Barriers to Menstrual Hygiene Management Faced by Adolescents and Young People with a Disability, and their Carers in the Kavrepalanchok District, Nepal

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Abstract

Background Menstrual hygiene management (MHM) is a recognised public health, social and educational issue, which must be achieved to allow the realisation of human rights. People with disabilities are likely to experience layers of discrimination when they are menstruating, but little evidence exists on this topic.

Methods The study aims to investigate the barriers to MHM that people with a disability, and their carers, face in the Kavrepalanchok, Nepal, using qualitative methods. Twenty people with disabilities, aged 15 to 24, who menstruate and experience ‘a lot of difficult’ or more across one or more of the Washington Group functional domains were included, as well as 13 carers who provide menstrual support to these individuals. Two stages of purposive sampling and snowball sampling were applied to identify participants. We used different approaches to investigating barriers to MHM including: in-depth interviews, PhotoVoice and ranking, market survey of menstrual products and user preference with ranking, accessibility and safety audits of the water and sanitation facilities. We analysed data thematically, using Nvivo 11.

Results Barriers to MHM experienced by people with disabilities differ according to the functional limitation. Inaccessible water, sanitation and hygiene facilities were a major challenge for people with mobility, self-care and visual limitations. People with intellectual impairments had difficulty accessing MHM information and their carers despaired when they showed their menstrual blood to others, which could result in abuse. No support mechanisms exist for carers for MHM and they felt overwhelmed and isolated. Menstrual discomfort was a major challenge; these were managed with home remedies, or not at all. Most participants followed menstrual restrictions, which were widespread and expected, for fear of being cursed if they did not. As disability is often viewed as a curse, this demonstrates the layers of discrimination faced.

Conclusion Issues related to MHM for people with disabilities is more complex than for others in the population due to the additional disability discrimination and functional limitations experienced. Attention to, and resourcing for disability inclusive MHM must be prioritised for progress to be made towards the Sustainable Development Goals, which aims to ‘Leave No One Behind’.

1. Background

Menstrual hygiene management (MHM) is a recognised public health, social and educational issue (1). Research shows that the realisation of human rights is inhibited by lack of provision for MHM, including the right to education, health and work (2-7). This can happen when there is: inadequate physical water, sanitation and hygiene (WASH) infrastructure to support menstruation at home and in public spaces, a lack of affordable, comfortable and appropriate menstrual products, a lack of accurate information on the menstrual cycle and how to manage it with dignity, as well as harmful social beliefs and taboos related to menstruation.

Underlying these issues is menstrual stigma, which is rooted in power and gender inequalities, and means that menstruation is not often openly discussed. This discourages sharing accurate information on the menstrual cycle, and how to manage it hygienically and with dignity (8). It also leads people to be unsure how they can seek support at home, at school or through healthcare services (8). This is the case in Nepal, where menstruation is not spoken about openly, and many pre-pubescent girls do not receive information about menstruation, so their first menstrual cycle can be a frightening experience (9, 10). Accurate information on the menstrual cycle and how to manage it hygienically is likewise limited (11). Management of menstrual discomfort is limited and menstrual hygiene information is predominantly shared between family members, and focuses on the use of menstrual products and maintaining the current social beliefs and taboos surrounding menstruation (9). In this context, unhygienic practices are common (9).

Cultural, religious and behavioural expectations related to menstruation varies globally and within countries, as does the extent to which these impact on people’s ability to fully participate in society when they are menstruating. A recent study in Nepal, found that 89% of women and girls experienced restrictions whilst menstruating (12), which involves the seclusion from the community and within the home (10, 13, 14). Within Nepal, the extent to which menstrual restrictions are followed relates to caste and religion; 81.3% of the population are Hindu and adhere to the caste system, which is based on ritual impurity and purity (11, 15). Caste can determine individual’s behaviours, including how strictly menstrual restrictions are followed. As Brahmins are the upper-caste, they tend to follow

menstrual restrictions closely so that they are not contaminated by menstrual blood (12, 16, 17). Another group who often experiences difficulties with MHM are people with disabilities (5). Disability is the largest minority group: 15% of the world's population have a disability and 80% of people with disabilities live in LMICs (18). In many countries, misconceptions exist around disability in relation to MHM, such as people with disabilities do not have the same reproductive systems as non-disabled people so may not menstruate and cannot have children, or people with disabilities are considered contagious, dirty and impure (18-21). Without social support, carers struggle to support another person's menstrual cycle (22-25). Management strategies applied include putting the person with a disability on long-term contraception, limiting their physical mobility during menstruation and sterilisation (23-27). Therefore, people with disabilities living in low- and middle-income countries may face layers of discrimination when they are menstruating. These may negatively impact on the extent to which they can fulfil their human rights, including education, water and sanitation, and sexual and reproductive rights, but little evidence exists on this issue (5, 28, 29).

The study aims to investigate the barriers to MHM that adolescents and young people with a disability and their carers face in the Kavrepalanchok (Kavre) district, Nepal using qualitative methods.

2. Methods

2.1 Research design

Phenomenological research methodology underpins this study (30). It recognises menstruation as a physiological and social phenomenon: a participant's life experiences of menstruation are situated within socio-cultural factors, and menstrual related behaviours and opinions are shaped by individual and external influences.

2.2 Study site

The Kavre district was selected as the study site as the research partner, WaterAid implements MHM programmes there with local NGOs, Karnali Integrated Rural Development and Research Centre (KIRDAC) and Centre for Integrated Urban Development (CIUD). The Kavre district is one of Nepal's 77 districts, with a population of 381,937, it is classified as 'mid-hilly' (31). The district's basic water coverage is 89% and basic sanitation coverage is 98% (unpublished data). The Kavre district was the epicentre of the 2015 earthquakes and much of its infrastructure was destroyed, including

household latrines. Efforts to rebuild infrastructure remain ongoing.

2.3 Study population and sample size

The study population and inclusion criteria comprised:

1. 20 individuals, aged between 15 and 24 years, who menstruate and were considered to have a disability (i.e. experience 'a lot of difficult' or more across one or more of the following functional domains: seeing, hearing, walking, remembering or concentrating, communicating, and self-care (32)). We aimed to identify at least two potential participants across each functional domain.
2. 13 carers who provide menstrual support to these individuals.

Details are captured in Table 1.

Table 1
Study population characteristics

Study population	**Variables**
Person with a disability	*Age group*
	15-19
	20-24
	Location
	Urban
	Rural
	Functional domain
	Seeing
	Hearing
	Walking or climbing steps
	Remembering or concentrating
	Self-care
	Communicating
	Multiple
Carer	*Location*
	Urban
	Rural
	Functional domain of the person with a disability
	Seeing
	Hearing
	Walking or climbing steps
	Remembering or concentrating
	Self-care
	Communicating
	Multiple
	Person providing care
	Relative
	Professional

Two stages of purposive sampling were applied to identify potentially eligible participants. Firstly, the lead author explained the Washington Group short set of questions (25) to WaterAid's partner

organisations: KIRDAC, CIUD and government social mobilisers, who had knowledge of people with disabilities living in the study area. These representatives identified 20 females they thought experienced ‘a lot of difficulty’ or more across any of the functional domains, and were aged between 15 and 24 years. Secondly, the research team visited the potential participants and asked them the Washington Group short set of questions (25), their age and if they menstruate to confirm if they met the inclusion criteria. Those that did not qualify based on self-report, age group or menstruation status were excluded. We did not meet our target sample through purposive sampling alone, so applied snowball sampling as a secondary approach until our target sample size was reached.

2.4 Data collection methods and activities

Data collection was carried out in September 2017. The study applied four different qualitative methods: In-depth interviews, Photovoice, Accessibility and safety audit, Market survey and product attribute assessment (described in Table 2). Data saturation was discussed by the research team throughout the data collection process, and data collection continued until this was reached. Transcripts were not returned to participants for comment or correction, but overall research findings were shared with participants at a later date (see Wilbur and Bright, 2019(33)).

Table 2

Summary of methods

Description	**Purpose**	**Method**
In-depth interviews	To understand barriers to MHM, and how these effect participants’ lives	Interviews were undertaken at the participant’s h hospital and lasted up to one hour. With consent, Nepali and recorded on a voice recorder, and trar Field notes were made after the interviews.
PhotoVoice / PhotoVoice ranking	To allow participants to express themselves visually; allow participants time to reflect on the issues, and rank their experiences against perceived levels of importance	Cameras were given to participants, who were as their own menstrual experience or of caring for a cycle. Photos were printed and discussed with the captions and ranked the photos according to whic important issue. The process took 0.5 to 1 day pe
Accessibility and safety audits of the water and sanitation facility	To observe if any participants face accessibility or safety barriers when using them (revised version of *WEDC, WaterAid (2013) Accessibility and safety audit* (34))	Rapid observation of the place the participant cha menstrual product and bathes, conducted after th analysis.
Market survey and product attribute assessment	To understand the menstrual products available, preference and reasons for this; conducted during the in-depth interview	A range of menstrual products available on the lo participants during interviews. Researchers asked any, their preference with reasons for why, and to to preference. A photo was taken of the products

2.5 Data analysis

Data was analysed as it was generated. For instance, each team member took field notes, and the lead author coded and analysed transcriptions during the data collection. The research team met regularly to discuss their influence within the data collection process, emerging themes, and to review

and revise the interview technique and topic guides. Emerging themes were explored in subsequent interviews.

Interviews were captured on voice recorders, and were translated and transcribed into English. The translated transcriptions were checked for accuracy by Nepali researchers in the team and WaterAid Nepal staff. A thematic analytical approach was used to analyse findings, which involved: 1) familiarisation with the data, 2) generation of initial codes that were structured according to the adapted socio-ecological framework for menstrual hygiene management (5), 3) searching for themes, 4) reviewing themes, 5) defining and naming themes and 6) producing the report (35). Codes were compared and relationships between codes were identified and analysed using analytic memos in NVivo 11.

2.6 Research team and training

Qualitative data was generated by the lead author (JW), a Nepali Research Coordinator (SK) and two Nepali Field Researchers (AS and AG). As we are committed to disability-inclusive research, we recruited AS (with visual limitations) and AG (who has mobility limitations) as field researchers and the lead author and SK mentored them throughout the data collection so that they could develop their research skills. All the research team members were women.

The research team participated in a week-long training, led by the lead author and a second experienced qualitative researcher on how to conduct research ethically with people who have a disability and their carers. Topics covered included the informed consent process, generating data with people who have different impairments using qualitative methods, and MHM. Data collection tools were tested and refined during this training.

3. Results

3.1 The barriers to MHM differ depending on the functional limitation

People with mobility limitations identified challenges related to their use of the menstrual product. For instance, some reported that the type and positioning of the product made it uncomfortable to sit in a wheelchair all day. Many other participants were concerned that the product was not absorbable enough and worried about leakages.

"*When I sit in the wheelchair the pads may fold or something like that might happen which makes me feel uneasy […]. It becomes very uncomfortable to sit. Unlike my sisters who keep moving around, I have to sit in a place continuously. I get angry then and gets difficult"* (person with mobility and self-care limitation).

Inaccessible WASH facilities affected people who had mobility limitations most severely as they were unable to easily or safely reach the place they change their menstrual product, comfortably change, wash or dry their menstrual product, or wash their bodies in private.

"[I] need to wash menstrual cloth in toilet. There is no water in the toilet…. I have to carry water in a bucket while also managing the crutches […] I can't wash [the menstrual] cloths either. [……] I keep it under my bed when I can't wash it, and wash it when I get water. I have problem during menstruation when there is no water" (person with mobility limitation).

"For those with spinal cord injury, it is easier and necessary for them to use this kind of [raised] toilet. During period they can't stand to change their pads so these kind of toilet become more essential" (person with mobility limitation).

All of the participants with functional limitations who participated in PhotoVoice took images to show how inaccessible WASH facilities presented a major challenge. Of the nine photos taken by Sharmila and Babita (who have mobility and/or self-care limitations), five images related to inaccessible WASH facilities. Tulasa, who has self-care limitations, took four photos and one related to a lack of safe and private WASH facilities (see Supporting document 1).

Some participants with limitations in remembering or concentrating, had difficulties retaining MHM information. Carers repeatedly told them how to change and wash the menstrual cloth every month and every time it needed changing, which carers found frustrating.

People with visual limitations highlighted difficulties seeing blood on clothes and bed sheets, and disposing of the product discretely, which was stressful and worrying because of the prevailing menstrual taboos:

"While washing the pants we know which parts to wash properly, but in the bed sheets since I was not able to see the stains it was difficult for me to clean the stains properly [….] For throwing the pads in

the dustbin, sometimes dustbin may be outside the toilet, so I might have to throw them outside of the toilet. At those times I feel worried if some male person from my family would see them (person with visual limitation).

Participants with self-care limitations felt humiliated when asking another person to change their menstrual product, and guilt seeing their carer handle their menstrual blood as they were driven by the shame and disgust related to menstruation and menstrual blood. Consequently, they changed their menstrual product less frequently than they wanted to.

"She says that the blood smells during my periods. [….] She finds it disgusting. […] I feel bad. If I had my own hands, I didn't have to suffer so much. I didn't have to depend on someone else. I could do it on my own; it's not something you show it to others. I feel like crying. I feel bad" (person with self-care limitation).

"Even to change a pad I have to wait until my sister comes in the evening and helps me change, if not, I will have to wear the same pad till tomorrow" (person with self-care limitation).

In contrast, people with hearing limitations interviewed said they did not face any specific challenges explicitly related to their disability. However, these participants all attended a school for children with hearing impairments and said they read about menstruation in books, and were supported by friends and teachers to practically manage menstruation. This finding may not reflect the experiences of people with hearing limitations who do not attend this type of school.

3.2 Disposable menstrual pads are preferable, but disposal practices and services are inadequate

Results from the menstrual product market survey show that preference is highly individualised.

Table 3 captures the results of the market survey across all participants and demonstrates that disposable commercial pads with wings were the most preferred, and cloth the least. No data was recorded for five participants.

Table 3

Market survey: most and least preferred menstrual product

Menstrual product	Preference			
	Most preferred	%	Least preferred	%
Disposable commercial pad with wings	8	50%	0	0%
Disposable commercial pad without wings	2	13%	3	23%
Cloth	3	19%	5	38%
Reusable tailor-made pad with wings	3	19%	4	31%
Reusable tailor-made pad without wings	0	0%	0	0%
Nappy	0	0%	1	8%
Total	16	100%	13	100

Though the disposable commercial pads with wings were preferred by participants, hygienic and environmentally friendly disposal behaviours were often inadequate. Many participants threw used disposable commercial pads in rivers or down hillsides, so other people were less like to see the used product. Some wrapped the pads in plastic, so they were less visible. Reasons include a lack of waste disposal options and little knowledge about the consequences.

There were no clear preferences for product type by functional limitation, because of the small number of participants in each category (results are captured in Supporting document 2). Through PhotoVoice, Sharmila (who has a mobility limitation) explained that she prefers using disposable commercial pads as they do not require washing, which she finds particularly challenging as she is unable to carry water and use her crutches (see Supporting document 1).

3.3 Pre and menstrual symptoms are not well understood or managed

Many participants said that menstrual cramps were one of the biggest challenges they face when menstruating. Pain management strategies included home remedies, such as drinking warm water, sleeping and tying a cloth tightly around the abdomen. There is a belief that pain relief tablets can damage your health, so few people took them and few carers provided them.

“If I take medicine I will have more pain during the next period that’s why I don’t take any medicine” (person with mobility limitation).

A lack of pain management may have more negatively impacted people who experience difficulties communicating, or remembering or concentrating as they may not have understood the cause of the discomfort, or been able to communicate if they were in pain. Changes in behaviour reported before and during menstruation for these participants included withdrawal, increased hyperactivity, self-

injury, showing their used menstrual product to others, excessive sleeping, being frightened, withdrawn and refusing to eat. Without social support mechanisms to help understand and respond to the changes in behaviour, carers felt frustrated and overwhelmed by these behaviours.

3.4 Menstrual restrictions add additional layers of challenges for people with disabilities and carers

Most participants, especially Brahmins, followed menstrual restrictions, which dictate that menstruating people must sleep separately, are not allowed to worship, enter the kitchen, cook or touch plants, because it is believed that menstrual blood is dirty and contaminating.

“Dirty blood leaves the body during period so we should not worship during that time” (person with hearing limitation).

Of the three participants with functional limitations who completed PhotoVoice, two images focussed on menstrual restrictions. Tulasa took a photo of the hut, outside her home that she sleeps in when she is menstruating. During an in-depth interview, one participant also explained she lived in a cow shed during menstruation when at home, which may make her vulnerable to abuse and violence.

“I had to be banished in the cowshed for seven to 12 days” (person with hearing limitation).

If a person does not adhere to the restrictions, it is believed that the gods will curse the family. Disability was also viewed as a curse. Therefore, people feared that they will be doubly cursed if they did not follow restrictions.

“….I am already suffering like this and people anyway say that my disability is a curse, so if I don’t obey I will be further cursed” (person with mobility limitation).

People with visual limitations reported that menstrual restrictions were a major source of concern, fearing that they might inadvertently touch a ‘restricted object’, and thus lead the gods to curse the family.

“In house, when I move here and there, I may touch things [that are not allowed to]. I also cannot go against my family. It has been followed by our family, it is a tradition. […] I feel odd to move around because I was worried that I might touch them” (person with seeing limitation).

Two of four photos taken by Bishnu (a carer of a young person with limitations

remembering/concentrating) during PhotoVoice, focused on menstrual restrictions. She ranked these as the biggest challenges she faces when her daughter menstruates. Similarly, during in-depth interviews, carers of people with limitations in remembering or concentrating reported being worried that their family would be cursed if restrictions were not followed. Additionally, carers of people with remembering limitations explained some people did not wear a menstrual cloth, preferring to soak up the menstrual blood with underwear or trousers. Some participants isolated themselves when they are menstruating and others went out with blood stained clothes. One carer explained*:*

"She just walks like that with blood on her clothes" (Carer of a person with remembering and concentrating, self-care, communicating limitations).

"She would take it out and show it to others and would tell them to look at it. It was embarrassing" (Carer of a person with remembering or concentrating limitation).

These behaviours angered community members and made carers stressed, angry and exhausted. The result was that verbal and physical abuse was directed at the person with a disability by family members and members of the public.

1.1 Lack of menstrual hygiene information, training and support

Some mothers were surprised when their daughters reached menarche and one mother did not believe her daughter who told her she was bleeding until she saw it. The belief that people with disabilities do not have the same reproductive systems as non-disabled people (18, 20), means they are even less likely to receive it than non-disabled people. Additionally, information on menstrual hygiene was commonly withheld from people with remembering or concentrating limitations, because of the perception that they would not understand it. However, one carer explained that her daughter *"took one year to understand the process and experience"* (carer of a person with remembering or concentrating, self-care, understanding or communication limitations). This quote demonstrates that people may be able to understand information about the menstrual cycle, if it is tailored to their level of understanding and repeated regularly, though this would be dependent on the type and extent of their functional limitation.

Menstrual hygiene information is mainly delivered at schools, but many participants with remembering or concentrating limitations did not attend school so were excluded from receiving this information. One participant was sent home from school at the onset of menarche, marking the end of her formal education.

“That day, [her] teacher showed up at the house and suggested not to send [her] to the school because [she] had her menstruation in the classroom and the blood leaked on the bench she was sitting on. They said that it is difficult for [her] to take care of herself during the mensuration so it would be better that she stays at home and we take care of her” (carer of a person with remembering or concentrating, self-care, understanding or communication limitations).

Providing menstrual care by carers was viewed as a very private issue: very few carers discussed this subject with other people, including medical professionals. No support or support networks existed for carers, and many carers felt isolated and overwhelmed. Some carers were unable to leave the home because of caring duties. This meant they were unable to access MHM information shared at community meetings and events.

“We don’t know anything else. I don’t go anywhere. I hear that people come to our village to teach about those things, but I haven’t been taught about the menstruation management” (carer of a person with remembering or concentrating, communicating, self-care limitations).

Two carers of people with self-care limitations requested MHM training for the young person in order to increase the young person’s independence. A motivation for carers was fear for the future, as they worried about who would look after their daughter when they are no longer able to.

“For now, I am here, but in future we don’t know what will be the situation. […]. I won’t live long but she has lots of time, I am very worried" (carer of a person with remembering or concentrating, self-care limitations).

4. Discussion

This qualitative study among people with disabilities and their carers living in Nepal responds to the calls for information on the MHM barriers faced by people with disabilities, and contributes new evidence to the global discourse on MHM for the largest minority group (5, 36-39). To the authors’

knowledge, this is the only study to date which investigates the barriers experienced across all the functional domains. It found that the barriers to MHM are complex and differ according to functional limitation. Furthermore, these barriers inhibit the person with a disability's ability to live a dignified life and fulfil their human rights, including going to school. For instance, menstrual discomfort was a key challenge expressed by participants and carers did not always manage this, which raises concerns that unmanaged pain which may negatively impact on behaviours. A study in New Zealand found that only one of nine people on the autistic spectrum in the sample were able to inform their carers that they were experiencing menstrual discomfort, even though all had good communication skills (40). Three studies linked an inability of people on the autistic spectrum to understand the reason for menstrual discomfort or communicate when in pain, with increased hyperactivity, self-injury, fatigue and anger, which was also highlighted in this study (22, 23, 40).

A new contribution to existing literature made by this study, is the fear expressed by people with disabilities that they would be 'doubly cursed' if they did not adhere to the menstrual restrictions; this demonstrates the layers of stigma and discrimination faced by people with disabilities in Nepal when they menstruate. However, the finding that carers were particularly concerned that the young person with difficulties remembering or concentrating would not follow cultural and social norms (including menstrual restrictions), and that they would refuse to wear a menstrual product and go out with menstrual blood on her clothes is highlighted in studies carried out in India (23), Taiwan (41), the UK (42) and Canada (26). Our study showed that there is a lack of social support and information about how to care for another person's menstrual cycle, and that menstrual care is viewed as a private issue by carers is prevalent in other studies (22, 23, 43-45). In this study, as in others, a lack of social support and information about how to care for another person's menstrual cycle, contributes to carers feeling overwhelmed and isolated (22, 23, 43-45). This can negatively affect carer's wellbeing, which in turn could impact on the person they support (5).

4.1 Study implications

To meet the MHM requirements of people living with a disability, water, sanitation and hygiene facilities must be located close to where the person lives, and MHM interventions must be developed

appropriate for each functional domain. For instance, people with mobility, self-care and seeing limitations may require an accessible water point inside latrines, accessible locks on toilet doors, raised toilet seats, non-slippery toilet floor, accessible washing and drying area for the body, clothes and menstrual products, as well disposal mechanisms that can be easily used by everyone. Building on existing approaches, menstrual hygiene information should be communicated in ways that are accessible for people with hearing and seeing limitations (46, 47). People with difficulties in remembering and concentrating need simple and repetitive information on menstrual hygiene and how to manage menstruation with dignity.

The study findings demonstrate that people with disabilities can be separated into those who manage their menstrual cycle independently, but with great difficulty, and those who are reliant on carers for MHM. Existing MHM interventions are delivered directly to the person who menstruates, but for people with disabilities, there may be a third party involved who also requires MHM information and support so that they can help another person manage their menstruation comfortably, hygienically and with dignity. Low cost lifting devices to support carers bathe and change a menstrual product should also be widely promoted to support carers and protect the person with disability's dignity (see section 4.4 in Rosato-Scott et al (2019) (48).

More research is needed to identify comfortable, appropriate and affordable menstrual products for all people with disabilities, including people who are unable to sit out of bed unaided and / or who experience incontinence. Clear information on each product option, their implications for use and disposal need to be disseminated so that people can make informed choices. Policy makers and implementers should be encouraged to strengthen waste management service chains and incorporate menstrual waste management within it. Research exploring the barriers to MHM experienced by people with disabilities and their carers in different LMIC settings must be conducted to allow for comparison. Findings should be incorporated into the global MHM agenda alongside researching MHM for school going girls and non-disabled women (49-51).

As a result of this research, we developed, delivered and evaluated the Bishesta campaign: a MHM behaviour change intervention for people with intellectual impairments and their carers in Nepal (33,

52). It promotes communication between young people and carers about what menstruation is, and how to manage it hygienically and with dignity. Information is repetitive, simple and conveyed through role play and a doll that has removable clothes and a clean and used menstrual product, which participants practice changing and disposing of the hygienically. Campaign components, including a menstrual storage bag and visual stories are distributed to ensure target behaviours are attractive and easy to carry out. The campaign is implemented in a group setting to engender social support and peer to peer support is encouraged. Evaluation findings showed improvements across all the target behaviours and that the Bishesta campaign is now ready to be tested at a wider scale (52).

4.2 Strengths and limitations

The strengths of this study include the use of a range of qualitative methods to explore a very private topic with people who may never have spoken about menstruation to another person. Data triangulation was applied to compare information generated through different modes, and data saturation was perceived to have been reached. Another strength was the inclusion of people with disabilities on the research team; our perception is that they were able to challenge misconceptions of carers that people with disabilities are unable to work and therefore always reliant on family members.

In terms of limitations, several possible sources of bias arose due to different types of missing data. Though participants were recruited from each functional domain, we were unable directly interview one person who experiences difficulties remembering and concentrating. As participants in this functional domain were unable to fully understand the consent process, their carers were interviewed instead, which may not reflect their own perspectives. Furthermore, despite our efforts we were only able to complete the market survey with 80% (n=16) of participants with a disability; the remaining 20% (n-4) declined to answer.

5. Conclusion

This study highlights the additional barriers to MHM that people with disabilities, and their carers experience, as well as the negative impacts that these have on their physical, emotional, mental and social wellbeing. Issues related to MHM for people with disabilities is even more complex than for

others in the population, due to the additional disability discrimination and constraints experienced, so require innovative and adapted solutions to existing MHM approaches that often fail to reach them. Even though MHM is not explicitly included in the Sustainable Development Goals (SDGs), it is essential for achieving the goals on gender, health and education (53). Disability is the largest minority group, so attention to, and resourcing for disability inclusive MHM must be prioritised for progress to be made within the last 10 years of the SDGs, which aims to ‘Leave No One Behind’.

6. List Of Abbreviations

CIUD	Centre for Integrated Urban Development
CRPD	Convention on the Rights of Persons with Disabilities
KIRDAC	Karnali Integrated Rural Development and Research Centre
LMICs	Low and middle income countries
LSHTM	London School of Hygiene and Tropical Medicine
MHM	Menstrual hygiene management
WASH	Water, sanitation and hygiene
WEDC	Water and Engineering Development Centre

Declarations

Ethics Approval and Consent to Participate

Ethical approval for the study was granted by from the Research Ethics Committee at the LSHTM (reference: 12091) and the Nepal Health Research Council (reference: 102/2017).

Informed consent was obtained and witnessed from each participant before enrolment. An information sheet/consent form (in Nepali) was given to, or read out to the participants by the research team. Informed written (or a thumbprint if illiterate) consent was received from carers and implementers. Assent was sought from participants under 18 years, and consent sought from their carer or parent. Participants were given the option to have their carer present during the interview. Assent also was sought from people who could not fully understand the consent process, and then consent sought from carers, who were interviewed instead of the person with a disability. It was made clear that participation was voluntary. Methods were adapted to be fully inclusive. For example, for individuals who speak in sign language, sign language interpreters will be available. Simplified information sheets were available for participants with remembering or concentrating and communication limitations.

The ethics and consent process of PhotoVoice was very thorough to ensure that the participants understood the purpose of the activity and what they are agreeing to. Written consent was sought at the start of the process. The researcher explained how participants could take photos without

showing their face and how to represent menstrual issues in a dignified way. Secondary written consent was sought after the photos were printed. This consent related to how the photos could be used and if the photographer wanted to be credited by her real name or a pseudonym. This is done after the photos were taken, the interview conducted and the photo ranking so the participant could make a better judgement about how they wish them to be used. No conflict of interest is reported by any of the manuscript authors.

Consent for Publication

All of the PhotoVoice participants agreed to be credited for their photographs, using their real names. All participants agreed that WaterAid and the LSHTM could use the photos, their names and content from their interviews in their work.

No individual or identifiable personal details gained through in-depth interviews are included in this manuscript.

Availability of data and material

The authors confirm that the data supporting the findings of this study are available within the article [and/or] its supplementary materials.

Competing interests

The authors declare that they have no competing interests

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Authors' contributions

Conceptualisation, JW; methodology, JW, HK, BT, and SH; training of research team, JW formal analysis, JW; investigation, JW, SK, AS and AG; data curation, JW; supervision, JW, HK, TM, SH and BT; project management, coordination and administration, JW; funding acquisition, TM; writing—original draft preparation, JW; writing, review and editing, JW; visualisation, JW; manuscript review, HK, BT, SH, SK.

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