAO, 2006). GWID can experience more menstrual irregularities due to medical comorbidities and medication adverse effects (Quint, et al., 2016).

Menstrual products have become a major challenge in most developing countries, and girls from less affluent households or societies resort to the use of bark, paper, or cloth to absorb menstrual blood (Winkler & Roaf, 2014). This has, therefore, influenced the means of disposing of the menstrual products, either through burying, burning, or communal trash bins (Hayden, 2012). Menstruation is a natural process of development in females; however, it is an obstruction to health and gender equality in low- and middle-income countries (LMICs) (Sommer, et al., 2016). Most girls in African society are reluctant to openly speak about menstruation since it is seen as a shame and taboo (Schmit, et al., 2017).

Although there is high anxiety among parents or caretakers of girls with intellectual disabilities (ID), studies have revealed that most GWID experience menstruation as a burden due to the associated daily care (Yaacob, et al., 2012). Their parents, nonetheless, become psychosocially worried about how these GWIDs can handle the onset of menarche, existing menstruation, and the increasing risk of sexual abuse (Nurkhairulnisa, et al., 2018; Zacharin, et al., 2010). Therefore, this study seeks to explore and add to the limited literature by bringing to light the challenges and coping strategies adopted for effective menstrual hygiene management among intellectually disabled adolescents and their caregivers in the Asokore Mampong Municipality of Ghana.

## METHODS

### Research participants and sampling

The study employed a qualitative method. The qualitative method helped to explore an in-depth understanding of the experiences of ID adolescents and their caregivers (Fossey, et al., 2002; Creswell, & Poth, 2016; Abodey, et al., 2020). Again, the method enabled the researchers to interact and listen to the challenges and coping strategies adopted for effective menstrual hygiene management among ID adolescents and their caregivers. The approach involves an interpretive understanding of the subjective experiences of ID adolescents and their caregivers. The study was conducted from the 2<sup>nd</sup> of April, 2018 to the 28<sup>th</sup> of April, 2018 at the Garden City Special School in the Asokore Mampong Municipality of the Ahanti region of Ghana. The study purposively selected the municipality due to its geographical position (middle belt of Ghana) and its mixed characteristics of southern and northern Ghana. It is located in the north-eastern part of the Kumasi Metropolis and is bordered by the Kumasi Metropolitan Assembly to the east, south, and west. Kwabre East District to the north-west and Ejisu-Juabeng Municipal Assembly to the north-east (Ghana Statistical Service, 2013). The school was established in April 1977. It is one of the few special schools in Ghana that accepts learners with autism, cerebral palsy, and

other neurological disorders. Currently, the school has approximately two hundred students with intellectual disabilities who are taken through life skills, social, and technical training to become economically independent. The participants recruited were in-school adolescents and three school caregivers with a minimum of two years of working experience in the management of ID adolescents. The school caregivers were people who worked in the selected special school to provide care to the adolescents. The authors focused on this category of the population since little is known about students with disabilities, particularly issues about menstrual hygiene management. The authors employed several steps to recruit the participants. First, the authors extracted the names of all adolescents with ID aged 10–19 years and caregivers with a minimum of three years of working experience. The authors purposively selected participants and invited them through the head of the special school. The invitation contained a letter, a consent form, and a participant information sheet explaining the research purpose, how they were selected, and the risks and benefits of participating in this study. A total of 27 participants were purposively recruited for the study. Of this, 14 were caregivers of the adolescents with ID and 13 adolescents with ID.

### Data collection methods

In-depth interviews (IDIs) were used to collect data from all the participants. The IDIs allowed the research assistants to probe deeply to elicit information from caregivers and adolescents with ID. The in-depth interviews were conducted by two of the research assistants. The data collection instrument was an in-depth interview guide. All the interviews were conducted in two sessions. With the permission of the participants and their caregivers, all the interviews were audio recorded, with each interview session lasting about 45 minutes, often at a saturation point (where no new ideas or issues seemed to arise) (Braun, & Clarke, 2006). The interviews were conducted in the staff common room of the special school. The interviews were mostly conducted on non-school days (e.g., Saturdays and Sundays). All interview sessions lasted for an average of 40 to 60 minutes. Written informed consent was obtained from all participants prior to their participation in the interviews.

### Research instruments

The study used an open-ended interview guide, developed into a thematic section according to study participants. The interview guide covers sections on the socio-demographic background and the extent to which ID adolescents are able to manage good menstrual hygiene. The interview guide used several probing questions and clues that prompted the interviewee's thoughts regarding the subject.

### Inclusion and exclusion criteria

Home-based caregivers with at least one year of experience in the management of ID adolescents' menstruation were included. Also, adolescent females with ID aged 10 to 19 years with moderate to medium intellectual disability, a degree of near independence, and who are already menstruating or have menstruated in the past three (3) months were included. Adolescent females aged 10 to 19 who were neither menstruating nor had menstruated in the last three months before this study were excluded.

### Data analysis

Thematic analysis was used to analyze the data. Thematic analysis is a method for identifying, analyzing, and reporting

patterns within the data (Braun & Clarke, 2006). The thematic analysis helped to provide vivid descriptions and information regarding adolescents' menstrual hygiene. The thematic analysis followed six stages, which include familiarization with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report (Braun & Clarke, 2006). The authors agreed and developed codes. The coding process describes a formal system to organize the data, develop ideas, and provide a thematic description (Braun & Clarke, 2006). The coding was conducted until a saturation point was reached, and the authors reconvened to review and modify the final codebook and also discuss any discrepancies in the coding process. The thematic descriptions were grouped according to global, organizing, basic themes, and codes. The thematic description highlights issues regarding the accessibility of health care to students with disabilities. The organizing themes were supported with verbatim quotes or text from participants.

**Ensuring the trustworthiness of the study**

To ensure the quality of the data, the steps proposed by Lincoln & Guba, (1986) were adhered to (Johnson, et al., 2020). These include credibility, transferability, dependability, and confirmability. Credibility was ensured by the triangulation of data collection participants, whereby both ID adolescents, home caregivers and school caregivers were interviewed. All the interviews were audio-recorded. Field notes were also taken to supplement what was not recorded. The first author also had a prolonged engagement with the participants. Thick explanations of the research methods that include essential details that a reader would need to know in order to understand the results, the use of purposeful sampling that allowed the selection of information-rich participants that met the participation requirements, and the promotion of confidentiality throughout the study period, all of which ensured the transferability of information. We strove to use thick descriptions of findings with supporting quotes and context. Dependability was assured by the use of an emerging design analysis where, in the subsequent data collection and analysis phase, new problems that emerged were considered. The participation of more than one researcher in the study process ensured that data interpretations emerged through triangulation by researchers, which also increased the data source's dependability. All the authors are public health experts with some training in disability research, especially the first author, who was involved in the data collection and supervision. During data collection, a member-checking method was used to satisfy the confirmability criterion, and the outcomes were returned to these participants to check for accuracy and resonance.

**RESULTS**

**Socio-demographic characteristics of respondents**

Table 1 and 2 present results on the socio-demographic characteristics of the caregivers and the ID adolescents respectively. In relation to the caregivers, most of them were aged 40-49 (53.8%), female (91.7%), married (38.5%), had Junior high school education (53.8%), were civil servants (38.5%), and were the mothers of the ID adolescents (see Table 1). With the characteristics of the ID adolescents, most of them were aged 10-14 (57.1%), most of them could bath (57.1%), feed themselves (57.1%) and wash (57.1%).

Coping strategies adopted for effective menstrual management in ID adolescents

The study revealed that caregivers both home-based and institution-based have adopted their own means of dealing with the task. Home-based caregivers (5 out of 7) who were mothers elaborated that they brought forth the ID adolescents; hence, it is their responsibility to ensure good menstrual hygiene in them. All (3) institutional caregivers on the other hand felt it was their job and therefore it is expected of them to discharge their roles effectively.

Table 1: socio-demographic characteristics of Caregivers

Characteristics	f	%
Age		
20-29	1	7.7
30-39	2	15.4
40-49	7	53.8
50-59	2	15.4
60+	1	7.7
Sex		
Male	1	8.3
Female	12	91.7
Marital status		
Single	2	15.3
Married	5	38.5
Divorced	3	23.1
Widow(er)	3	23.1
Education		
No formal Education	1	7.7
Junior High School	7	53.8
Senior High School	3	23.1
Tertiary	2	15.4
Occupation		
Trader	4	30.8
Civil Servant	5	38.5
Unemployed	1	7.7
Student	1	7.7
Others	2	15.3
Relationship with Adolescent		
Father	1	7.7
Mother	4	30.8
Sibling	2	15.3
Aunt	1	7.7
Grandmother	2	15.3
Institutional guardian	3	23.2
Total	13	100.0

Table 2: Socio-demographic characteristics of the ID Adolescents

Characteristics	f	%
Age		
10-14	4	57.1
15-19	3	42.9
Total	7	100.0
Abilities to do Household Chores		
Bathing	4	57.1
Feeding	4	57.1
Washing (utensils, undergarments, etc.)	4	57.1
Sweeping	2	28.6
Toiletry	3	42.9
Dressing oneself	3	42.9
Walking	3	42.9
Undertake simple transactions	1	14.3

### Responses from institutional caregivers

Some school-based caregivers (2 out of the 3) reported that there were certain challenges they encounter during that period. One stated:

“During the period of menstruation, a few cause problems by destroying the pads we give them, also some of them refuse to wear the pads”.

Another responded added:

“The main problem is that, some of them are not conscious of what happens during their menstruation which create a lot of problem especially in washing of soiled clothes. Some of them go to toilet and urinate on top of their menstruation which makes their management very difficult especially in the removal of the soiled sanitary pads”.

This statement confirms an earlier statement made by the first respondent who said:

“Taking care of them is very challenging, it is time consuming because they need supervision every now and then”.

Responses from home-based caregivers

The study revealed that there were some (6 out of 10) home-based caregivers who did not have any difficulties in assisting the ID adolescents to manage her menstruation. They said most of the ID adolescents only need supervision during their menstrual period and nothing else. A respondent stated:

“She can do most of the things herself but we have to supervise her in doing them. She can bath, change herself and do everything herself”.

Another added:

“During her menstruation, she is able to take care of herself completely without needing much assistance from anyone. I don’t encounter any difficulties or challenges during those moments when she is in her period of menstruation”.

However, some (2 out of 10) reported that they encounter difficulties helping their ID adolescent manage their menstruation. One respondent stated:

“I am the only one who does everything for her during her menstruation; I find it a bit challenging since she can’t do anything, sometimes I have to stop going to market to attend to her”.

Another confirmed this claim when she said:

“She cannot manage herself during her menstrual period. It affects me a lot, because I am a teacher and I don’t have much time”.

Responses from ID adolescents

Some (4 out of the 7) ID adolescents complained of abdominal pains and discomfort as their main problems during their period of menstruation. A respondent said:

“When the period finally comes I feel pains in my lower abdomen”.

Another respondent added:

“I become weak, and dizzy and they (caregivers) assist and take me to my bed, I was even hurt the last time when I had my period, I hit my head”.

Another confirmed this claim when she said:

“It is very painful, and I feel pains in my lower abdomen and my waist”.

Also, there were some (2 out of the 7) that reported of certain challenges which were not related to pains during their menstrual periods. A respondent stated:

“It take long before it stops. I do not feel pains or anything when my period comes but I don’t want it to come”.

Another added:

“It comes like a red substance, I don’t like it when it comes”.

### DISCUSSION

Our study revealed that institutional caregivers encounter certain challenges during menstrual hygiene management for ID adolescents, which supports the findings that caregivers go through a lot of difficulties when helping ID adolescents manage menstruation (Atkinson, et al., 2003). Some institutional caregivers in the study reported having major challenges during their ward’s menstruation. These challenges included the ID adolescents’ refusal to wear pads and destroying menstrual pads given to them, which is consistent with the findings of a study in Zimbabwe (Chigunwe, 2021). The level of difficulties a caregiver may experience with regards to ID adolescents behaviour during their period may be associated with the level of impairment the institutional caregiver might be dealing with. This supports the findings of a study in the United Kingdom, where adolescents with autism, unlike their peers with Down syndrome or cerebral palsy, are more likely to demonstrate some abnormalities in their attitudes before and during menstruation (Rodgers & Lipscombe, 2005).

However, most of the home-based caregivers reported not going through these challenges managing the menstruation of their ID adolescents. This finding is consistent with the results of a study conducted in England (Chou & Lu, 2012). This could mean that home-based caregivers have learned to accept or adjust to this work. This agrees with a study in Taiwan where most caregivers have devised their own approaches to deal with the problems brought about by their wards menstruation without much discussion on the topic with others but only relying on information gained from social service workers (Okumoto, 2016).

Since home-based caregivers are largely blood relatives of the ID adolescents, they considered their menstrual management vital to a mother’s or relative’s role within society and may also not be comfortable speaking ill of their ID adolescents (Mason & Cunnungham, 2008). This could be the reason why some of the home-based caregivers reported that their wards were able to manage their own menstruation with little assistance.

On the part of the ID adolescent, one major challenge that was identified had to do with pains experienced during menstruation. The main problems some of the ID adolescents faced during menstruation were abdominal pain and discomfort. It seems that most of them were not concerned with their ability or inability to carry out certain tasks on their own during menstruation but rather with the pains they go through. The lack of concern among ID adolescents in this study about handling their own menstruation can be attributed to the fact that home or institutional caregivers were in-charge and this is consistent with the findings of a study in England (Carlson & Wilson, 1994). However, studies over the years have proven that some ID adolescents are capable of doing certain things on their own, even if not all (Carlson & Wilson, 1994; Chou, et al., 2008). These works revealed the degrees—well, medium, and low—of personal care. The fact that some ID adolescents were able to manage menstruation independently suggests that if proper measures are put in place, we can find better ways of

communicating or educating ID adolescents on how to carry out their own menstrual hygiene practices to some extent.

It is therefore necessary to make readily available information to ensure effective menstrual management for ID adolescents, although the likelihood of their understanding is not certain (Chou, & Lu, 2012). But the fact that some ID adolescents had to rely on their home-based caregivers to provide certain services for them could clearly mean that some ID adolescents, without assistance from others, would have difficulties carrying out certain roles in menstrual management (Carlson & Wilson, 1994).

#### Limitations

This study has certain limitations, despite its contributions. First and foremost, study results are based on single interviews and a cross-sectional sample of respondents.

Second, the study results are limited to carers recruited voluntarily whose wards were menstruating as well as mild ID adolescents. Further studies are required to determine whether these experiences and perceptions are common among caregivers and at other levels of intellectual disability.

#### CONCLUSION

Caregivers go through challenges when helping ID adolescents manage menstruation, which was revealed by the study to be time-consuming. Addressing this issue can begin with training caregivers on the best measures to practice good menstrual hygiene among the ID adolescents in their care. Motivation (monetary and in other forms) should be given to caregivers especially institution-based caregivers to keep up with their work.

#### ABBREVIATIONS USED

GWID: girls with intellectual disabilities;  
ID: intellectually disabled;  
PWIDs: persons with intellectual disabilities;  
LMICs: low- and middle-income countries;  
PMS: Premenstrual syndrome

#### ETHICS APPROVAL AND CONSENT TO PARTICIPATE

Ethical approval was granted by the Committee on Human Research, Publication, and Ethics of the Kwame Nkrumah University of Science and Technology, Ghana (CHRPE-KNUST) with reference number CHRPE/AP/523/18. Participants were informed that participation in the study was entirely voluntary and that they were free to withdraw from the study at any point in time. They were also assured of confidentiality and anonymity, as no information was collected on possible identifiers such as names, telephone numbers, or residential addresses.

#### COMPETING INTERESTS

The authors declare that they have no competing interests.

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#### AUTHORS' CONTRIBUTIONS

Conception and discussion: DO; analysis and/or interpretation of data: DO, BOA, and EKA-A; drafting the manuscript: EKA-A, DO, AS, and BOA; revising the manuscript critically for

important intellectual content; EKA-A, DO, AS, and BOA; all authors have read and approved the final manuscript for submission.

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