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Rosato-Scott, C orcid.org/0000-0002-7838-7773, Giles-Hansen, C orcid.org/0000-0001-8744-5915, House, S et al. (6 more authors) (2019) Case studies on supporting people with incontinence in humanitarian and low- and middle-income countries (LMICs). Report. LMIC-Incontinence-email-group.

<https://doi.org/10.5518/100/15>

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Case studies on supporting people with incontinence in humanitarian and low- and middle-income countries (LMICs)

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Version – August 2019

Prepared by - This document has been compiled by members of an informal international cross-sectoral email group focused on learning how best to work with and support people with incontinence in humanitarian and low- and middle-income contexts.

Associated documents - This document is one of a set of four, being:

- a) Guidance
- b) Summary guidance four-pager
- c) Case studies (this document)
- d) References

Suggested citation - Rosato-Scott, C. Giles-Hansen, C. House, S. Wilbur, J. Macaulay, M. Barrington, D. J. Culmer, P, Bhakta, A. N and Burke, L (2019) Case studies on supporting people with incontinence in humanitarian and low- and middle-income contexts (LMICs). LMIC-Incontinence-email-group. DOI: <https://doi.org/10.5518/100/15>

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1. Incontinence in images (Pakistan)

These images were taken as part of a photovoice research initiative to understand the experiences and challenges faced by people with incontinence. The project was led by Zara Ansari, a Masters Student at the London School of Hygiene and Tropical Medicine. If you wish to use these images please seek permission from Sian White at the London School of Hygiene and Tropical Medicine (sian.white@lshtm.ac.uk).

Ant on foot

"I can't keep myself clean.... "



Photo by: Bahadur Mohammad Yaqoob Unar

You see the ant on my foot. There are constantly ants and flies crawling all over my body, but I can't feel them or shake them off. It is hot and that is why the ants are there, but I can tell you why the flies are present and that is what makes me the most uncomfortable and sad. I can't keep myself clean and because I can't be clean, the flies come and sit on me all day. No matter how much we clean the area around me, the smell and dirt remains and then the flies come and sit on me. They know when I am dirty.

Friends hanging out

"I can't sit with them...."



Photo by: Poonmo

I can't sit with them. I have some friends but most of them left me and made me feel even more lonely and sad. I feel upset seeing them move around and sit together laughing and smoking. I sit and cry but then I don't want people to see me cry so I try and hold my tears back. They go off to the city, especially Thar, where we used to work and they harvest. You know, it is harvest season? We used to have so much fun in harvest season and now I can't even work.

Mother

"she finds it so difficult to change me"



Photo by: Bahadur Mohammad Yaqoob Unar

My mother is really old now. She makes me really happy but also very sad, so I don't know where to put this picture or what to say about it. She has been taking care of me for so long now, but she can't see properly and walks with her head near the ground. Her back is getting curved taking care of me. She finds it so difficult to help me up and change me, but she never complains. Not one day. She finally asked for someone to help her, so my aunt helps her move me around.

Home-made cloth diapers



Photo by: Zara Ansari

Water collection

“there is never enough water....”



Photo by: Poonmo

My sister goes to collect water two to three times a day. She has to walk about half an hour one way and so it takes her almost an hour to come back to me. We use that water to wash clothes and to clean myself. There is never enough water to make me feel clean. Many times I have been dirty and there has been no water in the house, so I have to sit in the filth until someone goes to the water point and brings some water back for me. I really need more water. If I had all this access to water, I would feel better because I would be cleaner.

Soap

“this makes me very happy....”



Photo by: Bahadur Mohammad Yaqoob Unar

This makes me very happy and makes me feel clean. I use it all the time to manage my cleanliness and smell. It cleans my clothes and it cleans my hands and the most important thing is that it keeps me clean. I always make sure there is soap in the house and keep asking to check if it is still available, because I will never feel clean or smell normal.

2. Case studies from humanitarian contexts

2.1 Proportion of households who have people with incontinence (Middle East and Nepal)¹

- A study undertaken by Handicap International (HI) and HelpAge in 2014 found that 5.7% of Syrian refugees in Jordan and Lebanon had a significant injury. People with spinal cord injuries (SCI) present mostly bladder and bowel issues after injury, needing lifelong management and follow-up. Within the Middle East project follow-up (in Jordan, Syria, Lebanon, and Iraq), HI identified over 350 SCI patients, presenting severe incontinence issues that are not properly managed in their living context.
- OXFAM noted most households in remote rural areas affected by the earthquake in Nepal had a family member who was either older or had disabilities; both groups that may be affected by incontinence.

2.2 Incontinence due to psychosocial distress (Middle East)²

- Psychosocial teams from the International Rescue Committee, Save the Children and from Handicap International have identified incontinence as an issue for children affected by sexual violence or stressful events in conflict or disasters. For example, humanitarian workers have seen a dramatic increase in bedwetting among children affected by the Syrian conflict due to psychosocial distress. This means that parents must deal with urine-soaked clothes and bedding, night after night, whether they are on the move across Europe or living in camps for refugees or internally displaced people, or in unfinished buildings with limited WASH services.
- The war and the siege have left deep psychological scars on children, many of whom have witnessed extreme violence. Parents, teachers and health workers all report a range of common symptoms among children in their care, including bedwetting and involuntary urination during class; recurrent nightmares; stuttering and speech difficulties; and social isolation. For example, *"Khalil's older brother was killed and his father was unable to get to the area. He was wetting himself frequently and many pupils wouldn't play with him. With careful teacher support he now goes to the bathroom before every class and gradually he's begun to recover, feel safe and make friends. Today he's well liked and doing well in class"*³.
- *"The children are really suffering. The problem is that the mothers have been trying to cope for so long that basically they've given up. Night after night of urine and they can't keep them clean. It's soul-destroying"*⁴

¹ Taken from: Hafskjold, B. Pop-Stefanija, B. Giles-Hansen, C. Weerts, E. Flynn, E. Wilbur, J. Brogan, K. Ackom, K. Farrington, M. Peuschel, M. Klaesener-Metzner, N. Pla Cordero, R. Cavill, S. and House, S (2016) 'Incompetent at incontinence - why are we ignoring the needs of incontinence sufferers?' [online], *Waterlines*, 35(3). Available at: <https://www.developmentbookshelf.com/doi/10.3362/1756-3488.2016.018>

² Same reference as 1.

³ Save the Children (2016) *Childhood under Siege – living and dying in besieged areas of Syria* [online], Save the Children. Available at: <https://reliefweb.int/report/syrian-arab-republic/childhood-under-siege-living-and-dying-besieged-areas-syria>

⁴ Venema, V (2015) *The unlikely sanitary pad missionary* [online], BBC. Available at: <http://www.bbc.co.uk/news/magazine-34925238>

2.3 People with incontinence in Cox's Bazar (Bangladesh)

The following case studies were identified from the Rohingya camps in Cox's Bazar, Bangladesh:

- In a study by HelpAge in a number of the camps in Cox's Bazar, Bangladesh⁵:
 - 17% of older people interviewed stated that they have an incontinence problem and of these, 77% stated that they were struggling and not getting any support;
 - 47% of older people and those with a disability who reported incontinence need someone to help them from bed to the chair and to undertake daily tasks; and
 - 46% of older people with incontinence also self-reported having other chronic health conditions such as non-communicable diseases that affect their quality of life.
- *"It was also noted [by HelpAge] that most older people have "functional" incontinence i.e. they are not able to get to the toilet quick enough. These finding highlights that some of the implications of the gaps in the WASH sector's response in not focussing on the needs of older people and people with disabilities, but effectively leaving them until last. Not being able to go to the toilet quickly and easily contributes to people with incontinence, including functional incontinence, in not being able to manage it effectively. This can mean, in simpler terms, people ending up soiling themselves and their clothes and the indignity and shame associated with this happening because they cannot reach a toilet quick enough"*⁶. Queues for communal toilet facilities can contribute to this.
- An old man who has incontinence calls out to his neighbours for help when his bedding gets wet, so that they can come to help and clean him and his bedding.
- *"As we were talking to a woman and her carer, a woman heard us talking about toilets and came out and wanted to talk about her husband who was injured and has a spinal injury. She said that he urinates in the bed and it is very difficult. She wanted to speak as they need help"*⁷.
- *"We came across a house which had a pathway installed to a latrine for a young man in a wheelchair... but the latrine was tiny, and the man clearly couldn't use it alone. His father also said that he has mental disability as well, so that he doesn't actually know when he needs the toilet, and regularly soils himself. On the ground along the path to the latrine were piles of soiled clothes, which the family had dumped outside as they didn't have enough water to wash them, and couldn't keep them in the house for the smell. I've asked our team to check in with the house on a regular basis to see what else they might need (soap or larger water storage containers), but it was sad to see that whoever had done the ramp, didn't think all the way through the other implications that the family were facing"*⁸.

⁵ HelpAge (2018) Needs and Gap Analysis Older Refugee Population Cox's Bazar, Bangladesh. Available at:

<https://drive.google.com/file/d/1ONvnk89W7BsqiM-h6VQbFI2S7tUB2QzM/view?usp=sharing>

⁶ House, S (2019) *Strengthening the humanity in humanitarian action in the work of the WASH sector in the Rohingya response; Gender, GBV and inclusion audit of the work of the WASH sector and capacity development assessment*, UNICEF and the WASH Sector, Cox's Bazar. Available at: <https://drive.google.com/file/d/1DFRrH-DnKHc5zz1aMgYa2ieNDI3SoDrh/view?usp=sharing>

⁷ Case-study provided by: Farrington, M (2019)

⁸ Case-study provided by: Farrington, M (2019)

2.4 Adult diapers: a necessary but neglected hygiene item in humanitarian responses (the Seychelles)⁹

- In January 2013, the Seychelles were hit by a tropical cyclone causing damage, flooding and displacement of 250 families. The Seychelles Red Cross Society, supported by the IFRC, responded to the emergency including hygiene and health promotion, vector control, and non-food item distributions.
- An evaluation of the overall response was conducted in June 2013, including a beneficiary satisfaction survey. Target beneficiaries received appropriate hygiene and menstrual hygiene items, either through direct distributions or vouchers.
- However, the evaluation team interviewed a household where an adult man lived with his brother who had learning disabilities. Although they had received support following the cyclone and were grateful for this, the man specifically mentioned that the one most important thing he had needed in the weeks following the cyclone were adult nappies for his brother, who suffers from incontinence.

2.5 Stresses associated with not being able to effectively manage incontinence (Lebanon)¹⁰

The stresses associated with not being able to effectively manage incontinence are clear for those who have talked with people who face this challenge, for example in Lebanon:

- *“I encountered many women that felt so helpless, as their husbands or sons had incontinence as a result of war injuries, leaving them in a wheelchair or with reduced mobility”¹¹.*
- *“I could feel the desperation of incontinence sufferers in the informal camps. One man, who had suffered a stroke, and his wife (who was pushing him in his wheelchair) clearly shared their problem of not having access to pads in front of a large group of people who had gathered around...I was struck by how desperate they were that they were prepared to share this stigmatising issue with a stranger who had just arrived in their camp, out loud and in public”¹².*

⁹ Case-study provided by: Giles-Hansen, C (2015)

¹⁰ Taken from: Hafskjold, B. Pop-Stefanija, B. Giles-Hansen, C. Weerts, E. Flynn, E. Wilbur, J. Brogan, K. Ackom, K. Farrington, M. Peuschel, M. Klaesener-Metzner, N. Pla Cordero, R. Cavill and S. House, S (2016) ‘Incompetent at incontinence - why are we ignoring the needs of incontinence sufferers?’ [online], *Waterlines*, 35(3). Available at: <https://www.developmentbookshelf.com/doi/10.3362/1756-3488.2016.018>

¹¹ Provided by: B. Hafskjold (2014)

¹² Provided by: S. House (2014)

2.6 Functional (or Social) incontinence and its implications

- Functional (or Social) incontinence occurs when a person is aware of the need to urinate or defecate, but they are unable to get to, or use a bathroom. In emergency contexts and low- and middle-income countries, household and public toilets may be a distance away, unsafe, and/or inaccessible.
- In Cox's Bazaar, Bangladesh, women reported giving their children less food to avoid using the latrine at night¹³.

2.7 Examples of where action has already been taken in humanitarian contexts¹⁴

- Norwegian Church Aid (NCA) has been considering incontinence when designing and distributing menstrual hygiene kits in emergency operations, for example in Liberia and Lebanon, meaning distributions which not only target women of reproductive age, but also older people. It offers underwear, disposable pads (currently the larger sanitary pads used by women who have just given birth), reusable sanitary pads or cloth for soaking up fluids. NCA is also currently including incontinence in its initial WASH assessment of the needs of people affected by the crisis in Burundi. Through this work it has found that incontinence is an issue for which WASH staff also need training and sensitization.
- In Iraq in 2015, Handicap International distributed washable diapers (children / adult sizes), water, soap and containers for their washing, responding to a lack of/unaffordability of disposable diapers.
- One woman, acting on her own initiative, supported the production of disposable sanitary pads in Za'atari camp in Jordan¹⁵. After hearing from people in the camp about their needs, she ensured that the machine she brought to the camp could also make incontinence pads.
- Handicap International produced materials to guide people with specific disabilities, and medical and rehabilitation staff in north Syria and in a post-earthquake project in Pakistan on how to manage incontinence, for example on how to hygienically insert catheters, and also provided disposable pads.
- Some medical focussed NGOs use disposable incontinence pads for the patients in their hospital facilities, but they do not always have programmes to support people with incontinence more generally when they go home. In Burundi Handicap International cooperated with Médecins sans Frontières to develop a continuum of care and follow up for the management of incontinence for fistula sufferers and social integration programmes to counter the stigma

¹³ Oxfam Rohingya Response (2018) *Women's Social Architecture Project: Phase 1 Final Report* [Online]. Cox's Bazaar, Bangladesh. Available from: <https://oxfam.app.box.com/s/gmiiqfdn7ntbxeve7fiklywfitnkcyj/file/384891125807>

¹⁴ Taken from: Hafskjold, B. Pop-Stefanija, B. Giles-Hansen, C. Weerts, E. Flynn, E. Wilbur, J. Brogan, K. Ackom, K. Farrington, M. Peuschel, M. Klaesener-Metzner, N. Pla Cordero, R. Cavill and S. House, S (2016) 'Incompetent at incontinence - why are we ignoring the needs of incontinence sufferers?' [online], *Waterlines*, 35(3). Available at: <https://www.developmentbookshelf.com/doi/10.3362/1756-3488.2016.018>

¹⁵ Venema, V (2015) *The unlikely sanitary pad missionary* [online], BBC. Available at: <http://www.bbc.co.uk/news/magazine-34925238>

3. Case studies from development contexts

3.1 Functional (or Social) incontinence and its implications¹⁶

- One man with disabilities in Uganda explained the consequences of not being able to get to a latrine in time: *"I am a councillor for the disabled...I was [once] in a meeting...I couldn't go to the latrine yet I had gotten an urgent call. I tried enduring but ended up urinating on myself. I felt so humiliated that I have never gone back for a single meeting"*¹⁷.
- Fear of soiling oneself can lead people to limit their consumption of food and drink. For instance, Anooda, a woman with disabilities in Bangladesh, explained how she relied on a caregiver to take her to the toilet. Often, when no one was able to help, she soiled her bed and would stay that way until someone was able to bathe her. She said, *"I was scared to eat and drink [before], no one would come and clean me"*.
- Anooda, now has a shower and a flushing latrine next to her bed that she can use independently after advising WaterAid and IDEA on its construction. This has greatly improved her ability to maintain her hygiene and sanitation independently and with dignity. It has contributed to her improved comfort and well-being. Anooda explains, *"Someone used to have to carry me to the toilet and now I can do it myself... Now my suffering has been minimized...I was in pain and suffering. I feel happy. I feel free. I am grateful and want other people like me to get these services"*¹⁸.

3.2 Woman with incontinence shows the community the implications in the village¹⁹

A WASH sector professional joined a Community-Led Total Sanitation (CLTS) triggering event in India to observe the processes. While she was there, she observed a woman who was living with incontinence share her difficulties with the community through the participatory exercises.

"I was in India to see a community sanitation triggering event and for those that don't know as part of the process the community draws a map on the ground usually using coloured sand to showing households, resources, defecation areas, water points and problems, to stimulate discussion. Instead of depositing the pile of sand in one place to show where she goes to the toilet, one older woman walked around the map trailing the coloured sand behind her. The rest of the group said she must have misunderstood what she was asked to do, but the women said no, she understood it, but this is what happens to her as she walks around the community. It was the first time I had heard this issue raised at a community event and it also left a powerful visual image on the map. Now we have to think how to address this in programming ..."

¹⁶ Taken from: Hafskjold, B. Pop-Stefanija, B. Giles-Hansen, C. Weerts, E. Flynn, E. Wilbur, J. Brogan, K. Ackom, K. Farrington, M. Peuschel, M. Klaesener-Metzner, N. Pla Cordero, R. Cavill and S. House, S (2016) 'Incompetent at incontinence - why are we ignoring the needs of incontinence sufferers?' [online], *Waterlines*, 35(3). Available at: <https://www.developmentbookshelf.com/doi/10.3362/1756-3488.2016.018>

¹⁷ Provided by: Wilbur, J (2013)

¹⁸ Provided by: Wilbur, J (2013)

¹⁹ Provided by: Cavill, S (2018)

3.3 Older man sleeping in urine-smelling room²⁰

A WASH sector professional was undertaking a learning exercise of a multi-country sanitation programme. During the visit to a rural community in a village in Malawi, they met an old man who was living with incontinence:

“We visited an older man. We had visited him to see the latrine that the family had been supported with by a local community-based organisation as part of a sanitation programme. The daughter of the old man said that he finds it difficult to walk to the toilet and he spends most of his time staying in his room. When we visited him, he was lying on the floor of a small room in the family’s mud built-house. He was lying on and under a blanket. There was a strong smell of urine in the room. So, whilst the family had been supported with a toilet, because the father had difficulties in walking, he clearly was struggling with incontinence and was unable to get to the toilet in time”.

3.4 Conflict over an older person who has a vision impairment making a shared latrine dirty²¹

This case study does not relate specifically to incontinence, but has direct relevance as the same situation could easily be happening for people with incontinence, both older people and others.

“Inaccessible toilets where a serious problem. Several interviewees said they could not reach the toilets on their own, or had difficulty using them. The interviews suggested that this deprived them of their independence and dignity. Family members said that helping their relative use the toilet also left them with less time for other activities. In one case, a family member said that the problems her mother had with using the inaccessible toilet had led to conflict with neighbours. The neighbours complained that her mother left the shared toilet “dirty” because she could not see well”.

²⁰ Provided by S. House (2016)

²¹ Sheppard, P and Polack, S (2018) *Missing millions: How older people with disabilities are excluded from humanitarian response*, HelpAge and the International Centre for Evidence in Disability at London School of Hygiene and Tropical Medicine. Available at: <https://www.alnap.org/help-library/missing-millions-how-older-people-with-disabilities-are-excluded-from-humanitarian>

3.5 Urine incontinence in perimenopausal and menopausal women in Ghana²²

Stress urinary incontinence management: “I haven’t thrown away my pad, just for security sake” (Felicity)²³

Concerns over MHM gradually shift to urinary incontinence as women pass through the perimenopause and the erratic patterns of menstruation are replaced by erratic urine leaks. Hygiene protection for perimenopausal women needs to be able to adequately absorb urine, and may be worn all the time:

- Perimenopausal women with ageing-related incontinence need good urinary incontinence management, through behaviour change and use of products. Behaviour changed through using toilets to prevent leaks: *“I have to make sure I’m consistent in my going to the toilet before I become desperate for the toilet. Maybe that’s one thing that has changed so recently for me, such that it makes me worry why my bladder has become so weak.”* (Felicity, menopausal)
- Incontinence or sanitary pads were used for protection, despite the cessation of menstruation: *“So as a result of not throwing away my pad because in case I leak before I get access to a toilet, so I haven’t thrown away my pad, just for security sake. That’s one thing that has changed recently but I wasn’t really good with my water before.”* (Felicity, menopausal)
- Urinary incontinence was a longer-term problem from prior to the perimenopause for the two women who experienced it in this sample, making it easier to deal with: *“But until a few years ago, I’ve always worn sanitary protection material of some form, at least panty liners, just to give you an extra... and if I have a cold, then I would wear pads all the time. So, for me it’s not quite as distracting because I’m used to doing that anyway.”* (Sally, perimenopausal)

Stress urinary incontinence

Stress urinary incontinence became a matter of concern for both perimenopausal and menopausal women. It is unclear whether this is due to declining oestrogen during the perimenopause or due to natural factors of ageing. This is an important consideration to make in the context of the women who participated in this study, as many were older and menopausal rather than perimenopausal, and provides insights into general issues of ageing. Leaking of urine impacted upon women’s health due to physical pain, and patterns of regular urinary discharge:

- *“Once in a while, I feel pains at my lower abdomen which means I want to urinate so I go and do that, but it comes in bits.”* (Abena, perimenopausal, Kotei)
- *“It comes once in a while and when I visit the urinal, I don’t urinate much, anytime I feel like urinating, it comes in bits it again and again. This happens from morning to afternoon, it is not like that in the evenings.”* (Oheama, perimenopausal, Kotei)
- Urine ‘came in bits’ and brought with it other bodily sensations for one woman. Kisi (aged 60, La) stated that *‘when I urinate it smells a lot’*. In this case, there was a mention of sensation of burning whilst urinating at the toilet in the early stages of onset of incontinence during menopause. These narratives indicate potential links to urine infections due to issues around burning, smell and a sense of urgency, but these women did not explicitly identify their symptoms with infections.

²² Bhakta, A. (2019) *Opening the doors to the water, sanitation and hygiene needs of women from the onset of the perimenopause in urban Ghana*. PhD Thesis, Loughborough University, Loughborough. Available at:

https://repository.lboro.ac.uk/articles/Opening_the_doors_to_the_hidden_water_sanitation_and_hygiene_needs_of_women_from_the_onset_of_the_perimenopause_in_urban_Ghana/8230220/1 – pages 190; 223-224; 255-256

²³ Names have been changed for privacy. A few of the case studies in this section are from women in a higher income context as well as the other case studies from women in Ghana.

Urine infections

- Urinary issues extended to urine infections, identified explicitly by some women. In one case, urine infections during the perimenopause led to incontinence: *“It was when I started having this problem, the urine incontinence came about as a result of the infection... [...] sometimes when I finish urinating, I feel my panty is wet.”* (Kisi, menopausal, La)
- When infections arose, women would seek a consultation with a doctor, having judged that they were facing problems. However, urine infections invoked a sense of confusion, with lack of clarity as to what was occurring: *“The appearance of my urine was not good so they asked me to go for urine test and later gave me some medications, but they didn’t explain to me what was wrong.”* (Afia, menopausal, Kotei)
- Discussions during a mapping session in Kotei identified that women faced issues with urine being ‘hot’, but there was lack of clarity concerning the relation of this directly to the perimenopause. Group discussions upon urinary infections overall were inconclusive.

Urinary incontinence management: “...I double the panty.” (Oheama, Kotei)

Urinary incontinence had various implications for hygiene practices, reflecting implications for meeting PM women’s needs as well as a generally ageing society with incontinence becoming a more prominent issue. PM women face issues with urinary discharge and frequent leaking, which leads to concerns regarding smell. Different hygiene practices are required for urinary incontinence management, which are influenced by various factors.

Toileting

- Toileting became an issue of importance for PM women who were experiencing incontinence. Uncontrollable and unpredictable leakage of urine warranted regular toilet use. Public community toilets were difficult to access for some incontinent women due to fears of leakage. Women resorted to trying to manage their toileting needs at home, *“I don’t urinate at the toilet, I urinate into a chamber pot at the bathhouse and later pour it into the drain.”* (Abena, perimenopausal, Kotei)
- A lack of household toilets led to use of the infrastructure available within easy reach in the home for some. Managing toileting needs at home depended upon the bathing patterns of incontinent women: *“I visit the toilet more often to urinate, if I have not taken my bath I go to the toilet but after taking a bath I just take a chamber to the bathhouse if I want to urinate and after urinating I pour it down the drain.”* (Oheama, perimenopausal, Kotei)
- Women therefore demonstrated a consciousness of cleanliness and smell. It was not only the smell of urine, but the additional smell of the public pit latrines lingering in their clothes which was a matter of concern. The disposal of urine from a chamber pot highlighted the need for better sanitation for excreta disposal, immediate access to which was lacking for PM women.
- This woman used the public WCs “more often”, because of the ability to flush the toilet, and because, *“...It’s more convenient urinating there.”* (Oheama, perimenopausal, Kotei)
- Using public toilets however, came at a financial cost: *“Yes because of money issues, I try to hold on at certain times.”* (Oheama, perimenopausal, Kotei)
- Delaying urination due to concerns over finance, despite a need to visit the toilet, has wider implications for the health and wellbeing of PM and menopausal women. Ultimately, needing to urinate more often was determined by access to clean toilets, which were low cost and within easy reach.

Doubling layers of clothing

- Women used their clothing alone as means of protection from urine leaks: *“...I double the panty.”* (Oheama, perimenopausal, Kotei)
- Protecting from leaks was particularly important when travelling out of the community and into the main town. This participant noted that doubling the layers of clothing was the only option available to her. Incontinence pads were noted as a preference for this woman, but the cost of incontinence pads was a barrier to access. Incontinence therefore had implications for laundry.