



Menstrual Health and Hygiene Management During COVID-19: A Qualitative Study of Adolescent Girls with Intellectual Disability

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Abstract: Adolescent girls with intellectual disabilities (AID) experience high physical and emotional vulnerability during menstruation. Impaired cognitive functions, along with a lack of ability to respond to accepted social behaviour and norms, make menstrual health and hygiene management (MHHM) onerous for them as well as for their caregivers. Based on a purposive sample design, the present study covers 31 adolescent girls with varying IDs in the UT of Chandigarh and intends to enhance understanding through qualitative investigation. The study seeks to examine the conditions and concerns of MHHM among adolescents with ID and their caregivers during COVID-19. It documents the challenges of MHHM while evaluating the impact of the pandemic on AID and their caregivers. Drawing on the experiences of the sample, the study suggests need-based early intervention through training and education to make menstruation a healthy experience for the AID.

Keywords: Adolescents, Caregivers, COVID-19, Intellectual Disability, Menstrual Management

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Introduction

Menstrual Health and Hygiene Management (hereafter MHHM) is the key to reproductive well-being (Panda *et al.*, 2024); it is also considered a significant process for adolescent girls with intellectual disability (AID) in view of the barriers they face (Altundağ and çalbayram, 2016). Their level of cognitive ability and the degree of physical and psychological dependence on caregivers largely determine their capabilities to manage their menstruation efficiently (Tracy *et al.*, 2016). The onus of MHHM of AID lies on caregivers including mothers, siblings, and others when they are involved in

the process. (Nurkhairulnisa *et al.*, 2018). Most intervention programmes and training for AID have an overriding objective: enhancing independence in managing menses while reducing the quantum of burden on carers. The concept of Menstrual Hygiene Management (MHM) among women and adolescent girls is based on the definition given by UNICEF in 2013:

“Women and adolescent girls use a clean material to absorb or collect menstrual blood, and this material can be changed in privacy as often as necessary for the duration of the menstrual period. MHM includes using soap and water for washing the body as required and having access to facilities to dispose of used menstrual management materials.”

Such a lucid, scientific, and practical classification delineating the contours of MHM may seem all-encompassing for menstruators in normal situations or for individuals with no disability, but in emergency or disaster situations, or in the case of AID, this definition of MHM falls short of meeting challenges in adverse conditions. Hence, for dealing with pandemic situations or for focussing on vulnerable girls, such an exposition must include in its framework a module for emergencies as well as for special children. Furthermore, the issue itself is not fully address at academic and policy level (McAllister *et al.*, 2025). Though in the year 2016, UNICEF focused on the term menstrual health and hygiene (MHH) which was a broader as it incorporated in the guidelines, the overall health and wellbeing of women and girls inclusive of menstruators in vulnerable situations by including persons with disability and persons with non-binary identities but it still lacks practical preparation and implementation at the grassroot level. The setback to period protection during the recent COVID-19 pandemic has been a point of reference in the literature without adequate focus on the trajectories of vulnerable sections like girls with ID, who have been the target of intervention in the Sustainable Development Goals (SDG). Against this backdrop, the present study is an attempt to fill the gap in the existing research literature by addressing the dynamics of period protection practices among the AID. The strategy of early intervention based on the ability of information reception, emphasising on awareness and constant practice of AID, would help them to be able to improve their self-efficacy in menstrual management (Tollan *et al.*, 2023). Insufficiency of the above definition of MHM is also reflected in the works of Wilbur *et al.* (2019). She stressed the need for a paradigm shift in approaching MHM by being more inclusive in covering girls with ID.

For an AID, who is already dependent on her caregivers for daily life activities, and is denied or given restrictive information on biological functions, menstruation

brings new challenges (Ramasubramanian *et al.*, 2019). This resonates with the study conducted by Thapa and Sivakami (2017) which brought out that as far as MHHM of AID is concerned, special attention and efforts are required for this vulnerable group. Ibralic *et al.* (2010) asserted that many AID do not have enough knowledge about menstruation. According to Crane (2017) as soon as girls with ID arrive at puberty, MHHM becomes a pivotal concern for the caregivers and, it intensifies due to their dependency on caregivers. Especially, while coping with catastrophic illness like COVID-19 (Moraes Silva Gomes *et al.*, 2023). The present study is based on a qualitative analysis of 31 adolescent girls with mild and moderate intellectual disability in Chandigarh for assessing their knowledge, awareness, practices on MHHM during COVID-19 pandemic. Further, the paper assesses the various challenges and coping strategies faced by them and their caregivers in attaining personal and menstrual health and hygiene status.

Objective

The primary objective of the study is to explore and analyse the pattern of menstrual health and hygiene management practices among AID in Chandigarh during pandemic, in a diverse socio-economic and demographic context setting.

Area, Data and Methods

The present study was conducted in the Union Territory of Chandigarh. Chandigarh is an advanced, modern, and planned city with the entire population living in an urban area. The city has one of the best infrastructures relating to the provision of education, health, and other services. According to National Family Health Survey-5 (NFHS), the city ranks high (86.7%) in female literacy. Chandigarh also remains at the top of the Indian *Sustainable Development Goals Index* (SDG), 2020-21 (NITI Aayog, 2021). Chandigarh has the highest share of wealthiest households among the states and UTs. The media exposure (use of the internet, newspaper or magazine, and television) of women in the city is one of the highest in the country as per the National Family Health Survey (NFHS 5), (IIPS, 2022). The city also reports the lowest incidence (0.8%) of teenage motherhood according to NFHS 5. NFHS 5 also indicates that Chandigarh has the maximum share of the population in the country living in the wealthiest households. A recent assessment of menstrual health and hygiene practices shows that most females (age 15-24) adopt hygienic methods (95%) according to NFHS 5. To be specific, 73 per cent of the females' use sanitary napkins, 24 per cent of them use locally prepared

pads and eleven per cent of the females adopt cloth as menstrual absorbent. In such backdrop, it is rewarding to examine the MHHM practices among AID, in Chandigarh. The natural corollary of such higher socio-economic development in Chandigarh would be to see, to what extent, the benefits have filtered down to the AID, in terms of menstrual health and hygiene practices pre and post COVID-19. Moreover, as no study has been conducted on this topic in Chandigarh earlier, the present exercise is expected to add to the understanding of MHHM practices in such a vulnerable and marginalized group.

The study adopted a qualitative research approach based on empirical data. The respondents were selected through convenient sampling both outside special schools and, in the community, after obtaining verbal consent from the caregivers. The data from AID was collected between August 2022- January 2023. Girls with mild and moderate intellectual disability were selected for the study as they better span of attention and comprehension in comparison with AID with severe and profound intellectual disability. Therefore, to select the sample for the study, 73 girls with ID were approached for data collection. Out of them, eleven girls with ID were not adolescents— three were below the age of nine years, and eight were above the age of 19 years. Whereas, three adolescent girls had not experienced menarche, at the time of data collection. Further, five girls were identified with profound intellectual disability, whereas, seven girls were recognized as having a severe level of intellectual disability. Four girls with ID were verbally challenged therefore; they were excluded from the sample. The caregivers of six girls with ID refused to give their consent on behalf of their daughters, whereas, two AID expressed their unwillingness to participate in the study and, four respondents withdrew from the study during data collection. Thus, the data was collected from 31 (ranging from 13-19 years) adolescent menstruating girls with varying intellectual disability, in the Union Territory of Chandigarh.

All the identified respondents (31) with intellectual disability, have been certified by the registered and authorized practitioner, as mild (20 respondents) and moderate (11 respondents), by established government institutes of Chandigarh such as the Government Rehabilitation Institute of Intellectual Disabilities (GRIID) and, Post Graduate Institute of Medical Education and Research (PGIMER). Out of the total identified AID (31), six respondents had down syndrome, four respondents reported epilepsy, and three had a learning disability as an associated condition. Since none of the respondents was aware of their level of intellectual disability and associated condition, thus, their caregivers were contacted for this purpose. A schedule was prepared to

conduct personal interviews with AID, to understand, issues faced by them and their coping strategies while experiencing periods, during COVID-19 pandemic. The schedule was kept short, simple, and direct. Considering the susceptibility of AID to give in-depth account of their experiences, their caregivers were approached for the details. However, answers procured from AID were included, to maintain the authenticity of the responses and to achieve the objective of the study. Verbal informed consent was obtained from the primary caregivers or mothers, before approaching their daughters with ID for interview. The girls with ID were interviewed in their homes, under the supervision of their caregiver. Interviews were conducted in the absence of male members, as most respondents had inhibitions about taking on menstruation in presence of male members. The average time of the interview conducted with AID varied between 30 to 45 minutes on an average. After coding and entering data in the excel sheet, data were tabulated and analysed by keeping the objectives of the study in primary focus.

Table 1: Socio-Economic and Demographic Characteristics of Selected Adolescent Girls, Chandigarh

| <i>Demographic characteristics</i> | <i>Variables</i> | <i>Percentage share in total</i> | <i>Sample size (N)</i> |
|------------------------------------|----------------------|----------------------------------|------------------------|
| Current age (in years) | | | |
| | 13 | 9.7 | 3 |
| | 14 | 16.1 | 5 |
| | 15 | 16.1 | 5 |
| | 16 | 22.6 | 7 |
| | 17 | 19.3 | 6 |
| | 18 | 9.7 | 3 |
| | 19 | 6.4 | 2 |
| Caste | | | |
| | General | 61.3 | 19 |
| | Schedule caste | 29.0 | 9 |
| | Other backward caste | 9.7 | 3 |
| Religion | | | |
| | Hindu | 87.1 | 27 |
| | Others | 12.9 | 4 |
| Level of disability | | | |
| | Mild | 64.5 | 20 |
| | Moderate | 35.5 | 11 |
| Associated condition | | | |

| <i>Demographic characteristics</i> | <i>Variables</i> | <i>Percentage share in total</i> | <i>Sample size (N)</i> |
|---|---------------------|----------------------------------|------------------------|
| | Down syndrome | 19.3 | 6 |
| | Epilepsy | 12.9 | 4 |
| | Learning disability | 9.7 | 3 |
| Enrolment | | | |
| | School going | 80.6 | 25 |
| | Non-school going | 19.3 | 6 |
| School type | | | |
| | Government | 80.0 | 20 |
| | Private | 20.0 | 5 |
| Place of residence | | | |
| | Urban | 61.3 | 19 |
| | Rural | 25.8 | 8 |
| | Slum | 12.9 | 4 |
| Annual household income (in Rs.) | | | |
| | 1,00,000- 1,99,999 | 19.3 | 6 |
| | 2,00,000- 2,99,999 | 35.5 | 11 |
| | 3,00,000- 3,99,999 | 22.6 | 7 |
| | 4,00,000- 4,99,999 | 6.4 | 2 |
| | 5,00,000- 5,99,999 | 3.2 | 1 |
| | 6,00,000- 7,99,999 | 12.9 | 4 |

Source: Field Survey 2022-23

Table 2: Socio-economic, Demographic and Health Profile of Selected Adolescent Girls, Chandigarh

| <i>Name of the adolescents (pseudonym)</i> | <i>Current age (in completed years)</i> | <i>ID type</i> | <i>Associated condition</i> | <i>School type</i> | <i>Place of residence</i> | <i>Annual household income (in Rs.)</i> |
|--|---|----------------|-----------------------------|--------------------|---------------------------|---|
| Anju | 14 | Mild | Down syndrome | Govt. | Urban | 2,22,000 |
| Ahana | 15 | Moderate | Learning disability | NS | Rural | 1,20,000 |
| Bina | 13 | Moderate | None | NS | Rural | 1,80,000 |
| Bobby | 15 | Mild | None | Govt. | Urban | 2,60,000 |
| Fiza | 16 | Mild | Learning disability | Govt. | Slum | 1,68,000 |
| Gazal | 17 | Mild | Down syndrome | Govt. | Urban | 2,28,000 |
| Girija | 16 | Moderate | ASD | Govt. | Urban | 2,40,000 |
| Honey | 19 | Mild | None | Govt. | Urban | 3,18,000 |
| Jeevan | 17 | Mild | None | Govt. | Urban | 5.40,000 |
| Komal | 14 | Mild | Down syndrome | Govt. | Urban | 2,12,000 |
| Lucky | 16 | Mild | None | Govt. | Urban | 2,80,000 |

| Name of the adolescents (pseudonym) | Current age (in completed years) | ID type | Associated condition | School type | Place of residence | Annual household income (in Rs.) |
|-------------------------------------|----------------------------------|----------|-----------------------|-------------|--------------------|----------------------------------|
| Mukti | 14 | Mild | None | Govt. | Slum | 1,80,000 |
| Neelam | 18 | Moderate | Epilepsy | NS | Rural | 1,20,000 |
| Nikki | 16 | Mild | None | Govt. | Rural | 2,40,000 |
| Nina | 13 | Mild | Physically challenged | Govt. | Rural | 3,00,000 |
| Pakhi | 18 | Mild | Microcephaly | Private | Urban | 7,08,000 |
| Parkash | 16 | Moderate | ASD | NS | Rural | 4,80,000 |
| Pooran | 15 | Mild | None | Govt. | Rural | 2,16,000 |
| Rajni | 13 | Moderate | Down syndrome | Govt. | Urban | 3,20,000 |
| Sanjh | 17 | Moderate | None | Govt. | Slum | 3,64,000 |
| Shama | 18 | Mild | Locomotor disability | Private | Urban | 2,40,000 |
| Shikhar | 16 | Moderate | None | NS | Rural | 2,77,000 |
| Shina | 14 | Moderate | Epilepsy | NS | Slum | 1,44,000 |
| Simran | 17 | Moderate | None | Govt. | Urban | 3,33,000 |
| Sita | 15 | Mild | None | Private | Urban | 2,40,000 |
| Simmi | 17 | Mild | Learning disability | Govt. | Urban | 3,76,000 |
| Tijinder | 15 | Mild | Epilepsy | Private | Urban | 6,00,000 |
| Vanika | 14 | Moderate | Verbally challenged | Private | Urban | 7,20,000 |
| Vardha | 19 | Mild | None | Govt. | Urban | 3,20,000 |
| Yami | 17 | Mild | Epilepsy | Govt. | Urban | 4,80,000 |
| Yashika | 16 | Mild | None | Private | Urban | 7,20,000 |

Note: ASD indicates autism spectrum disorder, and NS indicates non-school-going.

Source: Field Survey 2022-23

Limitations

The results of the study are to be interpreted against the backdrop of the sensitivity of the topic, the lower incidence of ID among adolescents in the city, the unwillingness of mothers or caregivers to participate in the interview, the lack of trust in outsiders, and the limited concentration of AID, constricted the sample to a large extent.

Results

Menstrual Health and Hygiene Management and Related Concerns

A large number of respondents were aware of menstruation. However, when asked “At what age did you start having periods?”, the majority of AID stated that they were neither informed about it prior to menarche nor could recall the exact age at menarche.

While discussing the beginning of the menstrual cycle, some girls shared that due to a lack of awareness about the process, they were confused and did not inform anyone about the onset of menstruation. For instance, one of the respondents stated:

“I was scared when I saw blood on my panty, I thought if I told my mother, she would scold me because it was red and dirty. It had a foul smell too.”

Most AID affirmed that, having experienced their first period, they learned about it from their mothers. This is evident from the views of a respondent who stated:

“My mother noticed blood on my clothes, and then she washed my clothes and said that this happens to all the girls.”

The study reveals that even after experiencing menstruation several times, most of the respondents are still unable to keep track of the menstrual cycle in terms of sensation and duration. Either the caregivers keep track of the periods, or AID are informed by the caregivers if they get their clothes stained. Only a few respondents were able to figure out that they were getting their periods. This is clear from the statement of a respondent:

“When I go to the washroom and see my panty stained, only then do I get to know about the arrival of periods.”

The other girl added:

“When I feel sticky, I check my clothes; then I come to know about it.”

More than half of the respondents with ID were unable to clearly count the number of days their period continued. Instead, during discussion, they provided a random number—ranging from 2-6 days—which did not match with the information gathered from their caregivers. It is pertinent to mention here that the above narratives have been given by girls with mild ID. Most of those with moderate ID, replied that they were not able to figure out the arrival of menstruation on their own, rendering them entirely dependent on their mothers and sisters. Later in the study, the tendency to avoid performing physical activities (walking, dancing, running, and exercising) during menstruation also appeared among almost half of the respondents. They said that such activities would lead to excessive loss of blood, tiredness, and weakness in the body and increase the chance of getting stained, as instructed by their mothers to them. For most of the AID, menstruation is not a normal process. Some consider it a disease and a cumbersome process to manage. One girl stated, *“ye bimari hoti he”*. More than two third of them, find it dirty and stinky as blood releases from the vaginal area. Less than

one third of the total respondents feel that menstruation is an important phenomenon as it clears the 'stomach' and flushes the dirty blood out of the body. One of the AID stated that:

"Periods should not stop because the stomach gets cleansed."

Furthermore, slightly more than two-thirds of the respondents said that they bleed periodically from the vaginal area, stating, '*niche se*', toilet '*wali jagah se*'. None of them was aware of the organ from which the menstrual blood was released. Some girls said that it comes from the stomach, whereas slightly more than half of them labelled the urinary tract as the path of menstrual blood. Few respondents (all moderate) did not even recognize body organs such as the vaginal area, gluteal region, and thighs, especially reproductive organs. They only touch those organs if they feel any sensation (pain, itching, irritability, etc.) or want to complain about it. The difference in knowledge and understanding of menstruation among mild and moderate girls with an intellectual disability is discernible. Girls with mild ID are found to be much more aware and vocal about periods. However, being vocal about it sometimes becomes an issue of embarrassment for the family in public when adolescent girls start discussing their periods abruptly, especially in front of male members. However, a few mothers stated that their daughters do not discuss the issue publicly if clearly instructed. The mother of one respondent shared that:

"During her first encounter with menstruation, my daughter revealed about her periods to our neighbour, then I told her to never discuss them with anyone apart from me. Though I told her that she could inform her teacher if she menstruates in school."

The study further analysed the effect of menstrual management on the routine of girls with ID. Most of the AID are enrolled in educational institutes, both in government and private schools in Chandigarh. The study found that more than half of them avoid attending school during menstruation. They usually stay at home for one to five days; however, the case varies from person to person. Some girls described that physical discomfort, fear of getting stains on clothes, and mothers' wish for their daughters to have a comfortable period were the major reasons they missed school. A few respondents revealed that their teachers asked them to stay at home as school benches get stained. A respondent with an ID stated:

"My teacher advised me to stay at home during periods because my clothes and benches get dirty in school and I cannot manage it."

When asked about the use of absorbents, the majority of AID confirmed that they use sanitary napkins. A few mothers, however, said that they make their daughters use cloth. According to them, due to their poor financial status, they cannot afford to buy sanitary pads often. A responding mother explained that:

“The use of cloth as a menstrual absorbent saves money. I use cloth during periods many times, so I also make her use the same.”

A respondent mother of a girl with moderate ID voiced that her daughter uses ‘diaper’ during periods, which she calls ‘Patti’ means tape. Some respondents use both sanitary napkins and cloth to soak up menstrual blood. The study further avows that slightly more than three-fourths of the AID are unable to place absorbents on their own and, are dependent on their mothers. The majority of the AID are either dependent on their mother or sister, or both, for the disposal of used absorbents. Study divulges that some girls with ID, do not wear panties even during periods. They are incompetent to use a menstrual absorbent, and in such conditions, get stains on clothes quite often. Nearly half of them reported that they avoid taking baths during periods. They do not clean their vaginal area while bathing and also do not change their underwear daily. Thus, data illustrates that AID are not only dependent on their caregivers for managing menstrual health and hygiene but they follow poor hygiene practices leading to poor menstrual health status. In addition to this, the psychological effects of menstruation on AID are also noticeable. Many female respondents complained about pain, mood swings, and sleep-related issues. Most of them reported ‘anger’ and ‘irritability’ as dominant feelings. A respondent talked about her mood swings:

“I don’t feel like doing anything and want to sleep the whole day.”

The irregularity of menstruation also appeared as a challenge among one-fourth of the girl respondents. The above data confirms that menstruation brings many issues and challenges to AID. It is observed that independent and healthy menstrual management rests on self-regulating menstrual health and hygiene practices and training on maintaining personal hygiene.

Effects of COVID-19

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The Availability of Basic Resources

In the present study, most of the caregivers disclosed that all brands of sanitary napkins as well as other absorbents were available in their vicinity in Chandigarh. Some caregivers stated that they stocked the sanitary pads, as soon as the lockdown was declared. They further added that even in lockdown, all the grocery shops and medical shops were open, so there seemed no need to stockpile sanitary pads. However, some caregivers had difficulty in changing their daughter’s absorbent in home due to the presence of all the members and all the time, especially when the entire family resided in one-bedroom accommodation. Sometimes girls with ID and their mothers had to wait till an appropriate place was available to them to change the absorbent. This was reflected in the discomfort of a girl:

“I tell my brother and my father to leave the room for a while; I need to change my clothes. Sometimes they immediately go out of the room and sometimes I have to wait.”

The above statement was also confirmed by her mother. Mothers of other respondents, from a lower economic background, also had similar views. As a larger share of the respondents resided in urban areas, living in small houses or in one-room accommodation was a common. Lack of private space—to change absorbent—continued to trouble these families, along with the need to share common toilet, especially in urban slums.

Exposure to Internet and Increased Screen Time

Those AID, living in better conditions did not experience above mentioned issues, however, they were also not free from problems completely. The sudden break in regular activities induced stress among persons with ID (Courtenay and Perera, 2020). Similarly, the present study shows that immobility during the lockdown triggered the mood swings of respondent girls, especially during menstruation. Data revealed that

slightly less than half of the respondents with ID, experienced increased restlessness during lockdown. One AID experienced a similar issue, she mentioned about her family in a statement that:

“They did not let me go anywhere. They kept saying that you will catch corona if you go outside. I got so bored of sitting at home all the time. I am annoyed with everyone.”

Further, physical proximity, due to the presence of all the members in the house during the lockdown, has also impacted interpersonal family relationships. Some respondents established cordial relations within the family, while, others reported a little stressful environment at home. Above all, there were issues that family members were unwilling to mention in front of their children. However, they were unaware of the fact that children have been getting exposed to such things inside the family itself. It got revealed in a statement of a respondent girl, while discussing about her menstrual hygiene practices, when she suddenly started talking about her parents’ private life. It was disturbing and embarrassing for both AID and her caregivers. Study observed that in order to get them engrossed in some activity, parents often give AID access to the mobile phones. As a result, it increased the screen time and, exposure to inappropriate internet content. One respondents’ mother had similar concerns as she explained:

“I noticed my daughter, as I peeped inside her room one day when she was sitting alone, watching some inappropriate content on the internet. I told her politely that such things are not meant for good kids. I did not give her a mobile for the next two days but then she became very furious and out of control. She was screaming badly out of anger. Then her father gave her mobile phone.”

Thus, parents were apprehensive that AID should not get exposed to any sort of sexual content as it would affect their innocent mind, behaviour as well as their mental health.

Low Immunity among Girls with ID

An important aspect of health that most caregivers were concerned of, during COVID-19, was their daughters’ low immunity. More than half of the respondents’ caregivers were afraid of the weak immune system of their daughters with ID. Caregivers strongly believed that only social distancing and frequent hand-wash was the solution to deal with the corona virus. Some of the them were strictly following the routine of giving their daughters, *kadha*, *giloy*, *haldi* milk, *tulsi*, and lemon juice. Those who could afford, also gave them fresh fruits like papaya, kiwi and seasonal fruits, to improve their

immunity. Few caregivers held the view that due to the warm nature of some ingredients in *kadha*, their daughters experienced a heavy flow of menstrual blood.

Effect of Pandemic on Daily Diet

The impact on nutritional diet was also inevitable during pandemic. More than half of the households of girls with ID have reported income less than Rs. 25,000/- per month (see table 2). Some of them reported that the only earning member of their family, either worked in the private sector or was self-employed. Lockdown affected their daily income, resulting in a cut down in daily expenses. Spending a limited amount on groceries and; cooking only once or twice a day, for the smooth running of the household tremendously affected the nutritional diet. When one of the respondents was asked about healthy diet consumption during the lockdown, she replied, “*I like to eat puri everyday*” On this, her mother said that:

“She is very fond of Puri, she wants to eat puri every day. Even during the lockdown, she had been asking for puri. Since my husband lost his job during the lockdown, how is it possible to make food of every person’s choice?”

In order to deal with sudden financial crisis, families of a few respondents borrowed money from relatives and friends, and further experienced stress and anxiety in repaying the loan.

Health Seeking Behaviour of Caregivers

Study further explains that most of the caregivers depend on traditional way of treatment and, home remedies for their daughters with ID, not only to build immunity but also for menstruation related issues. The study showed menstrual irregularity appeared as a challenge in around one fourth of girls with ID. Caregivers of respondents who experienced irregularity of periods believe more in homeopathy treatment. According to them, it is good for their daughter as these medicines have no side effects on them. A respondent’s mother stated:

“At first, we took her to a private doctor and then a gynaecologist. We spent so much money, but her periods were still not regular even after a year. Then on somebody’s suggestion, we consulted a homeopathy doctor. After taking homeopathy medicines for three months her periods are finally regular.”

Another respondent while narrating about menstrual irregularity, discussed a critical issue, she said:

“I went to the doctor regarding my period problem as I get periods after three months.”

She further added:

“My mother wants to stop my periods but the doctor said that it is not possible.”

The above narrative emphasizes caregivers’ concern towards menstrual health, and sexual vulnerability of their daughters. Menstrual suppression provides relief to the caregivers from the risk of unwanted pregnancy, and also from the burden of responsibility. Moreover, caregivers’ unavailability in the later years of the life of AID, make them feel much more responsible and burdened in the present time. Therefore, caregivers consider such strategies to ease and secure the life of their daughter with ID. As far as COVID-19 vaccination for AID is concerned, caregivers held different views. One respondent with ID (moderate) has not been vaccinated, due to the fear of side effects like sudden depression, mental breakdown, or cardiac arrest. According to the caregiver, there is no evidence of the effects of vaccines on people with ID. A mother of AID narrated:

“I am advised by many people including neighbours and relatives that I my daughter should not be vaccinated, considering her mental health status. I too agree with them.”

Therefore, lack of confidence on part of caregivers also appeared on vaccinating respondents with ID.

Challenges of the Primary Caregivers During Lockdown

The study, establishes that the COVID-19 has been challenging for the mothers as the primary caregivers of the AID. Lockdown has not only burdened them with household chores, it intensified their workload for taking special care of their daughters with ID. According to a few mothers, prior to the lockdown, they would send their daughters with ID to schools, and get some time for themselves. During lockdown, all the members were at home which not only increased their work hours but also often made them feel tired and overworked. Though they tried to get their daughters involved in studies during online classes. But girls with ID (mostly moderate) were usually not able to understand the online lessons. They were also not willing to do daily work assignments given by the school. This further acted as their daily challenge. Additionally, some caregivers reported their inability to get their daughters attend online classes, due to a lack of resources such as mobile phone or laptop. A mother explained that her husband passed away before

lockdown in a road accident. She has four children to look after including. All children have online classes but they have only two android phones at home. They are unable to buy another phone. Therefore, children attend classes alternatively. She added:

“Since my daughter with ID has the least requirement, I sometimes ask her to skip her classes and give phone to other children. I try to involve her to help me with household chores. She will anyway learn something by doing so.”

On asking if it would affect her daughter’s learning, mother replied:

“What can I do? I cannot afford to buy four mobiles, one for each child. After my husband’s demise, I run a small grocery shop. It is not possible to raise a big family these days. Corona has destroyed everything.”

Another caregiver also resounded similar; she told:

“My son lives separately with his wife. My husband and I have been looking after our daughter with our limited income. My daughter studies in a private school. But in lockdown, I was unable to pay the fee every month, even when children were not going to school. They were attending only online classes. So, I contacted my daughter’s school teacher to waive the fee for two-three months, due to my inability to pay.”

The above narratives describe that COVID-19 has not only affected the menstrual management of AID but it has also put a physical, psychological, financial burden on primary caregivers as well as other members of the family.

Discussion

It is pertinent to mention here that COVID-19, has a profound effect on menstrual Health and hygiene practices and management of AID. The study brought out that often for AID, menstruation is an unwelcoming and baffling experience, as they need extra care and are dependent on others, even for own life-skill activities. As both menstruation and intellectual disability are stigmatized, AID are doubly marginalized. Further, due to health issues, co-morbidities and lack of understanding about personal hygiene and management, the vulnerability of AID intensifies during turbulent times of pandemic. Moreover, the dearth of private space, washrooms, and hygienic menstrual absorbents specially for girls in lower income group add to the challenges faced by AID and their caregivers. Needless to say, the lack of appropriate training among AID on MHHM is *prima facie* responsible for over-dependence on caregivers. Further, the culture of silence acts as a major contributor to the lack of training on MHHM among the AID. As the caregivers apprehend that their daughters with ID might not be fully aware of the

consequences of the information on MHM, they fear that they may share the information with others which may enhance their vulnerability in terms of exposure to risks like sexual assaults. When both the parents of AID work for living, they are compelled to leave their daughters alone for some hours by locking them inside the room when they go out for work. If they think that their neighbours are aware about their daughter's presence inside the house, they worry about their daughters' safety till they return. Such apprehensions and fear continue till the daughters are married off. On one hand, caregivers are extremely protective of their daughters with ID that they even avoid to discuss about menstruation with them (they feel that girls will learn about menstrual management gradually, as they grow). Whereas, on the other hand, they do not want to surrender the idea of getting their daughters married. For some caregivers, marriage is considered as an ultimate goal, whereas, for others it is an arrangement of a permanent shelter for their daughters with ID. Therefore, few caregivers of AID (moderate) trained them daily life skills such as cooking, making tea, serving food, washing dishes, attending guests etc. instead of classroom assignments during COVID-19.

Furthermore, some AID demonstrated better understanding, in comparison to those respondents, whose mothers consider the menstrual management of their daughters an additional responsibility or burden. Girls with moderate ID were found more dependent on their caregivers. Their dependency ranged from pad placement to replacement, inability to understand when periods occur, and lack of training to handle blood stains (i.e., check often and wash or change clothes, if stained). The study further correlates poor menstrual hygiene practices during COVID-19, with the lower-economic status. More AID, from economically weaker households experienced the above-mentioned challenges as compared to those from the high-income group. The study investigates limited participation in social activities and impact on physical mobility, intensified dysmenorrhoea, and mood swings during the COVID-19 lockdown. This, along with menstrual management, impacted various dimensions of life like, inability to socialise with peers due to lockdown, change in the routine life through disruption in daily activities—restriction on outdoor sports as well as recreational activities and face-to-face interaction. The increased level of stress due to the sudden change in routine and monotonous home quarantine schedule heightened irritability and mood swings among AID. Whereas, low immunity, low nutrition, lack of learning, and excessive screen time, are some of the common concerns reported by the caregivers.

The present study affirms the availability of all the menstrual absorbents in the city during COVID-19. However, the inability to buy the menstrual products, unavailability

of space to change absorbents—due to the presence of family members and lack of training on menstrual management were the key concerns. The study emphasises that the absence of knowledge on menstrual management among AID, accentuates the patriarchal setup of the society, where having an open dialogue on menstruation is stigmatized and considered shameful. Moreover, in view of menstruation, an environment is constructed within, and outside the family, where shyness is highly significant, stain brings shame and defamation, discussion is stigmatised, and the dependent menstruating girl is considered dirty as well as a liability. Additionally, the quality of life of mothers as caregivers is also emphasised. The caregivers experienced more stress and workload like increased working hours but less division of labour at home. Loss of income with additional financial burden affected the mental health of the caregivers. Further, health-seeking behaviour of caregivers is also featured, concerning menstrual health issues. They preferred homeopathy, ayurvedic, and home remedies over allopathic treatment for issues related to menstruation.

Conclusion

The study assesses the impact of COVID-19 on the menstrual hygiene practices of AID and their caregivers. It further investigates the changes in the respondents' lifestyle during pandemic and their coping strategies to encounter such challenges. The study observes that the inappropriate knowledge and lack of training on MHHM among AID, make them dependent on their caregivers not only physically but also psychologically. Whereas, AID, whose parents imparted training on social skills, responses to emergency situations and menstrual management, encountered fewer challenges. Thus, the study is suggestive of need-based early intervention and training on life skills among AID, both at home and school level. This will enhance their holistic development by enabling them to effectively deal with the challenges under ever changing circumstances.

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