

Challenges Faced by Primary Caretakers of Adolescent Girls with Intellectual Disability during their Menstrual Cycle in Puducherry: A Mixed Method Study

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Abstract

Background: Adolescents with Intellectually Disability (ID) compared to their normal peers face greater challenges at menarche due to their caregiver dependence for their day-to-day personal care activities. **Objective:** The objective of the study was to know the sociodemographic characteristics of adolescent girls with ID and to explore the challenges faced by their primary caretakers during their menstrual cycle in Puducherry. **Subjects and Methods:** The study was conducted among primary caretaker of adolescent girls with ID from December 2018 to May 2019. The study adopted quantitative method to capture sociodemographic details among 73 primary caretakers of adolescent with ID who attained menarche and In-Depth Interview (IDI) was conducted to explore the challenges faced by primary caretakers. The caretakers of adolescents were selected using purposive sampling and conventional content analysis was followed for data analysis. **Results:** We discovered that 80.9% of adolescent with ID were not able to manage their menstruation of their own. Primary caretakers who were interviewed were mostly mother's 67.1%. Due to caretaker's dependency, 94.5% of the adolescent with ID were not going to school during their menstrual cycle. **Conclusions:** Majority of the caretakers faced problems such as rejection of sanitary napkins and inability to recognize about the start of period by their adolescents with ID.

Keywords: Adolescents, intellectually disability, menstrual hygiene

INTRODUCTION

The World Health Organization defines adolescence between 10 and 19 years of age.^[1] Menarche causes anxiety, depression, and other psychological disturbances.^[2] Intellectual Disability (ID) is significant impairment in cognitive and adaptive behavior. The term "Mental Retardation" has been replaced with ID by Diagnostic and Statistical Manual 5th Revision in 2013 and in 11th Revision of International Classification of Disease.^[3,4]

Caregivers of adolescents with severe cognitive disorders are concerned about their daughter's capability in handling menstruation.^[5,6] Even after teaching the techniques for managing menstruation to the adolescents, most of the caregivers claims that it is not helpful and very frustrating.^[7,8] Menstrual Hygiene Management by Ministry of Drinking Water and Sanitation, Government of India does not include differently abled children.^[9] Hence, we explored primary caretaker's challenges in managing menstruation of their

adolescent girl with ID, for creating framework for individuals with ID.

SUBJECTS AND METHODS

This cross-sectional study involves both quantitative and qualitative methods which were conducted during December 2018 to May 2019. The study was conducted among primary caretakers of adolescent girls with ID who attained menarche by universal sampling method. Those eligible individuals whom the investigators fail to meet to interview even after

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making two visits were excluded from the study. There are five to six educational institutions for ID children in Puducherry. Of those, one institution had four branches in urban area and three branches in rural area of Puducherry which was selected as our study area. That educational institution caters around 800 ID children of those 108 were adolescent girl with ID. For qualitative component, In-Depth Interview was conducted among the caretakers till the point of saturation.

Data collection procedure

The respective authorities of educationally institution granted permission and agreed to share their records with the researcher. The families of the selected adolescents were contacted by phone, the purpose of the study was explained and subsequently, permission was sought for an interview with the primary caretaker of the adolescent. Few mothers of adolescents agreed to be interviewed at the school itself, while some of the mothers wanted the researcher to visit them at their residence. The quantitative data were collected using pretested semi-structured questionnaire. For in-depth interview, an interview schedule was prepared and administered in the local language. The interview lasted for not more than 30–45 min. The interview was voice recorded after taking consent from the participant, and recordings were kept confidential.

The data collected were entered in Microsoft Excel and analyzed using Jeffrey's Amazing Statistics Program version 0.9.0.1. Mean and standard deviation were calculated to summarize continuous variables such as age. Number and percentage were used to present the categorical data. Socioeconomic status was classified as per modified BG Prasad's classification updated for August 2019. The analysis of IDI was done through a conventional content analysis approach.

Ethical consideration

Although this study involves vulnerable group, i. e., children <18 years of age with ID, only the caregivers were included in the study and hence, the study has minimal risk. Still, the recommended measures were taken to overcome the risk as per National Ethical Guidelines for Biomedical and Health Research Involving Human Participants by laid Indian Council of Medical Research in 2017. Informed consent was obtained from the caretakers of the adolescents with Intellectually Disability. Personal identity was protected, and confidentiality maintained.

RESULTS

In our study, 73 caretakers of adolescent girls with ID participated in the study and the majority of them were mother 67.1% with a mean age of 39 ± 3.3 years. Approximately over half of them had education level up to secondary school, 44% of them were currently unemployed and were belonging to middle class family according Modified B. G Prasad's classification (August 2019). Moreover, 57.5% belonged to nuclear family and majority 57.5% were from urban area. Majority of the adolescents 57.5% were in the age group

between 14 and 16 years with a mean age of menarche of 11.2 ± 2.4 years. Nearly 45.3% had IQ of 36%–50%. Majority 63% had a regular menstrual flow [Table 1]. Almost 80.9% of the adolescent girls were not able to manage their menses and 67.1% of mother was the person in assisting their daughter. Nearly 83.6% were not able to recognize about the start of the menstruation [Table 2]. Table 3 shows association of challenges faced by primary caretakers with degree of ID of adolescent girls during their menstrual cycle, it has been found that there was statistical significant association with $P < 0.05$.

A total of 12 IDI were conducted till the point of saturation. The themes that emerged from the IDIs are presented below as headings and supported by quotes/verbatim from the participants.

Although issues with menstruation and its management are relatively common around menarche among all adolescent girls, this transition is usually more complex among the adolescent girl with ID compared to others.

Theme 1: Inability to communicate about the start of menstruation

Adolescent girls with ID experience same kind of menstrual problems such as other females. However, caretakers of adolescent girls with ID experience more problems due to issues in communication.

She use to stain the bed and dress and she can't able to realize that her period has started, once I notice this blood I will change the dress and bed sheet "it's not changed despite of several training" (Participant E).

Theme 2: Refusal of sanitary napkins

Most of the adolescents resisted when their mothers attempted to make her wear a napkin. Some mothers use safety pins to avoid their daughter from throwing the sanitary napkins. The

Table 1: Menstrual history of adolescent girls with Intellectual Disability (n=73)

Variables	Summary statistics, n (%)
Age in completed years	
11-13	8 (11)
14-16	42 (57.5)
17-19	23 (31.5)
IQ range (records maintained in school)	
<20	11 (15)
21-35	29 (39.7)
36-50	33 (45.3)
Mean age of menarche (years)	11.2±2.4
Regularity of menstrual cycle	
Regular cycle	46 (63)
Irregular cycle	27 (37)
Absorbent used during menstrual cycle	
Sanitary pads	37 (50.6)
Cloths	30 (41)
Others (ash, no sanitary pads)	6 (8.4)

IQ: Intelligence Quotient

Table 2: Menstrual care for girls with intellectual disability (n=73)

Variables	Summary statistics, n (%)
Ability to manage menses by herself	
Yes	14 (19.1)
No	59 (80.9)
Person responsible for assisting the girl during menstruation	
Mother	49 (67.1)
Grand mother	8 (11)
Aunt	11 (15)
Caretaker	5 (6.9)
Recognizing about the start of her period	
Yes	12 (16.4)
No	61 (83.6)
Having increased behavioral problems during menstruation	
Yes	52 (71.2)
No	21 (28.8)
Surgical management to stop menstruation (hysterectomy done)	
Yes	4 (5.4)
No	69 (94.5)

Table 3: Association between challenges faced by primary caretakers with degree of intellectual disability of adolescent girls during their menstrual cycle (n=73)

Challenges faced by ID adolescent girls during their menstrual cycle	Degree of ID			P (Chi-square test)
	Mild, n (%)	Moderate, n (%)	Severe, n (%)	
Not able to manage menstruation on her own (n=59)	20 (34.0)	28 (47.4)	11 (18.6)	0.01*
Not able to recognize about the start of her period (n=61)	22 (36.0)	28 (46.0)	11 (18.0)	0.01*
Having increased behavioural problems during menstruation (n=52)	13 (25)	28 (54)	11 (21)	0.01*
Surgical management done to stop menstruation (hysterectomy done) (n=4)	0	0	4 (100.0)	0.01*
Not going to special school on menstrual cycle days (n=69)	29 (42.0)	29 (42.0)	11 (16.0)	0.07
Not playing on menstrual cycle days (n=69)	29 (42.0)	29 (42.0)	11 (16.0)	0.01*
Having irregular menstrual cycle (n=27)	2 (7.4)	15 (55.6)	10 (37.0)	0.01*

*P value derived from Chi-square test. ID: Intellectual disability

mothers reported significant stress and frustration at having to go through the same situation during every menstrual cycle and every time the napkins were required to be changed.

She always use to throw the pads in the bathroom when she goes for urine. I will ask "what are you doing?" she says, no I don't want to use it, I am fine" (participant A)

She is mentally weak. Even though I have told her several times and it very difficult for her to understand (participant B).

Theme 3: Not maintaining personal and menstrual hygiene

Ensuring proper hygiene during menstruation is an important step in preventing reproductive tract infection. Most of the adolescents in the study were often unaware about hygiene maintenance during menstruation. For instance, some of them did not understand when to change a soiled napkin and had to be reminded by their mother. Some others also had to be told to change their clothes, if they accidentally soiled them.

"She won't wash her hands after handling the stained pad and she eat without washing her hands, every time I scold her

to wash her after touching the stained pad ...but she never" (Participant H)

When I go outstation leaving her along with her grandmother during her menstruation

She even use to stay with the soaked pad the whole day saying that 'she won't change unless I come and help her' this happened last month and she had some itching in that area" (participant I).

Theme 4: Restriction practiced during menstrual cycle

Most mothers preferred to keep their daughters at home during their menstrual cycle. Almost all of the adolescents were dependent on their mothers for changing their sanitary napkins, and hence it became mandatory to stay at home during their menstrual cycle. There was also the anxiety that the adolescent will soil her clothes, as a result of which she was not allowed to go to school. These restrictions add to the disturbance in her daily routine caused by the menstrual cycle and its management.

"I use to keep my girl in home itself during her menses, mostly every month she will take three to five days leave due to this menstruation and its affect her studies" (Participant E)

“Sometimes it use to bleed more amount and I won't allow her out of house” (Participant F).

Theme 5: Not maintaining privacy

Being conscious of one's own body is a sense that an individual develops with age during the process of socialization as the adolescent grows into an adult. For adolescents with ID, this socialization is slow and sometimes even completely terminated. Some of the mothers mentioned that their daughters would not be conscious about maintaining privacy while using the toilet.

“Most sad thing is that my daughter don't know what is happening with her and she doesn't know completely that she is mature physicallyshe use to through the pad in the bathroom and she use to change the pad in front of her brother and father, I use to pray and cry to god that this should pass away and my girl should be completely recovered from this disease”(Participant C, D, F).

Theme 6: Surgical management to stop menstruation

Complete dependence of the adolescents for menstrual management sometimes resulted in the families opting for hysterectomy for their daughters. In the study, two of the participants had opted for hysterectomy for their daughters for menstrual management, and they belonged to higher socioeconomic status. The families with higher socioeconomic status had access to medical personnel who made them aware of the availability of such surgeries. Affordability also played an important role in the decision-making for hysterectomy. Hysterectomy as an option was sometimes suggested by other family members and friends, while in one case, it was sought directly by the mother.

“I used to do everything for her-changing the pads every four hours, taking her to the toilet and changing stained underwear's but she is not at all aware about things happening to her, Then when she was 17 years old, I realized that I could not do it anymore, and it was not helping her in anyway. Then we decided to remove her uterus.” (Participant C)

“When she was nine years old, she got her first period. She had heavy periods which lasted for eight to ten days it was very crucial and hectic to manage this ten days very month, so I discussed it with my relatives and friends and we got mentally prepared and we removed her uterus”(Participant E).

DISCUSSION

In our study, 73 caretakers of adolescent girls with ID have participated, and the majority of them were mothers 67.1% with a mean age of 39 ± 3.3 years. Out of a total of 73 girls, most of the girls 57.5% were between 14 and 16 years of age. The mean age of menarche was 11.2 ± 2.4 years and 63% had regular menstrual cycle Our findings correlate with the results done by Nurkhairulnisa *et al.* were the mean age attainment of menarche is 11.12 ± 1.76 years.^[6]

Most adolescents with ID have unique medical, technical, and social needs particularly in the areas of personal care. Nurkhairulnisa *et al.* found that as a result of their disability, they often require specialized care and guidance to manage their daily activities.^[6] In our study, we found similar results that the majority of the study participants 80.9% were not able to manage their menstruation. This inability to manage menstruation by the ID adolescents was found to be statistically significant in comparison with the degree of ID.

Moreover, mothers who were interviewed were intricately involved in the monthly menstrual management of their daughters since 83.6% of ID adolescents were not able to recognize the start of their menses. This difficulty of not able to recognize the start of menses was statistically found to be significant with a degree of ID. The respondents felt solely responsible for the menstrual cycle of their daughter. This was consistent with literature from Taiwan, where the mothers handled their daughters' menstruation in their own way without discussing it even with the fathers because it was not “something to be talked about.”^[10]

We asked the caregiver about the restrictions practiced during the menstruation of their adolescent girls and we found that a significant amount 94.5% was not going to the school and for playing. This restriction practice was found to be statistically significant with the degree of ID. The most common reason that was given by the caregivers about this condition was their daughters were not able to manage menstruation on their own and the majority of ID adolescents 71.2% had increased behavioral problems which were found to be statistically significant with the degree of ID. Our finding was in contrast with the study done by Yaacob *et al.* in Indonesia, in which they found that Down syndrome women's daily activities were not affected by menses. Even if they have menstrual pain, they still can go to work or school as usual. Just a small proportion of them have to be absent from work or school during the 1st or 2 days of menses.^[11]

In our study, when we asked about hygienic practice during menstruation, most of the mothers replied that their adolescents are not maintaining good hygienic practices. These findings correlate with the cross-sectional study done by Rodgers *et al.* reported that the majority of them had poor hygienic practices such as blood-stained cloths.^[12] When we enquired about surgical management to stop menstruation, 5.4% belonging to a severe degree of ID has undergone hysterectomy to stop menstruation, this was found to be statistically significant. Even though this is smaller in proportion, this finding reminds us how the caregivers suffered to manage their adolescent's menstruation. This finding correlates with the finding done by Jeffery *et al.* where they discussed management of menstrual problems in adolescents with learning and physical disabilities, one case with static encephalopathy underwent high dose estrogen therapy to halt her growth and a hysterectomy and mastectomy to stop puberty.^[13]

CONCLUSIONS

We believe our qualitative study is the first one of its kind in exploring mother perspective in managing menstruation of their adolescent girl with ID in urban and rural Puducherry. We discovered that majority of adolescents with ID were not able to manage their menstruation on their own. Primary caretakers who were interviewed were mostly mothers and they were the person assisting their adolescent during their menstrual cycle. Due to dependency on their caretakers, most of the adolescents with ID were not going to school during their menstrual cycle. Major challenges faced by them were rejection of sanitary napkins, not maintaining personal and menstrual hygiene, and inability to communicate about the start of the period by the adolescent.

Limitation

The study focused only on adolescents with ID who were enrolled in educational institutions. However, a large percentage of adolescents in India might not have access to special education institutions and hence would have a different set of challenges. As the information is taken from the caretaker of adolescent girls with Intellectual Disability, the information obtained may lead to positive or negative illusory bias.^[14]

Recommendation

There should be targeted Health education programs for the caregivers of ID adolescent girls to raise awareness regarding menstrual hygiene management and to handle the challenges faced by them which can be done through Sahyogi Caregiver training scheme implemented by Government of India.

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Conflicts of interest

There are no conflicts of interest.

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