

# “The weather is not good”: exploring the menstrual health experiences of menstruators with and without disabilities in Vanuatu

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## Summary

**Background** Menstrual health is essential for gender equality and achieving the sustainable development goals. Though currently lacking, understanding and addressing menstrual health and social related inequalities requires comparison of experiences between menstruators with and without disabilities.

**Methods** We completed a mixed-methods population-based study of water, sanitation and hygiene, disability and menstrual health in TORBA and SANMA Provinces, Vanuatu. Methods included a census, nested case-control study, in-depth interviews (IDIs), focus group discussions (FGDs), PhotoVoice and structured observations. We undertook a population census of 11,000+ households and recruited 164 menstruators with and 169 without disabilities (aged 10-45) into a nested case-control study. 20 menstruators across both groups were selected for the qualitative component.

**Findings** Menstruators with disabilities were five times (adjusted Odds Ratio [aOR] 5.5, 95% Confidence Interval 1.8 – 16.5) more likely to use different bathing facilities to others in the household, nearly twice as likely (1.8, 1.1 – 3.1) to miss social activities, and three times (3.0, 1.6 – 5.7) more likely to eat alone during menstruation. Menstrual restrictions were widespread for all, but collecting water and managing menstrual materials was harder for menstruators with disabilities, particularly those requiring caregivers’ support. These factors negatively impacted menstruators with disabilities’ comfort, safety and hygiene, yet they reported less interference of menstruation on participation.

**Interpretation** Negative factors affecting all menstruators disproportionately impact those with disabilities, compounding existing inequalities. Menstruators with disabilities may have reported less interference because they are accustomed to greater participation restrictions than others.

**Funding** Australian Government’s Water for Women fund and public donations.

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## Introduction

Menstrual health is an important global public health issue and essential for the achievement of the Sustainable Development Goals and gender equality.<sup>1-3</sup> Approximately 1.9 billion women and girls globally menstruate.<sup>4</sup> Many living in low-and middle-income countries (LMICs) lack the water and sanitation facilities and knowledge about menstruation to manage it

hygienically.<sup>1,5-9</sup> Without access to adequate menstrual health, menstruators may also be at risk of other health issues such as reproductive tract infections.<sup>10,11</sup>

Menstrual stigma and discrimination are widespread, and leads to the exclusion of menstruators from community life, school, and employment.<sup>12-14</sup> Menstrual health is defined as a “state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity, in relation to the menstrual cycle”.<sup>15</sup> Enablers for menstrual health include accurate information about the menstrual cycle and how to manage it comfortably and hygienically,

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The Lancet Regional Health - Western Pacific  
2021;00: 100325  
Published online xxx  
<https://doi.org/10.1016/j.lanwpc.2021.100325>

### Research in context

#### *Evidence before this study*

Menstrual health is a 'state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity, in relation to the menstrual cycle'. Many menstruators, particularly those living in low-and middle-income countries (LMICs), are unable to realise this. Menstrual health is a recognised public health issue which must be achieved. It negatively impacts gender equality, social participation, education, health, and employment. Experiences of menstruation are not homogenous, with evidence showing that discrimination experienced by those with disabilities is compounded during menstruation. However, an in-depth comparison between the experiences of menstruators with and without disabilities does not exist.

#### *Added value of this study*

This is the first mixed-methods study to explore menstrual health experiences of people with and without disabilities in a LMIC. Among menstruators with disabilities, we include analyses across different impairments experienced, and for those who require support from caregivers. The study was conducted in TORBA and SANMA Provinces in Vanuatu, which includes one of the country's most geographically remote locations. The study design enabled a deeper and more nuanced understanding of the phenomenon explored, enabling the development of evidence-based policy and practice recommendations to improve menstrual health for menstruators with and without disabilities living in Vanuatu, and other LMICs. This study was a collaborative effort across academic institutions, non-government organisations, Organisations of Persons with Disabilities and official statistical agencies.

#### *Implications of all the available evidence*

This study reveals the challenges faced by menstruators with and without disabilities in the SANMA and TORBA provinces. It highlights commonalities and differences, and demonstrates how menstruation intensifies inequalities already experienced by menstruators with disabilities, especially those who rely on caregivers. Findings highlight the importance of inclusive water, sanitation and hygiene facilities at the household level, challenging menstrual and disability related stigma and discrimination, and integrating disability within any effort to improve menstrual health. Due to the additional challenges experienced by menstruators with disabilities who are reliant on others, support must be provided to caregivers to enable menstrual health for individuals they assist. This includes increasing access to assistive devices, such as lifting devices. Mothers and sisters provided menstrual care to individuals, thus demonstrating the gendered nature of caregiving. People with disabilities must be at the front and centre of any development efforts, including those to improve menstrual health.

availability of appropriate and affordable menstrual materials, access to appropriate water and sanitation facilities and health services, and a positive environment that is free from stigma and discrimination.<sup>15</sup>

Experiences of menstruation are not homogenous. In addition to the issues faced by menstruators without disabilities, those with disabilities often face barriers in accessing the water and sanitation facilities. For instance, people with disabilities were stopped using public toilets in a study in Uganda because it was believed that disability is 'dirty' and 'contagious'.<sup>16,17</sup> Therefore, menstruators with disabilities may experience a compounded sense of shame and discrimination with both disability and menstruation considered taboo in many settings.<sup>18-22</sup> These issues negatively impact menstruators' ability to participate fully in daily life: the latest Joint Monitoring report highlights that women with disabilities were 50% less likely to participate in usual activities when they were menstruating compared to those without disabilities.<sup>4</sup> Disability is defined as an umbrella term for impairments, activities and participation limitations.<sup>23</sup>

Menstruators with disabilities, especially those with intellectual impairments, often receive little or no information about menstruation, or how to manage it hygienically and with dignity.<sup>18</sup> Furthermore, approximately 190 million people with disabilities rely on informal or professional caregivers for assistance, which may include supporting menstrual health.<sup>24</sup> Evidence shows that caregivers do not receive adequate support or information about how to care for another individual's menstrual health, that related tasks - such as changing a menstrual material, are not viewed positively and that some caregivers seek to suppress or permanently stop the individual's menstruation, through long-term contraception or sterilization.<sup>18,25-28</sup>

The first resolution on menstrual hygiene management, human rights and gender equality was adopted by the United Nations Human Rights Council on 5<sup>th</sup> July, 2021.<sup>9</sup> In it, the Office of the High Commissioner for Human Rights calls on Member States to integrate menstrual hygiene management into relevant policies (such as water supply and sanitation, education, and health policies), ensure that public and private water and sanitation facilities cater for menstruation, that menstrual hygiene management information and education is delivered, and that menstrual related stigma and discrimination is addressed. Encouragingly, this resolution recognises that menstruators with disabilities face 'compounding levels of discrimination' and inequalities.<sup>9</sup> Member States are called to ensure menstruators with disabilities have access to WASH facilities to manage menstruation; that menstrual health information and education is accessible, and delivered to menstruators with disabilities out of school, and to their caregivers.

While evidence about disability and menstrual health is increasing, much more is required, including comparisons between the experiences of menstruators with and without disabilities, impairment groups (visual, hearing, mobility, cognition and communication) and for those living in rural and urban areas.<sup>18,20,27-31</sup>

### WASH, disability and menstrual health in Vanuatu

Vanuatu is a Pacific Island Country made up of approximately 83 islands and is ranked 140 out of 189 countries and territories on the Human Development Index.<sup>32</sup> It is widely ranked as the country most at-risk to natural disasters in the world, often experiencing floods, drought, cyclones, earthquakes, tsunamis, and volcanic eruptions.

Since 2000, Vanuatu has made limited progress in national access to basic water and sanitation, and disparities between rural and urban areas are stark.<sup>4</sup> We have previously reported how inadequate clean water and sanitation, a lack of assistive devices (e.g. wheelchairs, bathing seats and lifting devices) and support structures (i.e. handrails, raised toilet seats, commodes) negatively impact the wellbeing of people with disabilities and caregivers in the country.<sup>33</sup>

A small-scale study in Vanuatu, undertaken by World Vision Vanuatu and Care International in 2018, found that menstruation was steeped in taboo and stigma, and limited knowledge about menstruation was widespread, though this was worse for menstruators with disabilities.<sup>34</sup> This trend is reflected in research from the Pacific region, which demonstrates that menstrual related disadvantages were amplified for menstruators with disabilities, as this population was excluded from receiving menstrual health information, and that physical access requirements were overlooked when designing WASH infrastructure.<sup>7</sup>

In response, the Water, Women and Disability study aimed to begin filling this gap by completing a mixed-methods population-based study in TORBA and SANMA Provinces, Vanuatu to explore disability, WASH and menstrual health experiences of menstruators with and without disabilities. These provinces were chosen because SANMA has the greatest burden of WASH-related diseases in the country,<sup>35</sup> and TORBA is the country's most geographically remote province, with the largest numbers of islands. The study informed the development of the Laetem Dak Kona (LDK, "shining light in dark corners") project: an inclusive WASH programme in the TORBA and SANMA Provinces, led by World Vision Vanuatu.

This article presents findings related to menstrual health among menstruators with and without disabilities, including the role of WASH facilities. Findings related to menstrual materials will be published separately. Details of how mixed methods were used to generate evidence for inclusive WASH policy and programming in Vanuatu, disability prevalence,

household and intra-household access to WASH and incontinence data are published in two other papers from this series.<sup>33,36</sup>

### Terminology

In this article we refer to 'menstruators' (people who menstruate) rather than women and girls who menstruate. This inclusive term recognises that gender is non-binary and that cisgender, transgender, gender-neutral people may menstruate.

### Methods

The study methodology is described in detail elsewhere.<sup>33</sup> In brief, we undertook a mixed methods population-based study of disability in TORBA and SANMA Provinces, Vanuatu to assess disability prevalence and demographics, associations with access to WASH and experiences of menstruation. This included a survey, nested case-control study, in-depth interviews, structured observations and PhotoVoice. The research forms the baseline data collection for the LDK inclusive WASH project.

### Study Setting

TORBA and SANMA provinces are the two most northerly in Vanuatu, and consist of small to medium sized islands accessible by boat or small plane. There is one urban municipality (Luganville, in SANMA) across the two, and TORBA is the most geographically remote province nationally.

### Population-based survey

We undertook a complete listing of all households (approximately 14,000) across the two provinces. For each household that agreed to participate, we completed a household roster and a reported functional limitation screen using the Washington Group Short Set and Mental Health Questions for all members 5 years and above. Supplementary material 1, *Household Survey, Section H. Disability Screen for Adults*, contains these questions. The Washington Group questions are the prevailing tool used for measuring disability in population-based surveys and endorsed by numerous United Nations agencies.<sup>37</sup> We report the results from the survey elsewhere.<sup>33</sup>

### Case-Control Study

Following Washington Group recommendations, we categorised respondents who reported "a lot of difficulty" or "unable to do" in any of the six domains of the Short Set as having a disability (see Supplementary material 1).<sup>38</sup> A sub-sample of 800 survey respondents in this group (stratified by sex and age group) were

invited to participate in a nested case-control study (“cases”) alongside an equal number of age (+/- five years), sex and location matched “controls” without a disability. We stratified the sample selection by age-sex group, to allow sufficient power for analyses related to menstrual hygiene among menstruators with and without disabilities. In-depth structured questionnaires were developed, using standardised modules where available, to explore access to and experience of WASH. Menstruators aged 10 or older who reported last menstruating within the last 12 months completed a menstruation module. Questionnaires were forward and back translated, and further modified in pilot-testing. The final questionnaire was delivered via Android tablet using the Open Data Kit software, which enforces data entry and prevents missing data or listwise deletion. The Cantil self-anchoring ladder was used for menstruators to report the interference of menstruation on their daily activities from a scale of 0 to 10.<sup>39</sup>

**Qualitative Study**

**Research team and training.** The qualitative research team consisted of the lead author, and three ni-Vanuatu women who worked for World Vision Vanuatu and Vanuatu Society for People with Disabilities (JI, SS and RP). The research team took part in week-long training, which included menstrual health and how to discuss it confidently, but sensitively within the socio-cultural context. The team were coached and mentored throughout the data collection by the lead author.

**Sample population and size.** The qualitative study sample of menstruators with (n=12), and without (n=8) disabilities was purposively drawn from the nested case-control sample, and is described in Table 1. Two participants with disabilities conducted PhotoVoice, whilst the remaining menstruators with disabilities were interviewed directly or by proxy. Caregivers were interviewed as proxies where menstruators with disabilities were unable to communicate independently

or complete the consent process on their own. We included menstruators with a range of functional limitations, ages and from different locations. All menstruators without disabilities formed focus group discussions.

**Data Analyses.** Methodological triangulation was applied across the following qualitative methods: in-depth interviews, focus group discussions, PhotoVoice and ranking, and observation. Data were analysed iteratively through discussions of emergent findings and review of daily field notes among the research team. On completion, interview recordings were translated and transcribed into English before being checked for completeness by the ni-Vanuatu members of the research team. Drawing on Thomas and Harden’s (2008)<sup>40</sup> guidance on thematic synthesis the whole research team analysed the findings and grouped them into overarching themes. Two researchers then coded data into sub-themes using NVivo 11. Any overlaps or differences between the codes were discussed, agreed and finalised. Quantitative data from the case-control study was analysed in STATA 14.0 using descriptive analyses and multivariate logistic regression to compare outcomes for menstruators with and without disabilities. Logistic regression analyses were adjusted for the potential confounders of age, location (rural versus urban) and socio-economic status (SES) through the following equation:

$$Y = \beta_0 + \beta_1 D + \beta_2 L + \beta_3 A + \beta_4 S + \epsilon$$

Where Y is the outcome of interest (e.g. individual uses a different bathing facility compared to other household members), D is disability status (set to 1 if individual has a disability, 0 if individual does not), L is location (each region assigned a dummy variable), A is age (categorical, in age bands) and S is SES quintile. We generated SES quintiles using Principle Component Analysis which we describe in detail elsewhere.<sup>33</sup> The regression coefficient  $\beta_1$  represents the adjusted odds of the outcome of interest amongst people with disabilities.

We held several participatory results workshops in Port Vila and SANMA to discuss and interpret preliminary findings with stakeholders, and across the

Study population	Method	Age range		Location		Functional domain*					
		18-30	31-45	Rural	Urban	Seeing	Hearing	Mobility	Cognition	Self-care	Communication
Disability (n=12)	In-depth interview, observation, PhotoVoice	4	8	5	7	3	2	2	2	2	2
No disability (n=8)	Focus group discussion	5	3	4	4	N/A	N/A	N/A	N/A	N/A	N/A

**Table 1: Study population**

\* Participants may experience limitations across more than one functional domain, so the total numbers across functional domain are greater than the sample size of 12.

	Menstruators with disabilities (n=346)		Menstruators without disabilities (n=307)		Age, location, SES adjusted Odds Ratio (95% CI)
	N	%	N	%	
<b>Current Menstruation Status</b>					
Has never menstruated	46	13.3%	37	12.1%	1.2 (0.7 – 2.1)
Has ceased menstruating	136	39.3%	101	32.9%	1.0 (0.6 – 1.7)
Currently menstruate	164	47.4%	169	55.1%	Baseline

**Table 2: Disability and menstruation in women and girls age 10+**

ni-Vanuatu and international research team and LDK programme members before a final study report was completed.

### Ethics

We received ethical approvals from the Observational Ethical Committee of the London School of Hygiene & Tropical Medicine (Ref 16202/2019) and in the absence of an Ethics Committee in Vanuatu, the research proposal was endorsed in writing by the Ministry of Justice and Community Services (available on request).

We sought written informed consent before each qualitative and quantitative interview with participants aged 18 years and over. If participants were illiterate, a thumbprint was requested. Consent for children under 18 and adults unable to communicate independently was sought from adult caregiver proxies via the same mechanisms.

All adolescent participants (10-17 years) had a caregiver or guardian present throughout the interview process. For anyone unable to communicate, or fully understand the consent process, a parent or caregiver was interviewed as proxy. Sign language translation was provided where appropriate.

Any information disclosed was kept confidential, unless unmet child protection and safeguarding needs were disclosed, in which case, these were shared with World Vision staff, who were responsible for all follow-up. Participants were notified of the circumstances under which such information would be shared during the consent process.

For PhotoVoice, this included a repeat consent after photos had been taken and shared with participants, ensuring that they fully appreciated how their photos would be used. PhotoVoice participants were asked whether they wished to use their real names or a pseudonym, and all chose the former. Broad age ranges are used throughout the article to protect participants' identities.

### Results

Results presented in this article relate to a sub sample of the LDK study population containing people with and

without disabilities who menstruate and include results from both the qualitative and quantitative study components.

Table 2 describes the quantitative sample. 164 menstruators with disabilities (47.4% of the female case-control sample aged 10 or above) and 169 menstruators without disabilities (55.1%) reported having menstruated within the last year. There were no differences in likelihood of currently menstruating between menstruators with and without disabilities.

### Socio-cultural beliefs

Socio-cultural beliefs about menstruation in Vanuatu described in the qualitative component stipulate that menstruators should not work in the gardens or cook as they will kill crops and contaminate food, or lift heavy objects as that will lead to a heavier menstrual blood flow. In terms of WASH related tasks, menstruators should collect their own water, wash their own reusable menstrual cloth, and use a separate latrine and bathing shelter. Some participants expressed a belief that women should sleep separately from men during menstruation. These beliefs were internalised: participants described themselves as unclean when menstruating, that it would be unhygienic to cook for others, that they did not want to make their male relatives ill, and that this is customary (referred to as 'kastom' in Bislama).

*“When a woman menstruates, she mustn't live with her husband because she is sick. She can cause the husband to be sick with asthma, or they might have a pot belly or even get sick with intestinal gas. We women are different to men. This [menstruation] is a disease itself. That's why I had to come and sleep here by myself”* (Shamila, 31-45 years, visual impairment, urban).

Some participants with and without a disability reported that menstrual restrictions gave them a break from their daily tasks, which they valued: *“When I get my period, I feel like I can finally rest. I take a break, rest. . . for me it's like a holiday”* (Charlotte, 31-45 years, visual impairment, rural). Similarly, during a focus group discussion people without a disability living in a rural area reported that menstruation means they do not need to cook.

- Participant 1: Yes ahahaha. Time out!
- Participant 2: Rest day.
- Researcher: So, who cooks?
- Participant 3: Some husbands do!

However, menstrual restrictions do have negative impacts, particularly for menstruators with disabilities who usually rely on caregivers to collect water, support their bathing, do their laundry and assist with toileting. Without this usual assistance, they struggle to complete the tasks. Liti, who has a mobility impairment and uses crutches to help her balance, depicted how she found washing her menstrual material whilst standing difficult and painful (Figure 1).

All qualitative participants wanted to bathe every time they changed their menstrual material. Participants who did not have a disability, lived in urban areas and had water on the premises reported that they bathed much more when menstruating: “When I don’t

have my period, I just bathe in the afternoon [...]. But when I have my period, I would bathe four times – twice in the morning, twice in the afternoon and even again at night if I need to” (Focus group discussion, no disability, urban).

In rural areas (where only 5% of households surveyed had water on the premises<sup>41</sup>), all participants in the qualitative study found bathing during menstruation a challenge because they had to collect their own water: “That’s hard, because I’m on my period and walking a distance for water to wash myself and to wash the products” (Focus group discussion, no disability, rural). The distance to the water source, was particularly challenging for people with mobility impairments, as depicted by Liti (Figure 2).

### Bathing without privacy and dignity

Table 3 presents findings from the case-control study and shows that there were no differences in the main



**Figure 1.** Washing for myself is hard. © Liti



**Figure 2.** The water source is far. I want the water closer to me so I can get it easily. © Liti

	Menstruators with disabilities (n=164)		Menstruators without disabilities (n=169)		SES, Location adjusted Odds Ratio (95% CI)
	N	%	N	%	
<b>Household Bathing Location</b>					
Surface Water	159	19.6%	134	19.1%	1.1 (0.8 - 1.5)
Pump or standpipe outside compound	215	26.5%	206	29.3%	0.7 (0.5 - 1.0)
Piped or stored water inside the dwelling	93	11.4%	114	16.2%	1.2 (1.0 - 1.6)
Piped or stored water inside compound but not dwelling	282	34.7%	211	30.1%	1.5 (0.8 - 2.8)
Ocean Water	28	3.4%	18	2.6%	1.8 (1.0 - 3.3)
Other	36	4.4%	19	2.7%	
					Age, Location, SES adjusted Odds Ratio (95% CI)
<b>Uses a different bathing facility as other household members</b>	20	12.2%	4	2.4%	5.5 (1.8 - 16.5) <sup>†</sup>
<b>Reason for using a different bathing facility</b>					
It would be difficult or impossible for me	15	75.0%	0	-	-
People would abuse me verbally or physically	1	5.0%	1	25.0%	-
There is a lack of water	2	10.0%	0	-	-
Other	2	10.0%	3	75.0%	-

**Table 3: Bathing Facilities**  
<sup>#</sup> p<0.001 or <sup>†</sup> p<0.05 multivariate logistic regression

household bathing location reported by menstruators with disabilities compared to those without. Most commonly, respondents with and without disabilities stated that their household had access to piped or stored water within their compound, but not their dwelling (34.7% of menstruators with disabilities, and 30.1% without); or that their household used surface water for bathing (19.6% of menstruators with disabilities, 19.1% without). However, menstruators with disabilities were substantially more likely (Adj OR 5.5, 1.8 – 16.5) to use a different bathing facility to the rest of their household (12.2% versus 2.4% of menstruators without disabilities). Most common reasons among menstruators with disabilities for using a different facility were inaccessibility (75%) and a lack of water available (10%).

Some participants with and without disabilities in the qualitative study who lived in rural areas, did not have a safe and private bathroom. Menstruators without disabilities reported bathing in the sea or outside, meaning “they [could not] take off their panties” and wash thoroughly. Some people with disabilities managed by bathing after dark: “I have to wait till it gets dark and when everyone is asleep before I have a bath” (Evie, 18-30 years, visual impairment, rural). Issues of comfort, safety and privacy are also captured by Liti and Marie Chanelle during PhotoVoice (Figures 3 and 4). In Figure 3, Liti is standing in her bathing shelter, simulating how she would pour water over her head when bathing.

### Inadequate information on the menstrual cycle and how to manage it hygienically

Information about menstruation was transferred by older females in the family, including sisters, mothers and grandmothers once menarche was reached, but not beforehand. Guidance focused on using a menstrual material to absorb blood, but not how often to change it or dispose of it in a hygienic and environmentally friendly way. Several participants asked the researchers questions about how to use menstrual materials hygienically, demonstrating limited knowledge. Personal hygiene behaviours promoted centred on bathing regularly, but not washing hands with soap and water before and after changing the menstrual material. These trends were consistent across menstruators with and without disabilities.

*“I was crying and my heart was beating very fast because I was scared, I had contracted a terrible disease [...] My mother explained to me that it’s not a disease, rather it’s the women’s sickness. Then she gave me some calico [menstrual cloth] and explained how to use them” (Shamila, 31-45 years, visual impairment, urban).*

Menstruation was not openly spoken about because it was considered disrespectful: “in most of the islands and villages, most mothers will not speak about it with their daughters out of respect”. This led to widespread use of euphemisms. For instance, terms used to communicate



**Figure 3.** I would like a better bathroom where I can properly sit. © Liti

when a person is menstruating included: “women’s sickness”, “the weather is not good,” “it’s raining”, “jekem bihaen” (check my clothes near my bottom). Very few participants received formal education on sexual and reproductive health (including menstruation), so poor understanding of the biology of menstruation was widespread across all participants. One participant, without a disability, reflected on what she was told by a boarding school matron when she reached menarche:

*“She [matron] said that: “Now that you’ve got your period, if you sleep with a boy, you could have a baby.” And so I was afraid and thought no... so girls sleep near boys and this will happen!”* (Focus group discussion, no disability, urban).

Some, but not all people with and without disabilities predicted menstruation by monitoring physical signs, including abdominal pain and back ache, using a paper calendar or tracking the phases of the moon. No

participants (including caregivers) said that an ability to accurately track the menstrual cycle was important for them. All participants managed menstrual discomfort by resting, and people in rural and urban areas preferred not to take commercial pain killers because of the belief that they would stop the flow of menstrual blood.

### Support required for menstrual health

Menstruators with disabilities who were unable to manage menstruation independently needed support from caregivers. Those who provided support were mothers and sisters. However, some participants spoke to their fathers if they required support:

R: When Chloe menstruates, who would she normally go to for help or to share her thoughts or when she gets belly aches?

P: Myself and her dad. Sometimes her dad would pray for her.

Menstrual related support provided for menstruators with intellectual impairments included reminding them to bathe regularly, and to use a menstrual material, including how to place and change it. For participants with self-care limitations, caregivers changed and disposed or washed and dried a reusable menstrual material. One participant who experiences incontinence and relies on a caregiver to manage her menstruation felt ashamed:

*“When I was just lying-in bed, I really hated getting my period. And the first time I got my period while in this bad condition, it was so difficult, because when I have my period, I don’t like to wear panties, because I’ll make a mess – who will take them off me? Who will pull them off me? And then who will put them back on me? [. . . .] I cried, and I hated it* (Jane, mobility and self-care limitations, 31-45 years, urban).

### Impacts of menstruation on levels of restrictions

Table 4 shows the reported impact of menstruation on restrictions among participants in the quantitative study. During their last menstruation, those with disabilities were nearly twice as likely (Adj OR 1.8, 95% CI 1.1 – 3.1) to miss out on social activities compared to menstruators without (29.3% versus 18.3%). Similarly, they were 4 times more likely (4.0, 1.6 – 5.7) to miss out on eating with others (24.4% versus 9.5%). In contrast to the qualitative component, which found that many participants with and without disabilities living in rural areas were unable to wash and change their menstrual material in private (see section 3.2), approximately three quarters of menstruators with and without disabilities (77.4 and 74.0%) in the quantitative component reported that during their last menstrual period,





**Figure 4.** I need a safe and private bathroom. © Marie Chanelle

they were able to wash and change in privacy at home, with no differences by disability status. On average, menstruators without disabilities scored the level of interference from their menstruation in daily life as 5.6 (95% CI 5.1 – 6.1) out of 10; slightly higher than menstruators with disabilities (4.8, 4.2 – 5.3,  $p < 0.05$ ).

Qualitative data reflected these trends as people reported that menstruation inhibited menstruators' participation in daily activities, and that this was more keenly felt by participants with disabilities. Fear of leaks during a heavy menstrual flow, stopped many menstruators with disabilities going to church: “she would tell her sister that she must not go to church because she is having a ‘bad time’” (proxy interview for Islay, 31-45 years, cognition, rural). Caregivers of menstruators with intellectual impairments explained their aversion to wearing a menstrual material. Rather than the individual being seen with blood-stained clothes, caregivers preferred to keep them at home during menstruation.

*“When she gets her period, I would tell her not to come outside. I would tell her to sit still and not to move around a lot [...]. The problem with her is that when she menstruates, she doesn't like to use the calico or a sanitary pad”* (Proxy interview for Chloe, 18-30 years, multiple impairments, urban).

However, menstruation did not inhibit the movements of participants without disabilities living in urban areas to the same extent. Reasons included the need to continue going to work for fear of being dismissed, and having access to effective menstrual materials that would not leak.

### Discussion

This study aimed to understand access to, and experiences of WASH, and menstrual health for menstruators with and without disabilities in TORBA and SANMA Provinces, Vanuatu. There were no differences between the proportion of people with and without disabilities who menstruate. Menstrual stigma and inadequate water and private bathing facilities at home impacted all menstruators in the sample. Menstruators without disabilities who lived in urban areas had more positive menstrual experiences, partly because they had greater access to WASH services at home. Experiences were far worse for menstruators with disabilities compared to menstruators without disabilities, particularly for those

	Menstruators with disabilities (n=164)		Menstruators without disabilities (n=169)		Age, Location, SES adjusted Odds Ratio (95% CI)
	n	%	n	%	
<b>Missed out on social activities</b>	48	29.3%	31	18.3%	1.8 (1.1 – 3.1) <sup>†</sup>
<b>Missed out on eating with others</b>	40	24.4%	16	9.5%	3.0 (1.6 – 5.7) <sup>†</sup>
<b>Able to wash and change in privacy at home</b>	127	77.4%	125	74.0%	1.2 (0.7 – 2.0)
	Av Score (95% CI)		Av Score (95% CI)		p value <sup>§</sup>
<b>Menstruation Interference Score</b>	4.8 (4.3 – 5.3)		5.6 (5.1 – 6.1)		0.026

**Table 4: Impact and experience of menstruation (last menstrual period)**

<sup>†</sup>  $p < 0.001$  or <sup>†</sup>  $p < 0.05$  multivariate logistic regression

<sup>§</sup> t-test

with self-care limitations and mobility impairments, and those who relied on caregivers.

A common misconception exists, that people with disabilities do not have the same reproductive systems as non-disabled people, and therefore that people with disabilities do not menstruate.<sup>24,42</sup> Though data is limited, this can lead to the exclusion of people with disabilities from sex education and menstrual health interventions.<sup>24,43,44</sup> This myth is dispelled in our study, which shows no statistical difference in the proportion of people with and without disabilities who menstruate.

'Stigma', which is a 'process of dehumanising, degrading, discrediting and devaluing people in certain population groups',<sup>40,45</sup> drives discrimination and exclusion and this can negatively impact on mental health.<sup>46</sup> Stigma, 'self-stigma' (when a person holds negative attitudes about themselves<sup>40,45</sup>) and discrimination has been documented in relation to disability<sup>46-50</sup> including in Vanuatu,<sup>33</sup> and menstruation;<sup>17,51-53</sup> some primary research studies highlight how these overlap in low-income countries.<sup>18,26,54</sup> This research provides further evidence about how disability and menstruation stigma and discrimination intersect to deepen inequalities.

Our study found that menstrual taboos were widespread and internalised (self-stigma), and this is common in many other settings.<sup>55-60</sup> For instance, menstrual blood is considered 'dirty', contaminating and impure in Papua New Guinea, Solomon Islands, Fiji, Nepal, India and Uganda,<sup>56,57,61,62</sup> and these widespread menstrual taboos impact both menstruators with and without disabilities. Restrictive practices are common in those countries, as well as in Ghana, Brazil and Egypt.<sup>63-66</sup> Interestingly, some menstruators in Vanuatu were encouraged to sleep separately from men; a practice that also occurs in Ghana, and remote areas of the Solomon Islands, Papua New Guinea, and Nepal.<sup>57,67,68</sup> However, in our study one participant with disabilities did communicate about menstruation with their father, which could indicate a more open space to discuss menstruation with fathers, than was recorded in Nepal.

During menstruation, all participants prioritised bathing regularly. This is reflected in Hennegan and colleagues' (2020)<sup>69</sup> study in Uganda, where all menstruators prioritised staying clean and keeping menstruation secret. This was viewed as "being a responsible woman"; any challenges faced in completing these tasks symbolized "a failure of womanhood" and this resulted in shame and disgust.<sup>69</sup> In our study, the additional barriers that menstruators with mobility impairments faced when menstruating could result in a heightened sense of shame and disgust, as well as being regarded negatively by others. Another study in the series of articles from the LDK baseline study,<sup>33</sup> shows how this is set within the wider context of disability

discrimination: the status of a woman in the community reduced when she became disabled.

We also found that menstrual restrictions can be positively viewed as 'time off' from carrying out daily tasks related to traditional gender roles like cooking, and this is also reflected in existing evidence.<sup>57,70,71</sup> However, our comparison between the experiences of menstruators with and without disabilities highlights how menstrual taboos and restrictions have an exponentially negative impact on those with disabilities. This is of particular note in relation to water collection, bathing, doing laundry and changing menstrual materials. These impacts include increased levels of pain, indignity and shame during menstruation. The latter is particularly expressed by menstruators with self-care or intellectual limitations who rely on caregivers to manage their menstruation. Our findings are similar to those from Nepal, where people with physical impairments and self-care limitations found water collection for washing menstrual materials a major challenge, and felt shame that caregivers had to handle their menstrual materials.<sup>18</sup> Care should be provided with dignity, and caregivers must be supported to carry out this role. These findings are reflected in other settings, but evidence is limited.<sup>18,25,26</sup>

A growing, but still limited body of evidence shows a strong association between urinary tract infection and lower reproductive tract infections, such as Bacterial vaginosis, Candida and Trichomonas vaginalis, and poor menstrual hygiene practices.<sup>6,10,11</sup> The latter includes not having a private and safe space to change and wash menstrual materials, or the body, and not changing the menstrual material regularly enough.<sup>10,11,72</sup> Though our study did not investigate prevalence of urinary tract infection and lower reproductive tract infections, we can assume that participants who bathed in ocean or rivers are at higher risk of both, as they are unable to effectively wash their genitals. As menstruators with disabilities are less likely to be able to use household bathing facilities, they may be at a greater risk of infection. These hypotheses need to be tested.

In our quantitative data, three quarters of all participants reported being able to wash and change in privacy at home (which was a binary yes/no question), but on further exploration via the qualitative study, we found that many participants, with and without disabilities living in rural areas, did not have water at home for bathing, or a private bathing shelter. The qualitative findings reflect the latest Joint Monitoring Programme data for Vanuatu, which shows access to basic water supplies and hygiene is worse in rural areas:<sup>73</sup> 88% of the rural population has access to water, compared to more than 99% in urban; only 49% of people in rural areas have handwashing facilities at home, whereas 65% of urban dwellers do. Existing evidence on whether people with disabilities can use the same water and bathing facilities as other household members is more

variable.<sup>19,22</sup> This is likely related to the type of water source the family has access to and how accessible that is; for instance, if it is piped into the compound or if it is a communal water point.

In the last decade, documentation has increased that highlights how inadequate WASH facilities at home, can increase vulnerability to violence if people bathe at night, defecate in the open or collect water from remote locations.<sup>74,75</sup> These factors increase risk of violence for everyone, but research from different settings show that people with disabilities are at a greater risk of violence than people without disabilities.<sup>76-80</sup> Vulnerability to violence is greater for women with disabilities,<sup>77</sup> those with intellectual impairments<sup>76</sup> and older adults with disabilities,<sup>78</sup> thus showing how inequalities intersect and perpetuate discrimination. Furthermore, Vanuatu has one of the highest prevalence rates of violence against women and girls in the world,<sup>81</sup> and 60% of women reported to have experienced physical or sexual violence in a relationship in 2011.<sup>82</sup> Within this context and drawing on existing evidence, it is likely that the fear of violence would have had a major impact on whether or not participants included in this study felt comfortable bathing at night.

Inadequate information on the menstrual cycle and how to manage it with dignity drives menstrual stigma, taboos and silence around the issue. This is documented widely, including across 35 LMICs in a recent systematic review of 87 qualitative studies on women and girl's experiences of menstruation.<sup>7</sup> As seen in other settings, participants with and without disabilities reported that menarche was a frightening experience.<sup>59,83</sup> Information that was conveyed by influencers once menarche was reached, dictates a need to cope, rather than a sense of pride in reaching puberty and an ability to reproduce. The use of euphemisms to describe menstruation, and partial information about menstruation, sexual and reproductive health demonstrates embarrassment; this fuels confusion and enables menstrual taboos to continue to be passed down through generations. Our study findings showed no difference between menstruators with and without disabilities.

Studies on menstruation consistently highlight the negative impacts of poor menstrual health on social participation, including education and the practice of worship.<sup>84-87</sup> Our findings show that menstruators with disabilities in quantitative data were twice as likely to miss out on social activities and four times more likely to miss out on eating with others compared to those without disabilities. However, self-rated levels of interference of menstruation on participation was slightly lower for menstruators with disabilities than for those without disabilities. This may be related to self-stigma, whereby disability and menstrual discrimination is internalised and people with disabilities limit their own participation and therefore self-rated interference. It may also be because people with disabilities are

generally less able to participate in social events than those without disabilities.<sup>47,49,50</sup> For the latter, who generally can actively participate in daily life, the "interference" on participation by menstruation will likely be higher.

Key differences in levels of participation within the study population without disabilities was determined by employment status. The fact that participants without disabilities who worked in formal employment feared losing their jobs if they were absent during menstruation, demonstrates their lack of power to demand supportive menstrual health facilities at work, as well as an absence of workplace standards that are supportive to menstrual health. In this study and Hennegan *et al's*<sup>69</sup> study, which explored menstrual experiences in the workplace in Uganda, menstruators working in formal employment returned home to change their menstrual material because of inadequate water supplies and a desire to bathe. In the qualitative sample of this study, most participants who lived in rural areas worked in agriculture. As stated by Sommer and colleagues,<sup>12</sup> employers in the informal sector do not have any legal obligations to support the sanitation requirements of their workers, which makes managing menstruation difficult. Though an under researched topic, there is a growing demand to improve workplace standards for menstrual health to combat economic loss during menstruation.<sup>12</sup>

Finally, caregivers of people with intellectual impairments limited the participation of individuals when they menstruated, with reasons including a desire to ensure an individual does not leak menstrual blood onto her clothes in public. This is reflected in evidence in Nepal, where carers of people with intellectual impairments were fearful that the individuals who did not want to wear a menstrual material would go out in public with blood stained clothes.<sup>18</sup> When individuals did, they were abused by the general public and family members for doing so.<sup>18</sup>

### Implications for further research, policy and practice

Study findings reveal the experiences of menstruators with and without disabilities in the SANMA and TORBA provinces, so may not be generalisable for the rest of the country or other LMICs. However, the following areas for further research, policy and practice are recommended for Vanuatu and similar contexts.

To fully understand menstrual health related issues and disparities between menstruators with and without disabilities, research should be conducted to investigate how different water sources used for washing the body and bathing locations impacts on menstruators' privacy, dignity, security, and infection risk.

The Republic of Vanuatu should continue to invest in improving coverage of accessible household water supplies and private bathing facilities, particularly in

rural areas, and for households that include persons with disabilities. The lack of availability of water at the household was one reason some participants used a different source, and that in our first paper we highlighted that 30% of households reported having insufficient access to water.<sup>33</sup> All menstruators will struggle during menstruation in the absence of a reliable water supply, so this is needed as a building block for improved menstrual health.

Even though menstrual health is gaining more coverage globally,<sup>88,89</sup> there is an urgent need to address harmful menstrual related social beliefs and taboos. Therefore, those working on WASH, education, health and disability should promote positive menstrual social norms which celebrate menstruation, challenge harmful beliefs and avoid using euphemisms. Challenging disability discrimination, which compounds inequalities for menstruators with disabilities, must be interwoven through any efforts for improving menstrual health. In particular, seeking to address self-stigma and break down all barriers affecting the participation of menstruators with disabilities should be prioritised.

Any menstrual health intervention, whether it focuses on providing accessible WASH facilities and menstrual materials that are supportive to menstrual health, or increasing menstrual health knowledge and dispelling stigma and taboo, must address the requirements of menstruators with disabilities, different impairments experienced and caregivers who provide support. Caregivers must be supported to understand how to assist another person to manage their menstruation hygienically and with dignity. Recommendations about developing sustainable and locally produced assistive devices and lifting devices have been made elsewhere.<sup>36</sup>

Throughout all research, policy and practice, menstruators with disabilities must be at the centre of this process to ensure this group drives their own development agenda. Organisations of Persons with Disabilities should be invested in, and supported to work with WASH, health and education stakeholders to integrate disability in development efforts and overcome attitudinal, institutional and structural barriers to participation that become internalized by people with disabilities.

### Strengths and limitations

A key strength is that this study was mixed methods, with a large sample size, including a census across two provinces as well as a quantitative case control and qualitative component. To the best of the authors' knowledge, it is the only in-depth, mixed-methods study which compares the experiences of menstruators with and without disabilities. Finally, as the study formed the baseline to inform the design of the LDK inclusive WASH intervention, participants will benefit from sharing their experiences.

A few limitations must be considered when interpreting the results. Menstruation is a taboo topic and therefore may be challenging to study. This is particularly so for quantitative data collection as researchers have less time to build rapport, but this was managed by applying the qualitative component where the research team could focus on developing this. Finally, only one locality across the two provinces is officially recognised as urban, thus limiting our quantitative exploration of differences between rural and urban settings.

### Conclusion

This study has demonstrated the multiple difficulties experienced by menstruators with and without disabilities in TORBA and SANMA provinces, Vanuatu. It has highlighted how menstruation compounds disadvantages already experienced by people with disabilities, highlighting inequalities compared to menstruators without disabilities, and especially among those who are reliant on caregivers. Addressing menstrual taboos and restrictions, and improving access to water, bathing and laundry facilities are vital. Alongside this, efforts to dispel disability stigma and discrimination must be prioritised to improve the ability of people with disabilities to participate more fully in daily life, as well as when they are menstruating. Methodologically, future studies should seek to disaggregate by disability status to monitor and overcome these inequalities.

### Contributors

JW: Literature Search, Study Conceptualization, Study Design, Data Collection Oversight, Verification of underlying data, Data Analysis, Data Interpretation, Manuscript Writing

CM: Data Collection Oversight, Data Interpretation, Manuscript Review

LB: Study Design, Data Collection Oversight, Data Interpretation, Manuscript Review

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JS: Data Collection, Data Interpretation, Manuscript Review

JJ: Data Collection, Data Interpretation, Manuscript Review

RP: Study Design, Data Collection Oversight, Data Interpretation, Manuscript Review

LMB: Manuscript writing and review

IZM: Literature Search, Study Conceptualization, Study Design, Data Collection Oversight, Verification of underlying data, Data Analysis, Data Interpretation, Manuscript Writing

JW, IZM, PS and JT had full access to the full data in the study, and accept responsibility to submit for publication

#### Data sharing statement

Access to an anonymised dataset for secondary analyses may be provided on reasonable request. Approval for all requests must be jointly provided by Vanuatu National Statistics Office, World Vision Vanuatu and the LSHTM before data can be shared.

#### Declaration of competing interest

Jane Wilbur, Philip Sheppard and Islay Mactaggart reported grants from World Vision Vanuatu during the study. All other authors have nothing to declare.

#### Acknowledgements

Thank you to all the participants who shared their experiences so openly with us. The study was endorsed by the Vanuatu Ministry of Justice and Community Services, and was designed and delivered in consultation and collaboration between the Vanuatu National Statistics Office (VNSO), World Vision Vanuatu and the London School of Hygiene and Tropical Medicine (LSHTM), Vanuatu Society for People with Disability and Vanuatu Disability Promotion and Advocacy Association.

#### Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:[10.1016/j.lanwpc.2021.100325](https://doi.org/10.1016/j.lanwpc.2021.100325).

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