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# Lost in transition: menstrual experiences of intellectually disabled school-going adolescents in Delhi, India

*POORNIMA THAPA and MUTHUSAMY SIVAKAMI*

*Issues around reproductive health of intellectually disabled adolescents have received limited attention in India. This study aimed to bring to light these issues to inform policy and practice surrounding reproductive health among intellectually disabled adolescents. The objectives of this study were to understand the problems encountered by intellectually disabled adolescents and their primary caretakers during management of the adolescent's menstrual cycle, and to explore the strategies adopted to overcome them. Using qualitative methodology, in-depth interviews were carried out with 23 primary caretakers (all mothers) of adolescent girls in the age group of 11–19 years with IQ of 20–50 were interviewed using in-depth interviews. The mothers of adolescents were selected using purposive sampling and grounded theory methodology was followed for data analysis. The adolescents faced a whole range of issues; from not being able to change sanitary napkins due to physical constraints, to not being able to communicate their physical discomforts, such as stomach cramps, to their caretakers. Their caretakers adopted various strategies such as changing the sanitary napkins for the adolescent themselves, trying to train the adolescent to maintain hygiene, or in some cases even surgical removal of the adolescent's uterus for the cessation of menstruation. Overall, the adolescents did not play a very significant role in the management of their own menstruation, which might prevent them from achieving reproductive health to the best of their potential.*

**Keywords:** menstrual hygiene, intellectual disability, adolescents, reproductive health

INTELLECTUAL DISABILITY IN INDIA has never received much attention in the public realm. This is exemplified by the fact that the first ever survey on mental disability was conducted by the National Sample Survey Organization (NSSO, India) only in July–December 2002 (58th round). This survey estimated that 699,500 persons in the rural areas and 295,100 persons in the urban areas were intellectually disabled in India (Government of India, 2003). However, other studies have suggested that the number of people living with intellectual disability may actually be much higher

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*Poornima Thapa (poornima.thapa@uni-bonn.de) is a doctoral candidate at the Centre for Development Research, University of Bonn, Germany; Muthusamy Sivakami (sivakami@tiss.edu) is Professor and Chairperson at the Centre for Health and Social Sciences, School of Health Systems Studies, Tata Institute of Social Sciences, Mumbai, India.* *The authors would like to express their gratitude to the participants for providing such valuable information and to the reviewers for their feedback that sharpened the paper considerably.*

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(Reddy and Chandrashekhar, 1998). These discrepancies may be due to difference in operational definitions, assessment techniques (Kabra and Gulati, 2003), ascertainment biases, or under-reporting (Daley, 2004). This lack of accurate estimates prevents a clear visualization of the magnitude of intellectual disability in the country and obfuscates the gap between the demand and supply of services for people living with the disability.

Ideally, the complete rehabilitation of a child with intellectual disability requires a whole team of specialized personnel comprising a psychiatrist, a special educator, a psychologist, a physiotherapist, an occupational therapist, a social worker, a neurologist, and a paediatrician (Shastri, 2008). However, in the Indian context, there is an absence of any active involvement of the state in health-related matters, or financial support given to the families of adolescents with intellectual disability. The only options available are 'special schools' run by private and non-governmental organizations (NGOs). However, according to Peters (2007), only 1–2 per cent of all disabled individuals attend such schools. Accessibility to private services is limited for most families due to their prohibitive cost. On the other hand, the NGO-run facilities often suffer from inadequate funds and infrastructure and can only assist at a micro-level. As a result, the management of most issues that the intellectually disabled individuals encounter are home-based and the responsibility of the individual is relegated to the family (Alur, 2001), usually the mothers or sisters. The avenues for information and support for the family members of individuals suffering from intellectual disability are also almost non-existent (Gupta and Singhal, 2005; Edwardraj et al., 2010), leaving them ill-equipped to handle the special needs of their children (Wikler, 1981). Kamaruddin and Mamat (2015), Lim et al. (2013), Chou and Lu (2012), and Lin et al. (2011) indicate such similar inadequacies in the informal and formal support available to the parents of intellectually disabled children in Malaysia, China, and Taiwan. This not only places considerable demand on the family, but creates a situation of complete dependency on family members, sometimes throughout the lifetime of the individual.

As the child grows up and reaches adolescence, she undergoes marked physical and emotional transformation. Menarche and other pubertal changes pose considerable complexities for the adolescents and have been associated with anxiety, depression, risky behaviours, and other psychological disturbances (Patton et al., 1996; Ellis et al., 2012). Adolescents with intellectual disability might face greater challenges at menarche due to their dependence on their caretakers for day-to-day personal care activities. Further, the menstrual cycle is periodic and requires repeated attention. In some cases, additional disorders like epilepsy, thyroid disease, and polycystic ovarian syndrome complicate the menstrual management further, by causing irregularities in the menstrual cycle (Quint, 2008). Associated disabilities such as impairment of vision or speech and cerebral palsy may also be present (Quint, 2008) that may create additional vulnerability. Maintaining menstrual hygiene might also be complicated in some adolescents with intellectual disability due to the behavioural manifestations such as temper tantrums, crying spells, and self-abusive behaviours, which may get aggravated due to the discomfort brought on by menstruation (Quint, 2008). Adolescents with severe

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intellectual disability may also be non-ambulant and incontinent (WHO, 1985) which might further impede menstrual hygiene management, confounding the tasks of the caretaker.

Until recently the standard management for women with severe intellectual disability (especially the institutionalized women) in most societies was to induce amenorrhea by the continuous use of progestagens or surgical approaches (Grover, 2002). However, in the latter half of the 20th century, society began to view reproduction as a fundamental right of an individual and involuntary sterilization was branded as a violation of this right (Diekema, 2003). In the US for instance, deinstitutionalization and disability rights movements in the 1970s brought about legislation change and a judicial review of the cases became mandatory (Tilley et al., 2012). In the UK as well, all requests for sterilization by parents are required to be heard by a judge. In Australia, legal authorization from the family court is mandatory for seeking the surgical procedure (Grover, 2002). Even though parental concerns within families with intellectually disabled adolescents often continue to remain unaddressed, most developed nations legally regulate involuntary surgical procedures in intellectually disabled youth, performed solely for the purpose of menstrual termination (Tilley et al., 2012). India, like some other developing nations, however, remains far behind as far as the reproductive rights of the disabled are concerned. The Indian Parliament recently notified the Rights of Persons with Disabilities bill, created to bring the Indian laws in line with the UN Convention on Rights of Persons with Disabilities (CRPD), which India ratified almost a decade ago (*Hindustan Times*, 2016). Although the much awaited legislation provides for equal opportunities for disabled individuals in education and jobs, it does not venture into the area of reproductive rights. Holness (2013) and Chou and Lu (2012) indicate similar inaction in the case of South African and Taiwanese legislations, respectively, in dealing with reproductive health policies for the disabled.

Menstruation, as exclusively a woman's issue, does not receive enough attention in popular discourse and is a sensitive topic for public discussion, especially in the South and South-east Asian context. In most communities in the region, menstruation continues to be surrounded with secrecy, taboos, and stigma. The menstruating women are referred to as 'ritually unclean' and are subjected to social, religious, and cultural restrictions (Garg and Anand, 2015; Bhartiya, 2013). In some rural communities in India and Nepal, menstruating women are not allowed to live in the same household with other family members and are banished to a 'menstrual hut' or a cowshed with potentially harmful implications (Sapkota et al., 2013). In contemporary urban India, the extent to which menstrual restrictions are followed vary from one household to the next. According to Chou and Lu (2012), menstruation is culturally regarded as 'polluted and unclean' in Chinese society as well and is seldom discussed openly. The same study discovered that the mothers viewed menstrual management assistance of their intellectually disabled daughters as a 'motherhood task' and provided support independently without any support from other family members or public services. This is in stark contrast with the scenario in the United States where the mothers usually received considerable support from the local health department, school staff, and books (Park, 2013).

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Although there have been several studies pertaining to menstrual hygiene management among Indian adolescents, these do not explore the area of intellectual disability. The Ministry of Drinking Water and Sanitation, Government of India also recently issued national guidelines for menstrual hygiene management, but these do not consider the needs of the differently abled (Government of India, 2015). It is hence imperative to bring into focus this intersection of reproductive health and intellectual disability. Keeping this in mind, the present study aims to explore experiences of adolescents and their primary caretakers surrounding menstrual hygiene management so as to enable the creation of a framework for informing welfare and health policy for individuals with intellectual disability.

## Methodology

The aim of the study was to understand the experiences of adolescents with intellectual disability and their primary caretakers with respect to menstrual management of these adolescents. The study adopted a qualitative research approach and in-depth interviews (IDIs) were conducted with the mothers (who were also the primary caretakers) of 23 intellectually disabled adolescents. The inclusion criteria were: an adolescent whose IQ was between 20 and 50, in the age group of 11–19 years, and who had attained menarche at the time of interviews. IQ between 20 and 50 indicates moderate to profound disability and these adolescents were assumed to be most severely affected with physical and psychological limitations. A list was drawn of all the educational institutions for intellectually disabled children in Delhi and 10 institutions were randomly selected. Of the 10 institutes, seven granted permission and agreed to share their records with the researchers. Of these seven institutions, one was a trust-run senior secondary school for non-disabled children with a small, separate department for intellectually disabled children, five were small special schools run by NGOs, and one was a specialized private school exclusively for intellectually disabled children. The adolescents were selected using purposive sampling to get a group with varied socio-economic characteristics, thus ensuring a rich source of data.

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, who in all cases was the mother. The participants (mothers of adolescents) were informed that participation was voluntary and their decision would not affect their family in any way. Informed consent for audio recording was also sought prior to the interview. Mothers of adolescents who consented to participate in the study were interviewed and the final sample size was based on information saturation. Strict confidentiality was maintained during the interviews as well as while handling the data. Only the researchers had access to the audio recordings and transcripts, and pseudonyms were used to maintain anonymity of the adolescents and their families.

The mothers of 20 adolescents agreed to be interviewed at the school itself, while three of the mothers wanted the first author to visit them at their residence.

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For Hindi speaking participants, the interview guidelines were translated in Hindi. The interviews were conducted in April and May 2013 and were transcribed and translated into English. Codes were developed and the analysis was carried out with the help of Atlas Ti 5.0. Grounded theory methodology was adopted to allow for spontaneous emergence of themes from the transcripts.

### *Background characteristics of participants*

Of the 23 mothers, nine had enrolled in school but hadn't completed schooling, three had completed schooling, eight had progressed to higher studies, and three were illiterate. Only six of them were currently engaged in some form of employment, while two had retired and 15 were homemakers (see Table 1).

Twenty adolescents were moderately disabled while three were severely disabled. One of the adolescents was between 11 and 13 years, five were between 14 and 16 years, while 17 were between 17 and 19 years (Table 2). The respondents were divided into three income groups of low, middle, and high (decided by the researchers)

**Table 1** Profile of mothers interviewed

| *Characteristics* | *Number* | *Percentage* |
|---|---|---|
| **Monthly family income (rupees)** | | |
| < Rs. 50,000 | 7 | 30.4 |
| Rs. 50,001–100,000 | 5 | 21.7 |
| > Rs. 100,000 | 11 | 47.8 |
| **Educational status of respondent** | | |
| Illiterate | 3 | 17.4 |
| Class I–XII | 12 | 47.8 |
| Graduate | 7 | 30.4 |
| Postgraduate | 1 | 4.3 |
| **Occupational status of respondent** | | |
| Housewife | 17 | 73.9 |
| Employed (informal) | 2 | 8.7 |
| Employed (formal) | 4 | 17.4 |
| **Family structure** | | |
| Nuclear | 13 | 56.5 |
| Joint | 10 | 43.5 |
| **Type of school** | | |
| Private | 7 | 30.4 |
| NGO | 13 | 56.5 |
| Trust | 3 | 13.1 |
| **Total number of respondents** | **23** | |

Note: US$1 = Rs 65.52 (correct at September 2017)

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**Table 2** Profile of the intellectually disabled adolescents

| *Characteristics* | *Number* | *Percentage* |
|---|---|---|
| **Age (in years)** | | |
| 11–13 | 1 | 4.3 |
| 14–16 | 5 | 21.7 |
| 17–19 | 17 | 73.9 |
| **IQ** | | |
| <20 | 0 | 0 |
| 21–35 | 3 | 13 |
| 36–50 | 20 | 87 |
| **Total number of adolescents** | **23** | |

based on the monthly income of the households (Table 3). The respondents from different income groups were distributed among all three kinds of schools, but the private school was attended mostly by adolescents from the high income group.

## Results

### *Menstrual issues encountered by adolescents with intellectual disability*

Although issues with menstruation and its management are relatively common around menarche among all adolescents, this transition is usually more complicated among the adolescents with intellectual disability compared with their non-disabled counterparts. Most of the mothers mentioned that they had been handling their daughter's menstruation-related issues all by themselves without much support from other avenues. Adolescents who had an elder sister received some assistance from the sister as well, but the mother remained the primary caretaker.

*Rejection of sanitary napkins*. The mothers found it difficult to negotiate sanitary napkin usage with their intellectually disabled daughters. Some of the adolescents did not want to use the napkins and often resisted when the mothers attempted to make her wear a napkin. The mothers often had to use inducements (such as a new dress, or a trip to the park) to get their daughters to wear a sanitary napkin. Some mothers mentioned that the adolescents repeatedly complained about the napkin and also asked them to remove the napkin despite repeated efforts to make their daughters comply. The mothers reported significant stress and exasperation at having to undertake the same coercion towards their daughters during every menstrual cycle and every time the napkins were required to be changed. Some mothers also reported losing their temper when their daughters failed to comply.

> She says that she does not want to use a pad (sanitary napkin). I said, 'What are you doing, all your clothes will get spoilt. What will everyone think at school?' She says, 'No, I don't want to use it, I am fine' (P, daughter's age: 17 years, IQ: 50).

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**Table 3** Individual characteristics of the caretakers of intellectually disabled adolescents

| *Respondents* | *Educational institution attended by the respondents' daughter* | *Age of respondent* | *Employment status of respondent* | *Marital status of respondent* | *Highest education level attained by the respondent** | *Household structure* | *Income of the household* |
|---|---|---|---|---|---|---|---|
| C | Trust | 52 | Retired government employee | Married | Graduate | Nuclear | 50,000–1 Lac |
| B | Trust | 48 | Homemaker | Married | Graduate | Joint | 50,000–1 Lac |
| D | NGO | 48 | Homemaker | Married | Primary | Nuclear | < 50,000 |
| H | NGO | 30 | Homemaker | Married | Illiterate | Nuclear | < 50,000 |
| HM | NGO | 40 | Homemaker | Married | Illiterate | Nuclear | < 50,000 |
| K | NGO | 42 | Homemaker | Widow | Middle | Joint | 50,000–1 Lac |
| M | NGO | 46 | Homemaker | Married | Secondary | Joint | < 50,000 |
| NK | NGO | 45 | Homemaker | Married | Senior secondary | Joint | > 1 Lac |
| N | NGO | 38 | Homemaker | Married | Middle | Joint | > 1 Lac |
| P | NGO | 42 | Homemaker | Married | Middle | Joint | > 1 Lac |
| PR | NGO | 38 | Informal employment | Married | Illiterate | Nuclear | < 50,000 |
| PT | NGO | 34 | Homemaker | Married | Primary | Nuclear | < 50,000 |
| RK | NGO | 39 | Homemaker | Married | Primary | Nuclear | < 50,000 |
| RE | Private | 46 | Retired government employee | Married | Graduate | Nuclear | > 1 Lac |
| R | Private | 50 | Homemaker | Married | Middle | Joint | 50,000–1 Lac |
| S | Private | 44 | College teacher | Married | Graduate | Joint | > 1 Lac |

*(continued)*

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**Table 3** *(continued)*

| *Respondents* | *Educational institution attended by the respondents' daughter* | *Age of respondent* | *Employment status of respondent* | *Marital status of respondent* | *Highest education level attained by the respondent** | *Household structure* | *Income of the household* |
|---|---|---|---|---|---|---|---|
| SH | Private | 46 | Businesswoman | Married | Senior secondary | Nuclear | > 1 Lac |
| SR | Private | 37 | Homemaker | Married | Middle | Nuclear | < 50,000 |
| SU | Private | 43 | Self–employed (home-based) | Married | Graduate | Nuclear | > 1 Lac |
| SW | Private | 44 | Government employee | Married | Graduate | Nuclear | > 1 Lac |
| T | Private | 53 | Homemaker | Widow | Graduate | Joint | > 1 Lac |
| U | Private | 58 | Homemaker | Married | Graduate | Nuclear | > 1 Lac |
| V | NGO | 40 | Formal employment | Married | Senior secondary | Joint | 50,000–1 Lac |

Note: * Primary stage: Class 1–5, Middle stage: Class 6–8, Secondary stage: Class 9–10, Senior Secondary: Class 11–12, Graduate: completed Bachelor's; 1 Lac = Rs. 100,000 = $1,526

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Most of the adolescents were not provided with any information or training pertaining to menstruation before menarche, since they were thought to be too naive to understand menarche by the families. Hence, the sensation of wearing a sanitary napkin was completely unfamiliar to the adolescents and is often accompanied by menstruation-related discomfort. The adolescents' refusal to accept sanitary napkins is often misconceived as their inability to accept or understand menstrual management and this might preclude the adolescents from receiving the training and guidance which might have allowed them to participate in the management of their own menstrual cycle.

> She is mentally weak. How would she have understood if I would have explained it to her? (H, daughter's age: 15 years, IQ: 40)

> She had no idea. Since she is the eldest, she had not seen it happening to anyone (PR, daughter's age: 19 years, IQ: 40).

Hence, when the adolescents attained menarche, they were completely unfamiliar with the sensations associated with the monthly bleeding and sanitary napkin use. It is probable that resistance to (and sometimes rejection of) sanitary napkins is a result of unfamiliar sensations. Adolescents with elder sisters, who had achieved menarche in the past, fared better than the adolescents with no elder sisters, possibly because these adolescents are likely to be familiar with sanitary napkins and the process of menstruation before they themselves attained menarche. Such adolescents were also the ones who received additional support in menstrual management from their elder sisters.

*Restriction of physical mobility*. Most mothers preferred to keep their daughters at home during their monthly menstrual cycle. Almost all of the adolescents were dependent on their mothers for changing their sanitary napkins and hence it was imperative that they stayed at home during their menstrual cycle. There was also the anxiety that the adolescent would be oblivious if she were to soil her clothes, as a result of which she was discouraged from engaging in activities that required her to leave the house. These restrictions add to the disturbance in her daily routine caused by the menstrual cycle and its management.

> Sometimes, when it seems like the bleeding is more than usual, we don't let her go to school (C, daughter's age: 19 years, IQ: 45).

> There are times when her periods last for more than eight days. So she gets irritated saying, 'I don't want to stay inside the house'. Actually I don't send her to school on those days. So she would want to know why I'm not allowing her to leave the house (B, daughter's age: 19 years, IQ: 44).

For adolescents with intellectual disability, school is often the only avenue for social interaction with people other than their family members and, for most of them, the time they spend in school is the most enjoyable part of the day. The school is also often the only place where they have an opportunity to interact with special educators and fellow adolescents. According to the mothers, the adolescents also resented being confined at home for days, during menstruation. Hence,

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missing school not only causes considerable distress to these adolescents, but might also be detrimental to their learning.

*Maintaining hygiene*. 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 accidently soiled them.

> 'She does understand, but she cannot wash her soiled clothes properly. So I wash them for her. And I have to tell her that your clothes are soiled, take them off and wear this' (M, daughter's age: 16 years, IQ: 45).

Hygiene maintenance is usually taken for granted in the case of non-disabled adolescents. They learn by trial and error, guided by their own experiences and the experiences of their peers, along with the guidance they receive from their elder female family members at home. They also sometimes participate in reproductive health and hygiene workshops at school (Datta, 2017). Most of these resources are absent in the case of adolescents with intellectual disability. For them, menstrual management training takes a different course. The caretaker is often the only external source that these adolescents rely on for information, guidance, and training. Also, special attention and instruction along with constant reinforcement is required to enable these adolescents to internalize the steps of menstrual management.

*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 intellectual disability, this socialization is slow and sometimes even completely redundant. Some of the mothers mentioned that their daughters would not be conscious about maintaining privacy while using the toilet or sometimes would mention it to male family members or even to non-family members such as neighbours and other acquaintances.

> She will leave the door open while changing her pad, and doesn't understand that her elder brother is at home. So I tell her, 'Always bolt this door from inside.' Sometimes she understands, but sometimes she starts changing in front of them (D, daughter's age: 19 years, IQ: 38).
>
> I have told her that it happens only to girls, but sometimes she would loudly say, 'My clothes are getting spoilt', even if someone is sitting. So I told her, 'You shouldn't say it in front of anyone. All the girls get it'. She does not have a lot of knowledge about it (S, daughter's age: 19 years, IQ: 50).
>
> She used to go and tell everyone. A few times, she went up to someone and said, 'See Aunty, this is happening to me.' Then I explained to her that one should not talk about these things. Then she would also say something in front of Papa, or even speak to Papa about it. She does not know that one is not supposed to talk about these things (PR, daughter's age: 19 years, IQ: 40).

The adolescents in the study were often unaware about being discreet about their menstrual cycle. They would speak about it with other people including male family

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members or leave the toilet door open while changing sanitary napkins. This was especially stressful for the mothers and caused considerable embarrassment and anxiety. Although, intrinsically, discussing the menstrual cycle is not inappropriate, it is still a taboo topic in Indian society. This indicates the rigidly patriarchal nature of the society which relegates the issue to be solely the 'mother's responsibility'.

*Cognition*. Since the inclusion criterion of the study was IQ 20–50, cognition and adaptability were intrinsic issues among the adolescents. Some of the adolescents were heavily dependent on their caretakers for their daily ablutions. Despite repeated instruction by the caretaker, these adolescents were not conscious about the menses and the sanitary napkin; hence they could not participate in any way in the management of their own menstrual cycle. This created a lot of anguish among the mothers.

> She is not aware that something is happening. I only have to take care, even now. I tried to explain it to her, but she does not listen, she is not able to concentrate. No matter what happens, she does not respond to it (M, daughter's age: 16 years, IQ: 45).
>
> She knows nothing. I will change her pad for her, and then she will get satisfied. Everything, A to Z is handled by me. She cannot do anything herself (N, daughter's age: 17 years, IQ: 40).
>
> Like I said there is no urine sensation, so what would she feel? She did not feel anything. She was not aware at all about what was happening (NK, daughter's age: 18 years, IQ: 35).

One of the adolescents suffered from inadequate neural control manifesting as incontinence, which complicated menstrual management considerably. However, the rest of the adolescents had healthy neural responses. Some of the mothers reported that they would be in a better position to assist their daughters in menstrual management if they could communicate with them better. Some mothers mentioned difficulties in making themselves understood to their daughters and also comprehending what their daughters wanted to express.

> And when she gets her period, she never tells me. I have tried to teach her so many times to tell me. She will keep sitting (C, daughter's age: 19 years, IQ: 45).
>
> See, when the pad gets used up, she should tell me that they have to be changed. But she doesn't say anything (N, daughter's age: 17 years, IQ: 40).

Some of the mothers felt defeated and frustrated because the adolescents would not follow their instructions. But since none of the mothers had received any kind of specialized training regarding intellectual disability, it was only natural for them to be at a loss while trying to encourage their daughters to handle their menstrual cycles.

*Cyclic behavioural issues*. The menstrual cycle is accompanied by hormonal changes which bring about emotional turbulence in adolescents. These are common and

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usually do not have serious repercussions among non-disabled individuals. However, this transition may manifest in a more severe manner among adolescents with intellectual disability, since they are often unable to express or comprehend it. The unexpressed emotional turmoil combined with physical discomfort during menstruation might lead to increased probability of irritable or agitated behaviour among adolescents with intellectual disability.

> She also gets irritated, but what can we do, there's no solution. There is no cure for this (B, daughter's age: 19 years, IQ: 44).
>
> She gets short tempered. But it's not her fault. She can't speak very well, so I think that's how she expresses herself (H, daughter's age: 15 years, IQ: 40).

*Physical discomfort*. Physical discomfort during menstruation is common among all adolescents. However, it can be problematic for adolescents with intellectual disability if they are unable to understand the underlying cause of the discomfort or are unable to express it. Unlike in non-disabled adolescents, menstruation-associated discomfort may often go unaddressed. Their reaction to the discomfort may also be exaggerated and it may have various behavioural manifestations. According to some of the mothers, the adolescents complained of stomach aches and muscle cramps in the arms and legs. Issues such as rashes due to sanitary napkin usage were also reported, and if unaddressed may further lead to aversion towards sanitary napkins.

> Initially when I used to fix the pad and make her wear the underwear, she used to get rashes. She had no awareness about what is going up and what is going down, and when she used to walk, she used to get rashes on the side (N, daughter's age: 17 years, IQ: 40).
>
> She gets a severe stomach ache. I get to know way in advance. She is unable to even get up. So I massage her arms and legs, and then she gets better (R, daughter's age: 18 years, IQ: 45).

While these symptoms are benign, they have the potential to cause significant discomfort which may manifest as behavioural disturbances such as irritability or temper tantrums, further leading to defiance. Therefore, physical discomfort associated with menstruation requires special attention in the case of adolescents with intellectual disability.

### *Management of menstrual issues in adolescents with intellectual disability*

Strategies utilized for the management of menstrual issues in intellectually disabled adolescents generally varied with the adolescents' capabilities, level of dependence on the mother, and the life skills that the adolescent has been able to attain over the years. Some mothers reported spending considerable time and effort in training their daughters with the aim of making them self-reliant, while some families did not feel that there was any use in providing these skills to their daughters as they were thought to be too naive to understand. A considerable section of the adolescents

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were precluded from receiving any training or guidance for menstrual management. Based on the level of dependency of the adolescent on the mother for menstrual management, the status of the adolescents was categorized as complete independence, partial dependence, complete dependence, and permanent cessation.

*Complete independence*. Some of the adolescents were self-reliant as far as the management of their menstrual cycles was concerned. They handled the sanitary napkins all by themselves without much support from the mothers.

> Now she manages herself, there is no problem. She does everything herself, taking it out of the packet, and disposing it off (H, daughter's age: 15 years, IQ: 40).
>
> Now I have bought her a packet of sanitary pads and she uses them herself. I thought using cloth might be difficult for her. She won't be able to wash it properly. Now she just uses them and disposes them off. It is easier than using the cloth (HM, daughter's age: 13 years, IQ: 50).

This might have been the result of repeated training and reinforcements provided by the mothers. In some cases, the sisters had helped the mothers in training the adolescent. The training of these adolescents was carried out intermittently over a few weeks to a few months, beginning at menarche. Some of the adolescents were first introduced to menstruation when their elder sisters attained menarche and hence were familiar with menstruation and the use of sanitary napkins. Some caretakers had opted for sanitary napkins for the adolescents due to their ease of use, even though they themselves used cloth.

> My elder daughter used to live with us then, so she prepared her and showed her how to fix the sanitary napkin, 'Do like this, and do like that'. After her first time, she had them again in 15 days. So she explained it to her properly. Today, it has been three years and very rarely her clothes get soiled (stained) (D, daughter's age: 19 years, IQ: 38).
>
> When she got her periods for the first time, she came to me. I said, 'This is nothing. Don't worry' and I showed her how to use it, 'Put it like this, remove it like this'. The mother always has to teach the daughter. Even in case of an intelligent girl, the mother always has to teach her the first time. She is mentally weak, so I obviously had to train her (HM, daughter's age: 13 years, IQ: 50).
>
> The first time she got them, my elder daughter, our maid (female domestic help) and me sat with her and explained it to her. Then we showed her, 'This is how you fix it'. We just had to tell her a few times. Now she manages it all by herself (SH, daughter's age: 19 years, IQ: 50).

The mothers themselves took up the responsibility of training their daughters without any external help from special educators or other specialized personnel. However, the help of the adolescent's elder sister and the household's trusted domestic help was sometimes sought in providing menstrual management training to the adolescent.

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*Partial dependence*. Some of the adolescents could manage to place the sanitary napkin in their underwear and change it, if they were provided with one and were directed to use it. However, they needed assistance from their mothers in receiving periodic reminders about changing the napkin. The mothers' responsibility extended only up to providing their daughters with a fresh napkin or a piece of folded cloth and reminding them to change periodically. The actual placing or changing was done independently by the adolescent.

> I just give the sanitary napkin to her, and she puts it on herself. We have kept a few in her cupboard, so she does everything herself. I just have to give it to her, so that she gets to know that it is time to change (C, daughter's age: 19 years, IQ: 40).

> I fold the cloth and give it to her and she places it in her underwear. Then, when that gets dirty, she tells me and asks for a new one. I had told her, 'Let me know when it gets dirty'. I also keep a track of the time, because I have to make her change after a few hours (PR, daughter's age: 19 years, IQ: 40).

Both these adolescents also had other female family members apart from their mothers: elder sister and an aunt in the case of C, and three other sisters in the case of PR. Both the mothers mentioned that the other female members of the household were also actively involved in guiding the adolescent in menstrual management.

*Complete dependence*. Some of the adolescents were completely dependent on their mothers for the management of their menstrual cycle. While some of the adolescents were unaware about the menses, hence making assistance essential, others were conscious of the bleeding but were unable to handle sanitary napkins due to physical limitations such as lack of dexterity. As a result, these adolescents with intellectual disability were unable to participate in the management of their own menstrual cycle and were mere bystanders.

> I keep telling her to do it herself, but she is not able to concentrate. So when I know her date is approaching and she will not tell me, I fix a pad even before the periods have begun and then I go about my work (M, daughter's age: 16 years, IQ: 45).

> I keep a track of her date and get to know from her symptoms. She is fond of dresses, so I bring out a nice dress and persuade her not to go to school. But she knows nothing. Everything, A to Z is handled by me. She cannot do anything herself (N, daughter's age: 17 years, IQ: 40).

> Yes, she understands (menses) but because of her trembling hands she would not be able to fix it properly. Then it will spoil her clothes (PT, daughter's age: 15 years, IQ: 50).

In these scenarios, the mothers believed that menstrual management training would not be of much use and hence had not tried to involve the adolescent in the management of her menstrual cycle. As a result, there was a complete lack of training initiatives. There were also other factors such as an absolute absence of

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opportunities for the adolescent to receive any information about menstruation prior to menarche.

> She is mentally weak. How would she have understood if I had tried to explain it to her? (H, daughter's age: 15 years, IQ: 40)
>
> Training her is unthinkable. She should learn brushing first. She should be able to manage the easy tasks first (B, daughter's age: 19 years, IQ: 44).
>
> I have never let her try fixing the pad herself. I mean, I do try to explain things to her, but I have never let her do it herself (PT, daughter's age: 15 years, IQ: 50).

Although this had resulted in lifelong dependence of the adolescent on her mother, due to an apparent lack of other options, the mothers felt that this was the only solution.

*Permanent cessation of menstruation*. Complete dependency of the adolescents for menstrual management sometimes resulted in the families opting for uterus removal or hysterectomy for their daughters. In the study, three of the participants had opted for hysterectomy for their daughters for menstrual management and all of these were well educated and belonged to a high income bracket. Their socio-economic status afforded these women access to medical personnel who made the families aware about the availability of such surgeries. Affordability also played an important role in the decision making for hysterectomy, since it is an elective surgery which can only be performed in private hospitals. 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 – changing the pads every three–four hours, taking her to the toilet. But she was not aware at all; there were no feelings in her. Then when she was 16 years old, I realized that I could not do it anymore, and it was not benefitting her in anyway. Then we got her operated upon. We got her surgery done, and got her uterus removed. (NK, daughter's age: 18 years, IQ: 35).
>
> It went on for five years, she was completely dependent on me. Then we got her surgery done. I mean, we got her uterus removed. I did not want to burden my elder daughter after me (U, daughter's age: 19 years, IQ: 40).
>
> When she was eight years old, she got her first period. So I had already discussed it with my doctor, because I knew such a situation would arise. We had mentally prepared ourselves beforehand, that whenever she gets her first period, we will get her operated upon in the next month. So we got her operated (V, daughter's age: 13 years, IQ: 40).

While hysterectomy solely for the purpose of termination of menstruation is strictly regulated in several countries, it can be overtly performed in India in private medical centres, especially in the case of non-institutionalized women. The participants gave varied reasons for choosing surgical termination of menstruation such

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as not seeing any benefit in the exercise, not wanting to burden the older daughter with menstrual management once the mother was no more, and not wanting to expose her daughter to the risk of unwanted pregnancy.

> When she was 16 years old, I realized that I could not do it anymore, and it was not benefitting her in anyway. Then we got her operated upon (NK, daughter's age: 18 years, IQ: 35).

> I did not want to burden my elder daughter after me. As it is, she will have to bear the responsibility for her welfare after we are no more. I did not want to add to her burden (U, daughter's age: 19 years, IQ: 40).

> I told everyone that I have to manage her. If something wrong happens (sexual abuse) with her, even then I will have to manage everything. So why should I put her in this hell in the first place? (V, daughter's age: 13 years, IQ: 40).

All the participants were satisfied with their decision to choose hysterectomy for their daughters. All the adolescents had undergone the surgery only within the past 3–4 years and none of them reported to have suffered from any discernible behavioural or physical changes resulting from post-surgical side-effects. Some mothers had tried handling the menstrual management of the adolescent themselves before opting for hysterectomy and these adolescents had been completely dependent on their caretakers for the management of their menstrual cycle. However, one of the families had decided on it even before the adolescent had attained menarche. This was mainly because the family was worried about the adolescent attaining sexual maturity and hence becoming vulnerable to sexual abuse and pregnancy. This was in stark contrast with menstrual hygiene management literature from Taiwan, where the mothers accepted menstrual management assistance to their intellectually disabled daughters as their responsibility and fate, and regarded menstruation as a natural bodily function essential for physical health (Chou and Lu, 2012).

## Discussion

Most adolescents with intellectual disability have unique medical, technical, and social needs particularly in the areas of personal care (Kishore, 2011). As a result, they often require specialized care and guidance to be able to independently manage daily activities. In most cases, these are essential for the adolescent to develop to the best of her abilities. In the Indian context, however, access to specialized services such as speech therapists, physiotherapists, or special educators is often limited, or even non-existent, mainly due to affordability, availability, and accessibility issues, with families from weaker socio-economic backgrounds being disproportionately affected. In the present study, except for one family, none of the mothers had utilized specialized services such as special educators, specifically for the training of the adolescent to handle her menstrual cycle. The school personnel also did not venture into menstrual hygiene management training and only provided anecdotal information to the mothers. The lack of support

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from public health facilities puts the onus of skill development and training of the adolescent on the family, especially the mothers, who are the most common primary caretakers of female adolescents with intellectual disability. This is in accordance with existing literature from both developing and developed nations (Chou and Lu, 2012; Lim et al., 2013; Park, 2013).

Mothers are often not equipped with the appropriate skills to train and guide the adolescent to manage her monthly cycle. None of the mothers participating in the study had received any professional guidance about training her daughter to handle personal hygiene tasks. Often the only source of advice for the mothers were school teachers, who could only provide anecdotal information. As a result there was always a gap between the needs of the adolescents and the care provided by the mothers. Further, some respondents did not attempt to train their daughters, because they felt that it would be of no help. This indicates the nature of the relationship between parental attitudes surrounding menstruation, especially pertaining to uncertainty about the adolescent's capacity for understanding, and the preparation the adolescents receive for menarche (Griffin et al., 1994). In contrast to these findings, Park (2013), in her study in the USA, found that most of the participants trained their daughters before menarche was attained and even utilized innovative strategies such as creating communication symbols and personalized story books.

As a result there may be situations where the adolescent is unable to be self-reliant because of the lack of sufficient training expertise or effort even though she may have the capability to be trained to participate in her menstrual management (Grover, 2002). The current study found that all the mothers who were interviewed were intricately involved in the monthly menstrual management of their daughters. The respondents felt solely responsible for the menstrual cycle of their daughter and did not even discuss it with the adolescents' fathers. 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' (Chou and Lu, 2012).

Such dependence can add to the existing concerns such as financial difficulties, the stress of coping with disturbed behaviour, the disruption of household routine, and the restriction of social activities, among others (Sreeja et al., 2008) and might lead to life-long anxiety and stress for the mothers and the adolescents as well as other family members. This may eventually create conditions where the family may seek permanent 'solutions', hence exposing the adolescent to psychological and physical repercussions, when the adolescent could have been trained to achieve a certain degree of self-sufficiency. Three respondents in the study reported to have opted for hysterectomy for their daughters, two of whom felt excessively burdened by the effort and did not want to pass on the 'burden' to the other family members once they were no more. One of the respondents decided on it even before menarche was attained by her daughter. This indicates the serious consequences for the adolescents with intellectual disability in the absence of specialized care and support.

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Numerous studies have shown that principles which are used to guide menstrual management in non-disabled adolescents can effectively be used to plan strategies for adolescents with intellectual disability (Quint, 2008; Rodgers and Lipscombe, 2005). There is also often an increased development of adaptive skills of intellectually disabled adolescents with time, even among individuals dependent on their caretakers, which eventually leads to a gradual improvement in their ability to manage personal care (Grover, 2002). Gomez et al. (2012) have suggested that the provision of information and training to the adolescents with intellectual disability should begin way before menarche, at around nine years of age, so that they are prepared for the milestone, along with 'practice periods' as a sort of rehearsal before menarche, which included getting used to wearing a pad and spending time to select a pad of an appropriate shape and size. Klett and Turan (2012) developed a 'social story intervention' to teach menstrual management skills to three young women with autistic spectrum disorders with considerable success.

Four of the adolescents were handling their menstrual management almost independently and their mothers reported training them repeatedly, sometimes with the help of an older daughter or female domestic help. Some of these respondents also mentioned the early acquaintance of the adolescent with menstruation and sanitary napkins, on account of regularly witnessing the sister manage her own menstrual cycle. This confirms the significance of providing information to individuals with intellectual disability even though there may be uncertainty about their understanding capacity (Swenson and Havens, 1987). Although not every adolescent would eventually be able to achieve independent handling of the menstrual cycle, not providing the means and the opportunity to get involved in her own menstrual management would amount to deprivation of the basic human rights of the adolescent.

## Conclusions and recommendations

The management of menstrual concerns of adolescents with intellectual disability should follow approaches similar to those undertaken for non-disabled women, i.e. those which align with the human rights of disabled persons and the reproductive rights of women as well as recognize the intersection entailing the rights of intellectually disabled adolescents to reproductive freedom.

### *Policy level*

The newly notified Right of Persons with Disabilities Bill 2016 should be followed up with new provisions to bring into focus the concerns of intellectually disabled women, using UN CRPD as a road map. A protocol needs to be drawn up to ensure that elective surgical procedures in the case of non-institutionalized intellectually disabled individuals follow an objective process, with legal provisions to protect them from rights' abuse. Disability rights activists, gender specialists, and intellectually disabled persons associations should be involved to ensure inclusive decision making.

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The Menstrual Hygiene Management guidelines of the Government of India should explicitly acknowledge the special needs of the intellectually disabled adolescents and provide clear directions for the provision of additional support to the families, schools, and NGOs associated with intellectually disabled adolescents.

Interdisciplinary research in the area of menstrual hygiene management of intellectually disabled persons needs to be encouraged to put forth different approaches possible for the skill development of individuals with intellectual disability, followed by development of context-specific training resources for the caretakers of intellectually disabled adolescents. The dearth of specialized para-medical personnel needs to be improved by offering more courses and more positions in the area of special education and intellectual disability support.

### *Medical profession*

Medical professionals, especially gynaecologists, paediatricians, physicians, and other medical professionals in private as well as public facilities, who are usually consulted by families for reproductive health issues in intellectually disabled adolescents, should treat the young women on a par with their non-disabled peers. Incompetence should not be automatically assumed and the adolescent should be involved in the decision making as far as her capacities allow.

### *Civil society*

Civil society should aim to bring disabled persons and their families to the forefront of advocacy efforts while allowing them to set the agendas and drive the disability rights movement. In the absence of sufficient infrastructure, existing e-resources can be made available to support parents and adolescents. Special schools should support the creation of informal support groups and online forums for experience sharing involving the families of students with intellectual disability.

### *Family level*

At the family level the parents should reach out to parents of other intellectually disabled adolescents to form formal and informal associations and open new channels of dialogue.

## Limitations

The study focused only on adolescents with intellectual disability 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. Moreover, the study concentrates on only adolescents, and their current method of menstrual management might be an interim strategy. It is possible that their parents opt for another strategy as they grow older and the menstrual issues change.

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