



Dilemmas Being Encountered by Primary Caregivers in Handling the Hygiene of Menstruating Girls with Intellectual Disability (ID): An Exploratory Study

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ABSTRACT

This study explored the challenges faced by primary caregivers in managing the hygiene of menstruating girls with Intellectual Disability (ID) in Lucknow, India. Utilizing an exploratory research design, individual interviews were conducted with caregivers at special schools, employing a self-prepared Menstrual Hygiene Questionnaire for Girls with ID to ensure confidentiality and provide necessary language support. Findings indicated that girls with mild to moderate ID were trainable, leading to manageable dilemmas for caregivers. However, the study identifies a gap in understanding the experiences of caregivers of girls with severe and profound ID, warranting further research. It underscores the significance of family dynamics and advocates for the development of support programs to aid caregivers. Additionally, the study calls for increased awareness of the unique challenges faced by these caregivers and the implementation of tailored educational programs to address their specific needs effectively.

Keywords: Intellectual Disability, menstruation, primary caregivers, dilemmas, self-prepared questionnaire

INTRODUCTION

Females generally start menstruating between from 10 to 14 years of age and continue till menopause at around 51 years of age. Many females during this period, have mild-to-severe experiences like lower back pain, bloating, sore breast, food craving, abdominal cramp, mood swings, irritability, headache, and fatigue. Females also have pre-menstrual syndrome (PMS) – a group of physical-emotional symptoms that start 6 or 7 days before the onset of the periods. Young girls learn to identify and deal with these symptoms but if they have medical conditions like Intellectual Disability (ID) then the menstrual management and hygiene becomes a tedious job, especially for the primary care-giver. The process of comprehending, learning, and implementing the necessary skills for the management becomes a formidable challenge thereby amplifying the role of caregivers and the associated complexities.

Intellectual Disability (ID), in accordance with the criteria outlined in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), is characterized by developmental-onset deficits in both intellectual and adaptive functioning. These deficits encompass domains like social, conceptual, and practical skills, including reasoning, problem-solving, thinking, social responsibility, and communication, within community and home settings. Individuals affected by Intellectual Disability (ID) encounter challenges in managing their day-to-day activities. For females, an additional dimension arises with the management of menstrual hygiene, presenting a distinctive set of difficulties. ICD-11 (International Classification of Diseases), refers to Intellectual Disability (ID) as Mental Retardation characterized by incomplete development of the mind.

Conditions Girls with Intellectual Disability (ID) face when they are Menstruating

Adolescent girls with intellectual disabilities commonly experience menarche concurrently with their typically developing counterparts and often navigate through this phase similarly (Nurkhairulnisa et al., 2018). According to the DSM-5, females with Intellectual Disability (ID) encounter specific cognitive challenges in relation to menstruation (Tracy et al., 2016), encompassing:

- Grasping the concepts and skills essential for menstruation, including reasoning.
- Understanding the social aspects and skills associated with menstruation.
- Addressing the practical implications and acquiring necessary skills.

Many females with intellectual disabilities may require an extended period to acquire the skills necessary for the proper maintenance and management of menstruation. Absence of these skills may manifest in various ways, such as soiled clothing, improper placement of pads, divulging information without regard to time and place, and reactions from their surroundings. Behavioural changes, including manifestations like dysmenorrhea and premenstrual syndrome, may also be observed. Menstruation signifies the onset of sexual maturity, necessitating education for typical young women on sexual activities, relationships, and contraceptives. It is crucial to recognize the vulnerability of girls with Intellectual Disability (ID) in this context.

Dilemmas being Encountered by Parents/Primary Caregivers

Caregivers in this aspect face other sets of challenges as well in the management of the menstrual hygiene of girl with Intellectual Disability (ID). To begin with, the anxiety of the caregiver increases when the girl child reaches puberty which is directly proportionate to the severity of the disability (Zacharin, et al., 2009). They reported facing difficulty teaching the girl with ID periods etiquette being (Márquez-González, et al, 2018) not only difficult but it requires for more time and patience of the caregiver to educate or train the girl child (Carmine, Fisher, 2022).

Rationale

The rationale for this research is rooted in the understanding that managing menstruation of girls with ID is a significant challenge for primary caregivers, primarily due to societal taboos (Carmine, Fisher, 2022) and difficulties in accessing appropriate products and information (Rana, 2022). These challenges are likely to be amplified for girls with intellectual disabilities, who may have additional difficulties in expressing their needs and coping with the physical and emotional aspects of menstruation. Moreover, caregivers also play a crucial role in helping girls manage their menstrual cycles, yet they face their own set of challenges. Previous studies have explored the experiences of these adolescents and their caregivers, revealing a complex interplay of factors that can affect the well-being of both the parties (Thapa, et al., 2017; Karthikayini, Arun, 2021) However, there is a gap in understanding how these challenges are addressed on both physical and emotional levels by caregivers and families. This research aims to fill this gap by exploring how caregivers manage menstruation for girls with intellectual disabilities.

Objective

To study the dilemmas being encountered by primary caregivers in handling the hygiene of menstruating girls with Intellectual Disability (ID).

Hypothesis

Caregivers would face dilemmas while managing the hygiene of menstruating girls with Intellectual Disability (ID).

METHOD

Sample

The sample consisted of one caregiver for each of the 11 menstruating girls diagnosed with (ID) through purposive sampling. Data was collected using the self-prepared questionnaire (Menstrual Hygiene Questionnaire for Girls with ID) with inclusion criteria being that the informant should be the primary caregiver of the menstruating Girls with Intellectual Disability (GID).

TOOL

For the present research work, the authors developed a questionnaire having 39 open-ended questions divided into four domains of Emotional Reaction (ER), Physical Care (PC), Menstrual Hygiene (MS), and Family Support (FS).

The first domain of Emotional Reaction (ER), comprises of 9 items exploring the emotional responses of primary caregivers due to the birth of the child with intellectual disability. The second domain of Physical Care (PC), consists of 7 items exploring physical needs during periods for the menstruating girl with ID. The third domain of Menstrual Hygiene (MH) featuring 16 items explores the dilemmas faced by primary caregivers

while managing the conditions of girls with ID during menstruation. The fourth and final domain of Family Support (FS) consisting of 7 items, explores the behaviour of family members towards the menstrual conditions of the girl. The questionnaire (in the Appendix) has been named, “Menstrual Hygiene Questionnaire for Girls with ID”.

Research Design

Exploratory research design was used wherein the sample population consisted of primary caregivers of Menstruating Girls with Intellectual Disability (GID).

Procedure

The researchers approached special schools to contact the caregivers within Lucknow city, Uttar Pradesh, India. Purpose of the study was first explained to the school authorities who took the consent from the primary caregivers. Then, the researchers met the caregivers in the school premises to collect the data. Respondents were met individually and were given sufficient time to ponder over each question. Wherever needed, the questions were explained in Hindi to them. They were assured about the confidentiality of the information thus collected.

RESULT AND DISCUSSION

Emotional Reaction (ER)

Considering the patriarchy and stigma involved over the birth of a girl child (Salim, 2004) and contrary to these prejudices (Nagesh and Vohra, 2020), the primary caregivers in the present study reported they were happy with the birth of the girl child and felt good about it. Most caregivers were able to identify the problem within the first three years of age, one noticed it at the age of 5 years, and another one at 8 years of age. The diagnosis was mostly under one year except few within the age range of 3-5 years of age and one at around 12 years. All of the caregivers reported being disappointed, sad and shocked about the diagnosis except one who gave a supportive reaction. The father's reactions varied from shocking to, supportive to, managing to, angry to normal. These reactions are supported by the study done by Baral-Levy and Paryente (2023). All of the family members' reactions were normal except two who reported the child not being liked and feeling sorry for her. The child is taken to family functions by all of the respondents even when she's on her periods except one who doesn't when she's on her periods. Two of the respondents reported the family being supportive by one and ignorant by the other towards the child getting her periods. Every other respondent reported the reaction to be normal. The social events are well managed by taking the child along even when she's on her periods. The family being on the continuum of reactions, from one end supportive, to midway being ignorant can be due to menarche still being a taboo in eastern culture (Garg and Anand, 2015).

Physical Care (PC)

The participants were either approached at special schools or at vocational training centers so the level of the ID was either mild or moderate (Boat and Wu, et al., 2015). Out of 8 girls, 7 of them began menstruating between the age of 13 - 15 years.

One girl began menstruating at 12 years old and has had only 2 cycles of period till now and her mother as the guardian is managing it. One child's menarche was delayed via medication to come at the age of 10-11. Ages of the girls at which they started menstruating were normal (Elisabeth, et al., 2016) from 12-15. One of the child's doctor informed to delay the menarche as the child was suspected to get them at the age of 9. Medication was used to delay the onset to 11-12 years of age. This was due to the suggestion that it was too early for the caregiver to start with this responsibility and it was medical advice coming from a professional, the caregiver accepted it. As per the level of ID, the training to manage the etiquettes related to menstrual care has performed well for the participants. Almost all the girls are able to manage everything by themselves now because they started their menarche years ago and are now well trained in it. Except one which is 13 and started menstruating two months ago, her caretaker is still doing it. As menstruation is an experienced process for all the participants (mothers), management and training were easily done (Chou and Lu, 2012). This could be due to resources and information available for the caregivers. The opinion on periods was that it is a natural and necessary process. All of the mothers had the view that menstruation is a normal process and has nothing to do with the mental condition of the child. These views bring a positivism in this research as it contradicts the long-standing shame females faced for menstruation. (Mohammad, et al., 2020)

Menstrual Hygiene (MH)

All the respondents and girls were using sanitary napkins only one respondent was providing the girl with period panty. This shows the availability of resources and management (Thapa and Sivakami, 2017). All the girls were comfortable using it and knew how to use it except two whose mothers still put it for them. The girls are able to keep the pad from 3-8 hours with one exception of the child removing it after half an hour. All of them reported the period flow to be from moderate to heavy. All the girls were having none to some menstrual issues such as cramps and PMSing and mostly all caretakers reported to be handling it through talking and

explaining. Only one of them resorts to medical aid and another uses products such as v-wash to maintain menstrual hygiene. Almost half of them spoil their clothes. Except for one, all of them never thought of stopping menstrual bleeding but all of them did nothing. As they all consider it to be a natural and necessary process. It can be due to a lack of information and understanding as well as one caregiver hinted at the risks of the aid (Memarian A, Mehrpisheh, 2015). It is also an issue in middle-income countries which might be another reason for the lack of knowledge and acceptance (Chou and Lu, 2015; Márquez-González 2018). In some countries such as US the person with developmental disabilities who are unable to give consent may be sterilized only by court order. (Rights of persons with disabilities, California, US)

Family Support (FS)

The data reflected affection was expressed through simple means of hugging, pampering, etc. one reported it to be done through playful teasing and bickering with the child. Families are attentive towards the child's needs. Quality time is spent through talking, vacationing, playing and helping the child with homework. From one mentioning that nobody ever does it to most of them reporting whenever the child is being irritable and shouting, some thoughtless remarks have been made towards her. One respondent shared an incident where the child was affected by the thoughtless remarks. After the primary caregiver, the child's father and for one, her aunt takes care of the child. Mostly families try to make the child understand her mistake and let it go, one of them said that they sometimes reprimand the child. The child is very well appreciated for things she does well, sometimes they take her out, praise her and reward her for her actions.

DISCUSSION

In the quest to study the dilemmas being encountered by primary caregivers in handling the hygiene of menstruating girls with Intellectual Disability (ID) the researchers found novel results in the emotional reactions of the primary caregivers and the family of the child. This research added family support as an important aspect in the aid or management of menstrual hygiene which understood how the extended family acted as a supplement in this struggle. Some results were contrary to the previous researches while some were similar. Researchers concluded that the efficacy of management of menstrual hygiene was up to standard. The ideology regarding periods even though positive yet leaves a hint of regressiveness by not considering the medical aid (like hysterectomy) towards the cessation of menstrual cycle. Overall, the study was able to conclude positive results towards menstruation and its efficient management of hygiene with a lack of awareness of, misinformation about and fear from, the ways of discontinuation of this otherwise considered natural phenomenon.

Conclusion:

This investigation revealed that, girls with mild and moderate levels of ID, are trainable and hence the dilemmas here were of manageable level. This result warrants further replication of this study on the girls with severe and profound level of ID. The study also paves a way to consider the role of family and the aid/liability they become especially in these cases. The data was collected from a small sample size. The study was conducted on the primary caregivers of girls with only mild and moderate levels of ID from NGOs and special schools.

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