Journal of
Water, Sanitation & Hygiene for Development

IWA PUBLISHING

 Journal of Water, Sanitation and Hygiene for Development Vol 14 No 3, 220 doi: 10.2166/washdev.2024.199

Research Paper

'Do not forget us': the shared experiences and needs of people living with incontinence in humanitarian contexts

Claire Rosato-Scott[a,*], Samuel Adjorlolo[b], Michelle Farrington[c] and Dani J. Barrington[a,d]

[a] School of Civil Engineering, University of Leeds, Leeds, UK
[b] Research and Grant Institute of Ghana, Accra, Ghana
[c] Oxfam, London, UK
[d] School of Population and Global Health, The University of Western Australia, Crawley, Australia
*Corresponding author. E-mail: claire.rosatoscott@outlook.com

CR-S, 0000-0002-7838-7773; DJB, 0000-0002-1486-9247

ABSTRACT

The medical condition of incontinence is defined as the involuntary loss of urine or faeces. People may also wet or soil themselves due to not wanting, or not being able, to use the sanitation facilities available (social incontinence). Nascent research conducted in humanitarian contexts has consistently found that the consequences of incontinence are many and overwhelmingly negative. This paper contributes to the growing body of evidence on the lived experiences and needs of people with incontinence in humanitarian settings. It summarises shared learnings from research funded by the Humanitarian Innovation Fund which was conducted in Bangladesh, Ethiopia, Ghana, Malawi and Uganda. It also provides practical advice to researchers and humanitarian practitioners on how to better support people with incontinence: recommendations include public education campaigns to change the perception of incontinence; improving water and sanitation facilities by ensuring safe access for all and adapting to support use by all; and a better supply (in terms of quantity and functionality) of non-food items. It concludes with a reminder that as everyone experiences incontinence differently, sufficient time and resources must be allocated to engage with people experiencing incontinence and their caregivers to truly understand how to improve their quality of life.

Key words: children, fistula, health, older people, protection, sanitation

HIGHLIGHTS

- The many overwhelmingly negative consequences of incontinence justify it being on the agendas of researchers/humanitarian practitioners.
- The collaborative inclusion of incontinence in humanitarian programmes across at least the health, protection and water, sanitation and hygiene sectors is recommended.
- Time and resources are needed to engage with people experiencing incontinence/caregivers to understand how best to support them.

INTRODUCTION

Summary

Interest in the lived experiences and needs of people with incontinence in low- and middle-income contexts (LMICs), including humanitarian contexts, has been gaining traction in recent years (see Gjerde *et al.* 2013; Giles-Hansen 2015; Hafskjold *et al.* 2016; Rosato-Scott & Barrington 2018; Rosato-Scott *et al.* 2019, 2020; Bhakta *et al.* 2021; Imoto *et al.* 2021; Wilbur *et al.* 2021; Ansari & White 2022; House & Chatterton 2022; Red Cross Red Crescent 2022; Whiting *et al.* 2022; Basnet *et al.* 2023). This is particularly true in the water, sanitation and hygiene sector (WASH) as people that experience incontinence have significantly increased needs for water supply; hygiene items and for accessible and private toilet, bathing and laundry facilities. This paper summarises the shared learnings from research recently conducted in multiple humanitarian contexts, and provides practical advice to researchers and humanitarian practitioners (largely but not exclusively in the WASH sector) on how to better support people with incontinence.

Incontinence: definitions, prevalence and impact

The medical condition of incontinence includes urinary incontinence (UI), defined as the involuntary loss or leakage of urine, and faecal incontinence (FI), defined as the involuntary loss or leakage of faeces. Many people may experience UI and/or FI, but some groups of people have an increased risk of experiencing the condition. These groups include children; pregnant adolescent girls and women; adolescent girls and women who have given birth; women going through the menopause process (the process leading to the stoppage of menstruation); older people; people with disabilities; people with certain types of illness such as cancer; people who have experienced highly traumatic or stressful situations and people who have faced violent assault (Rosato-Scott *et al.* 2020). Leakage can be continuous or intermittent, and if intermittent can happen at any time, day or night (in children UI at night is also known as bedwetting or enuresis). Obstetric fistula-induced incontinence (OFII) is a severe type of UI and/or FI. An obstetric fistula (OF) is a hole between the vagina and bladder (vesico-vaginal fistula), vagina and rectum (recto-vaginal fistula), or both, through which urine or faeces leak (Adjorlolo *et al.* 2023). OF are caused by a prolonged and/or obstructed childbirth (often due to giving birth young), or from sexual assault. People may also self-wet or self-soil due to not wanting to use, or not being able to use, the toilet facilities available. This is known as social incontinence (SI) or functional (Ryan 2018). The term 'incontinence' is used in this paper to collectively mean UI, FI and SI unless stated otherwise.

It is very difficult to estimate the prevalence of UI and FI. Although many studies have been completed, comparison is rarely possible because study designs use varying definitions, study populations and methodologies. International Consultations on Incontinence reviews general population studies (largely based in high-income countries) and they have found that between 1 and 39% of men have UI; between 25 and 45% of women have UI; in children, the prevalence of daytime UI decreases with age (from 3.2 to 9.0% in 7-year olds to 1.1 to 3.0% in 15 to 17-year olds), as does bedwetting (from 6.8 to 16.4% at 7 years of age to 0.5 to 1.7% by age 16–17 years); and less than 15% of adults have FI (Abrams *et al.* 2017). To the best of the authors' knowledge, there is no prevalence data on SI.

Research, largely conducted in higher-income countries, has found that no matter why a person wets or soils themselves, the impacts can be the same. Rosato-Scott *et al.* (2020) summarised that health can be affected: a person with incontinence may experience rashes, urinary tract infections, pressure sores (which can be life threatening if infected) and dehydration/constipation if they restrict water/food intake to reduce the need to go to the toilet. They may have physical accidents trying to get to a toilet that is difficult to access. Mental and emotional health can also be affected: they may feel embarrassed and limit their participation in personal relations, social life and community life. They may experience loneliness, low self-esteem, anxiety and depression. The practical and financial impacts are far-reaching: managing incontinence is time-consuming and resource-intensive (including soap, water and items to help manage the condition such as pads). These resources may be difficult to access and/or costly. People with incontinence may not be able to find suitable income-generating opportunities, or they may exclude themselves from earning an income (due to, for example, embarrassment). Children may not want to go to school, or they may get sent home from school. People who experience incontinence may also suffer from verbal punishment or physical abuse from family and community members.

There will also be implications for the carers of people that experiencing incontinence (Rosato-Scott *et al.* 2020). A carer's health may also be affected from needing to move someone to help them go to the toilet or to bathe, and from handling urine and faeces. Their mental and emotional health can also be affected: they may experience shame and loneliness if they are not able, or do not want, to take part in community life. They may feel angry and frustrated towards the person they are caring for which can result in the carer being verbally and/or physically abusive. The time needed to support a person with incontinence may mean that a carer is not able to take part in income-generating activities, and child caregivers may not be able to attend school.

Incontinence in humanitarian settings

In 2024, the United Nations Office for the Coordination of Humanitarian Affairs (OCHA) anticipates that nearly 300 million people will need humanitarian assistance and protection (OCHA 2023). Little is known about how people in humanitarian settings (relative to low- and middle-income settings) experience incontinence and how best to support them. In 2018, Elrha's Humanitarian Innovation Fund (HIF) funded three projects to better understand the experiences of people living with incontinence and the barriers they face to inclusion in WASH humanitarian programming (Elrha 2018). These were led by University of Leeds and The University of Western Australia (UWA) for a study on incontinence in children in Bangladesh

and Uganda; Oxfam and HelpAge for a study on incontinence in older people in Malawi and Ethiopia; and Research and Grant Institute of Ghana (ReGIG) for a study on women with OFII in Ghana.

Although the projects focused on different groups of people (albeit groups that have a significant risk of experiencing incontinence) and conducted research in very different contexts, there were shared findings on both the experiences and needs of people with incontinence, and recommendations on how researchers and humanitarian practitioners (largely, but not exclusively in the WASH sector) can better support people with incontinence. It is hoped that sharing these findings and recommendations will keep incontinence high on the agenda of humanitarian discourse and continue to encourage the inclusion of incontinence in humanitarian programmes across multiple sectors.

METHODS

Summary

This paper summarises the shared findings and recommendations from research conducted by three separate HIF-funded projects across five disparate humanitarian contexts (Table 1). The Leeds/UWA-led project 'Understanding children and their caregivers' experiences with incontinence in humanitarian contexts' conducted research in Cox's Bazar refugee camps in Bangladesh and Adjumani District refugee settlements in Uganda. Research activities included focus group discussions with children aged 5–11 using a bespoke Story Book methodology; focus group discussions with caregivers (Uganda only); key informant interviews and the completion of sanitation facility observation checklists. The Oxfam and HelpAge International-led project 'Improving the lives of older people with incontinence' was conducted in Gambella refugee camps in Ethiopia and Cyclone Idai-affected areas of Malawi. Research activities included a Quantitative Needs Assessment Survey (QNAS), focus and small group discussions, key informant interviews and household visits. The ReGIG-led project 'Exploring the WASH needs of women with incontinence due to obstetric fistula' conducted research in the Central Region of Ghana. Research activities included a questionnaire, focus group discussions and key informant interviews. Findings and recommendations are based on a thematic analysis of both internal and publicly available project reports and presentations conducted by the lead author, and the project-specific knowledge and experience of the co-authors.

Ethical considerations

Approval to conduct the project 'Understanding children and their caregivers' experiences with incontinence in humanitarian contexts' was granted by the Research Ethics Committee, Faculty of Engineering, University of Leeds, United

Table 1 | Project details

	Leeds/UWA-led project		Oxfam/HelpAge-led project		ReGIG-led project
Detailed methods	Supplementary Material (SM) 1		SM 2		SM 3
Publicly available reports	Alam *et al.* (in press); Rosato-Scott *et al.* (2023); Wozei at al. tbc.		Farrington (2021); Farrington (2022)		ReGIG (2022)
Focus study population	Children aged 5–11 and their caregivers		Older people		Women with OFII
Location(s)	Bangladesh	Uganda	Ethiopia	Malawi	Ghana
Questionnaires	–	–	38 quantitative needs assessment surveys (QNAS)	41 QNAS	40 questionnaires
Group discussions	8 focus groups discussions (FGDs); 50 participants	14 FGDs; 95 participants	10 FGDs/4 small group discussions; 194 participants	9 FGDs/5 small group discussions; 104 participants	5 FGDs; 20 participants
In-depth interviews	39 participants	21 participants	7 participants	18 participants	30 participants
Household (HH) visits	–	–	22 visits	18 visits	–
Sanitation facility observation checklists	24 checklists	14 checklists	–	–	–

Kingdom (Reference MEEC 19-020). Approval to conduct the research in Cox's Bazar was granted by the Institutional Review Board of the Institute of Health Economics (University of Dhaka, Bangladesh), with authority to access the refugee camps granted by the Office of the Refugee Relief and Repatriation Commissioner. Approval to conduct the research in Adjumani District was granted by the UCU Research Ethics Committee (Reference 2021-82) and the Uganda National Council for Science and Technology, with authority to access the refugee settlements granted by the Prime Minister's Office of the Uganda Government.

Approval to conduct the project 'Improving the lives of older people with incontinence' was granted by the National Ethics Review Committee Secretariat within the Ministry of Science and Technology in Ethiopia, the National Health Sciences Research Committee in Malawi and the Institute of Development Studies (IDS) in the United Kingdom.

Approval to conduct the project 'Exploring the WASH needs of women with incontinence due to obstetric fistula' was granted by the Ghana Health Service Ethics Review Committee (GHS-ERC006/03/20) and Christian Association of Ghana Institutional Review Board (Reference 05012020).

RESULTS AND DISCUSSION

Summary

Findings were similar across all contexts: knowledge and understanding of incontinence was limited; the impacts of experiencing incontinence include physical pain; poor mental and emotional health; and adverse effects on daily activities; support from family members and communities is limited; and people experiencing incontinence have significantly increased needs for water supply; items to maintain personal hygiene; and for accessible and private toilet, bathing and laundry facilities.

'It is better to say not just bedridden' (FGD participant, Ethiopia): Understanding of incontinence

All three projects found that there was little understanding of the term 'incontinence' by people experiencing the condition; their caregivers or professionals across sectors including health, protection and WASH. This made having conversations about the condition challenging at times: '*People see incontinence as a severe thing … but when we explained that it could be a small leak we had people say … then yes, I have that*' (Researcher, Oxfam/HelpAge-led project). Researchers and humanitarian practitioners should be aware that in some languages, there may not be an equivalent word for incontinence: '*We call it Lichaleo, which means a frog which jumps while passing urine*' (Interviewee, Uganda). To avoid confusion an explanation of what incontinence is (using simple and culturally appropriate language) may therefore be needed when having conversations about the condition (see Rosato-Scott *et al.* 2020 for how to talk about incontinence).

Causation of UI and FI was not always well understood. Some recognised that they are medical conditions, for example due to a prolonged labour: '*When I was in labour, I was delayed at home. When I managed to get to the health facility, my vagina was torn in the process of delivery*' (Interviewee with OFII, Ghana). Others recognised that it can be experienced due to age (specifically, by young children and older people) or other factors such as depression, physical abuse or trauma: FGD participants in Ethiopia noted that '*it's very common for older people, as the body becomes weaker*' and '*[people with incontinence] were refugees coming from war in South Sudan, some people are traumatised*'. However, others believed that UI and FI could be due to spiritual forces, for which there is no medical evidence: '*God can give you this disease by damaging all your nerves*' (FGD participant, Ethiopia). Researchers and humanitarian practitioners should be aware that such beliefs regarding causation can contribute to the stigma associated with incontinence.

All three projects confirmed that self-wetting and self-soiling can be due to not being able to access the sanitation facilities available (for example, due to long distances or insufficient light at night); not being able to use the sanitation facilities available; or not wanting to use the sanitation facilities available (for example, due to a lack of cleanliness). In Malawi, one FGD participant noted that his grandfather '*is living with both urine and faecal incontinence, but this is because he has difficulties with walking*' (FGD participant, Malawi) and in Uganda one caregiver noted that '*the one aged seven years cannot go to the toilet at night she wets the bed*' (Caergiver Interviewee, Uganda). This is a further reminder of why emergency WASH programmes should continue to strive to achieve sanitation facilities safe for all to access and adapted for all to use, as guided by the Sphere Handbook (Sphere Association 2018).

'Life has been very difficult' (Interviewee with OFII, Ghana): The impact of incontinence

Although everyone experiences incontinence differently the three projects found the consequences of the condition to be many and overwhelmingly negative. There were reports of physical pain associated with experiencing the condition (for example, due to skin irritation): '*I noticed that the whole perineum is sored, I cannot even put the cloth there. There would be so much sores and when the urine gets into the sore it would be burning. I cry so much*' (Interviewee with OFII, Ghana).

The emotional impacts of experiencing incontinence were clearly painful too. People experiencing the condition discussed feelings of shame and embarrassment, due, for example, to the smell of urine or faeces, loneliness, sadness and depression. In Ghana, 38 (95%) of the 40 questionnaire participants reported incontinence-induced emotional distress and suicidal ideation was noted: '*It is by God's grace I am here; else I would have poisoned myself by now*' (Interviewee with OFII, Ghana). Suicidal ideation was also particularly noted in Ethiopia: '*I'm wishing for death but it is not coming. I punish myself by not eating to bring death quicker*' (HH visit participant, Ethiopia). In Bangladesh, when focus group participants aged 5–11 were asked to describe their drawings of how a child would feel after they wet themselves the most common answers were unhappy (also described as won't feel good, feel bad, sad, upset, crying), ashamed and tense.

Caregivers also discussed experiencing negative emotions such as shame and embarrassment: '*I feel so worried because the house stinks something that disgusts the family and also the community thinks I am not training my daughter very well*' (Caregiver interviewee, Uganda). Feeling frustrated and angry towards the person experiencing incontinence was shown to manifest in verbal and/or physical abuse towards the person they are caring for. In both Bangladesh and Uganda, children aged 5–11 were asked to draw a picture of how a caregiver would respond to a child who had wet the bed: many children drew a picture of a child being beaten by their caregiver (Figure 1). In Bangladesh, a caregiver admitted physical abuse: '*My son is urinating and defecating, I have trouble washing their clothes. I beat the children and changed their clothes. I feel sad about that*' (Caregiver interviewee, Bangladesh).

Unsurprisingly, the three projects all confirmed that it can be challenging to manage incontinence. It is known that people experiencing incontinence need to frequently wash themselves, soiled clothes and soiled bedding which requires sufficient water, soap, spare bedding and clothes and time. In a humanitarian context these may be particularly difficult to access and/or costly: '*This [incontinence] increased my water usage at home. It again brought some financial demands because I was buying the water*' (Interviewee with OFII, Ghana).

Managing incontinence can also interfere with daily activities, including socialising (which can lead to isolation): 9 (24%) of 38 QNAS respondents in Ethiopia and 5 (12%) of 41 QNAS respondents in Malawi reported that incontinence stops them from socialising with others. Education and work (which can lead to loss of income) can be affected too: '*When incontinence*

Figure 1 | Drawings from FGDs with children aged 8–11 in Bangladesh and Uganda each depicting a caregiver beating a child who has wet the bed.

is unbearable and I tell my employer about my experiences, I am told that if this is what I'm having then we cannot work with you' (Interviewee with OFII, Ghana).

Such impacts on daily activities can also be experienced by caregivers: '*I'm a young man, I want to work, but I can't … I'm supposed to be earning*' (FGD participant, Malawi). Restricted socialising, education and income-generating activities can exacerbate negative emotions and the difficulties faced in managing the condition (for example, not being able to buy personal hygiene items).

'My family members do not help me' (Caregiver interviewee, Uganda): Help-seeking behaviours

In all research settings, support from family members and communities was limited: '*No family member assisted me. There was no support from anywhere*' (Interviewee with OFII, Ghana). Instead, treatment is sought from religious leaders, traditional healers and conventional medical practitioners. Who is approached is often a function of the patient's view of the causation of the condition: '*My grandmother said it was something spiritual so we should go and consult one man of God*' (Interviewee with OFII, Ghana).

For those unwilling or unable to seek support, unconventional (and not recommended) methods are sometimes used instead to manage incontinence. These include restricting food and water (particularly at night to reduce the need to use the sanitation facilities, but which can lead to dehydration) and encouraging constipation (with drugs or food): across Ethiopia and Malawi 9 (11%) of 79 QNAS respondents reported they did not drink as much as they would like to. The use of locally available material to make mattress protectors (for example, cow hides in Ethiopia) and pads (for example, clothes and flour sacks in Ghana) was also noted: '*One of my aunts used to bake bread, so I used the flour sack as pad. I washed it with Dettol [antiseptic] and Powerzone [bleach]*' (Interviewee with OFII, Ghana). This can be an infection risk. That there is so little support available should be a reminder to humanitarian practitioners that there is much to do to improve the quality of life for people experiencing incontinence, and their caregivers, in humanitarian contexts.

'Now you have done this research, put it into practice, do not forget us' (Interviewee, Ethiopia): Recommendations

The primary recommendation for humanitarian researchers and practitioners is to engage with people experiencing incontinence and their caregivers to better understand the support needed. Guidance and training on how to have conversations about incontinence (including how to identify and engage with participants) is publicly and freely available (including Rosato-Scott *et al.* 2020; Norwegian Church Aid Unknown).

Public education campaigns to change the perception of incontinence are also recommended. It is hoped that normalising the condition will reduce the psychological challenges experienced by people with incontinence, and increase support in family and community settings (subsequently lowering protection risks): '*Public education has to be thorough because there are some persons with the fistula but because of the embarrassment that comes with it, take mine for example, I had to hide it until the surgery*' (Interviewee with OFII, Ghana). As an example, as a result of the research conducted in Bangladesh and Uganda posters will be distributed to normalise self-wetting by (a) promoting the idea that most children will grow-out of self-wetting and (b) encouraging caregivers and peers to support children who self-wet (Figure 2).

Improving water and sanitation facilities by ensuring safe access for all and adapting to support use by all (as guided by the Sphere Handbook) would lower the prevalence of SI (Sphere Association 2018). In Ghana, 20 (51%) of 39 questionnaire participants indicated that they are looking for better access to toilet facilities, and in Bangladesh a WASH practitioner suggested that '*small pans need to be done for children so that s/he can sit comfortably*' (Key informant interviewee, Bangladesh).

A better supply (in terms of quantity and functionality) of non-food items would also support people experiencing incontinence and their caregivers: in Ghana, 30 (77%) of 39 questionnaire participants indicated that they are looking for better access to sanitary products. Items mentioned by participants across the three research projects included extra soap, extra containers to store water and wash clothes, pads (disposable and reusable), clothes including gloves (to support hygienic cleaning), mattresses and mattress protectors, bedding, torches or solar lights and assistive devices such as wheelchairs and walking sticks (to facilitate accessing sanitation facilities and socialising with others). For example, in Ethiopia and Malawi 18 (23%) of 79 QNAS respondents indicated that they would like more soap to help manage incontinence and 16 (20%) of 79 QNAS respondents indicated that they would like more water. It should be noted that most of these items are

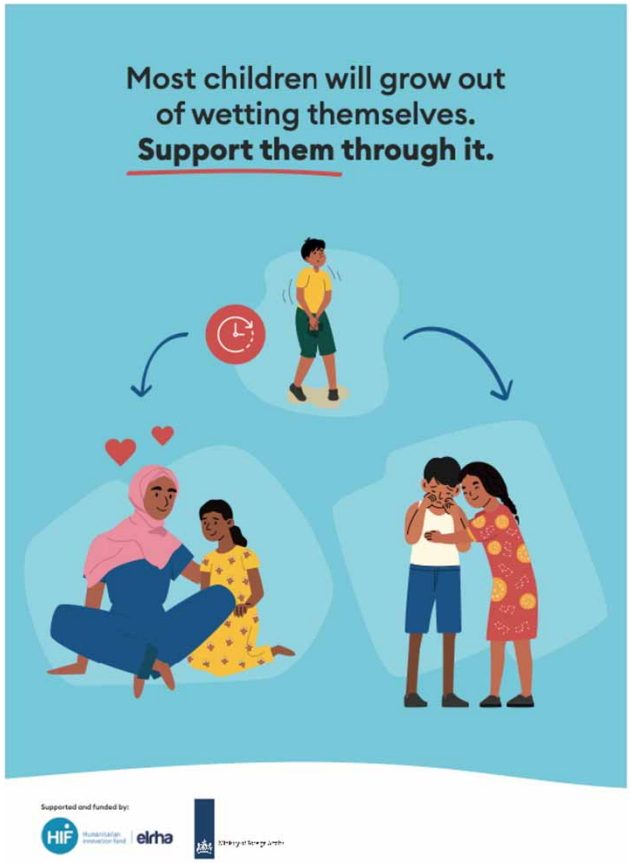

Figure 2 | Poster to normalise self-wetting in children (Bangladesh version) (editable version available open access from Barrington 2023).

not specific to the management of incontinence, and many are already included in hygiene kits. Ideally, engagement with people experiencing incontinence and their caregivers to determine what is specifically needed would guide a more appropriate distribution of such items. Depending on the item(s) requested, suppliers would also need to consider how items will be replenished; how reusable products will be washed and dried; how single use products will be disposed of and how to best manage health hazards associated with handling urine and faeces. Discretion would also need to be considered to prevent any negative consequences due to making a person's incontinence visible to others, or due to them receiving additional personal hygiene items relative to others. Longer-term suggestions included dedicated schemes to produce and distribute reusable sanitary pads and nappies; and sustainable financial support.

Other recommendations from across the projects included psychosocial support services for the person experiencing incontinence and caregivers; training for caregivers and community groups (for example, Older Persons Associations) and the creation of economic empowerment opportunities (for example, vocational and technical skills training): '*After surgery [for OFII], we should be given some skills training to help us earn a living when we return to our families*' (Interviewee with OFII, Ghana). Note that national-level policy recommendations are not deemed feasible at this stage as project-specific findings may not be representative of national populations.

The shared learnings of these three research projects align with and add to those of work completed to date across a variety of LMICs and (less so) humanitarian contexts (including Gjerde *et al.* 2013; Giles-Hansen 2015; Hafskjold *et al.* 2016; Rosato-Scott & Barrington 2018; Rosato-Scott *et al.* 2019, 2020; Bhakta *et al.* 2021; Imoto *et al.* 2021; Wilbur *et al.* 2021; Ansari & White 2022; Whiting *et al.* 2022; Basnet *et al.* 2023 and as collated and discussed in House & Chatterton 2022). This research has confirmed that even in disparate humanitarian contexts, people experiencing incontinence and their caregivers have similar lived experiences and needs. That such a body of evidence now exists should be sufficient to ensure that incontinence is unquestionably integrated into humanitarian responses by multiple sectors including – but not

limited to – health, protection and WASH. It should also be noted that the recommendations in this paper align with House & Chatterton's (2022) vast mapping study of support for people living with incontinence in humanitarian settings. This should provide reassurance to humanitarian practitioners that these recommendations are a valid starting-point to ensure the inclusion of incontinence in humanitarian response programmes.

Limitations

It should be noted that as random sampling methods were used, quantitative research findings in Ethiopia, Ghana and Malawi are not representative of the wider population; and qualitative research findings in Bangladesh may not be representative of the wider population. Qualitative research findings are also context-specific and despite there being shared learnings and recommendations across the five contexts discussed in this paper, findings may not be representative of all humanitarian contexts.

CONCLUSION

Research conducted in disparate humanitarian contexts in Bangladesh, Ethiopia, Ghana, Malawi and Uganda found that people experiencing incontinence and their caregivers have similar lived experiences and needs. These findings contribute to a growing body of evidence that the impacts of experiencing incontinence are many and overwhelmingly negative. These include physical pain; poor mental and emotional health and adverse effects on daily activities including education, work and socialising that more than justify the inclusion of incontinence on the agendas of researchers and humanitarian practitioners.

Needs are also clear: people experiencing incontinence have significantly increased needs for water supply; items to maintain personal hygiene and for accessible and private toilet, bathing and laundry facilities. The WASH sector is therefore well-placed to better support people who experience incontinence and their caregivers, but they are not the only sector that can help to improve their quality of life. The collaborative inclusion of incontinence in humanitarian programmes across at least the health, protection and WASH sectors is therefore recommended.

Finally, despite the clear shared findings and recommendations across the three projects, it must also be remembered that everyone experiences incontinence differently. Whilst the recommendations in this paper are a good starting-point for all researchers and humanitarian practitioners when considering how best to include incontinence in humanitarian programmes, sufficient time and resources must also be allocated to engage with people experiencing incontinence and their caregivers within any given context to truly understand how best to support them.

DATA AVAILABILITY STATEMENT

Data cannot be made publicly available; readers should contact the corresponding author for details.

CONFLICT OF INTEREST

The authors declare there is no conflict.

REFERENCES

Abrams, P., Cardozo, L., Wagg, A. & Wein, A. 2017 *Incontinence*, 6th edn. International Continence Society, Bristol, UK.

Adjorlolo, S., Ani-Amponsah, M., Hammond, E. & Esi Pantsiwaa Nyame, M. 2023 Obstetric fistula-induced incontinence and WASH programming in humanitarian settings: Agenda for research, innovation, and practice. *Journal of International Humanitarian Action* **8** (1). doi:10.1186/s41018-022-00133-y.

Alam, M.-U., Das Gupta, S., Rosato-Scott, C., Shoaib, D. M., Ritu, A. H., Nowshin, R., Rahat, M. A., Akram, N., Rose, J., Evans, B. E. & Barrington, D. J. (in press) Experiences of children's self-wetting (including urinary incontinence) in Cox's Bazar Rohingya Refugee Camps, Bangladesh. PLOS Global Public Health.

Ansari, Z. & White, S. 2022 Managing incontinence in low-and middle income-countries: A qualitative case study from Pakistan. *PLOS ONE* **17** (7), e0271617. doi:10.1371/journal.pone.0271617.

Barrington, D. 2023 *Understanding Children and Their Caregivers' Experiences with Incontinence in Humanitarian Contexts*. Available from: https://osf.io/e3khv/ (accessed 6 June 2023).

Basnet, U., Yangden, N. & Mandal, P. K. 2023 Knowledge on Urinary Incontinence among Women in a Community at Barahachhetra, Nepal. *Journal of Research and Development* **6** (1), 30–38. doi:10.3126/jrdn.v6i01.55237.

Bhakta, A., Esseku, H., Esseku, Y., Fisher, J. & Reed, B. 2021 The hidden WASH needs of perimenopausal women. *Journal of Water, Sanitation and Hygiene for Development* **11** (6), 1016–1025. doi:10.2166/washdev.2021.101.

Elrha 2018 *WASH Innovation Challenge: Exploring the Barriers to Inclusion Faced by People Living with Incontinence*. Available from: https://www.elrha.org/funding-opportunity/wash-innovation-challenge-barriers-to-inclusion-faced-by-people-living-with-incontinence/ (accessed 22 May 2023).

Farrington, M. 2021 Barriers to inclusion of older people with incontinence in humanitarian WASH programming. Emergency Environmental Health Forum. Available from: https://www.youtube.com/watch?v=P2×8dW8dDf4 (accessed 5 June 2023).

Farrington, M. 2022 Barriers to inclusion of older people with incontinence in humanitarian WASH programming. Initial findings from research conducted in Gambella, Ethiopia and Blantyre, Malawi. *Hygiene Promotion Technical Working Group Speaker Series*. Available from: https://www.youtube.com/watch?v=dsCCuh7gHNU (accessed 5 June 2023).

Giles-Hansen, C. 2015 *Hygiene Needs of Incontinence Sufferers: How can Water, Sanitation and Hygiene Actors Better Address the Needs of Vulnerable People Suffering From Urine and/or Feacal Incontinence in Low- and Middle-Income Countries, WaterAid and Share Research Consortium*. Available from: https://www.ircwash.org/sites/default/files/hygiene_needs_of_incontinence_sufferers_sept2015_final.pdf (accessed 22 May 2023).

Gjerde, J. L., Rortveit, G., Muleta, M. & Blystad, A. 2013 Silently waiting to heal. Experiences among women living with urinary incontinence in northwest Ethiopia. *International Urogynecology Journal* **24**, 953–958. doi:10.1007/s00192-012-1951-4.

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., Cordero, R., Cavill, S. & House, S. 2016 Taking stock: Incompetent at incontinence – why are we ignoring the needs of incontinence sufferers? *Waterlines* **35** (3). doi:10.3362/1756-3488.2016.018.

House, S. & Chatterton, C. 2022 *Mapping of Support for People Living with Incontinence in Humanitarian Contexts, Through the Lens of WASH, GBV and ASRH, Main Report, Norwegian Church Aid*. Available from: https://www.kirkensnodhjelp.no/en/wash (accessed 7 July 2023).

Imoto, A., Sarker, M., Akter, R., Matsuyama, A. & Honda, S. 2021 Health-related quality of life in parous women with pelvic organ prolapse and/or urinary incontinence in Bangladesh. *International Urogynecology Journal* **32**, 887–895. doi:10.1007/s00192-020-04410-5.

Norwegian Church Aid Unknown *Webinar on MHM and Incontinence in A Humanitarian Context*. Available from: https://fabo.org/enrol/?id=1875 (accessed 6 June 2023).

OCHA 2023 *Global Humanitarian Overview 2024*. Available from: https://www.unocha.org/publications/report/world/global-humanitarian-overview-2024-enarfres#:~:text=In%202024%2C%20the%20UN%20and,of%20the%20Global%20Humanitarian%20Overview (accessed 5 January 2024).

Red Cross Red Crescent 2022 *Supporting People with Incontinence in the Red Cross Red Crescent Context: WASH and Incontinence Fact Sheet*. Available from: https://watsanmissionassistant.org/mdocs-posts/ifrc_wash_incontinence_fact_sheet_oct2022_en/ (accessed 22 May 2023).

ReGIG 2022 *Water, Sanitation and Hygiene Programming for Women with Obstetric-Fistula Induced Incontinence in Ghana*. Available from: https://www.elrha.org/wp-content/uploads/2022/09/Fistula-Incontinence-Project-Brochure.pdf (accessed 5 June 2023).

Rosato-Scott, C. & Barrington, D. J. 2018 Incontinence in Zambia: Initial investigation into the coping strategies of sufferers and carers. *Waterlines* **37** (3), 190–206.

Rosato-Scott, C. A., Giles-Hansen, C., House, S., Wilbur, J., Macauley, M., Barrington, D. J., Culmer, P. & Burke, L. 2019 *Guidance on Supporting People with Incontinence in Humanitarian and Low- and Middle-Income Contexts (LMICs)*. LMIC-Incontinence-email-group. doi:10.5518/100/13.

Rosato-Scott, C., Barrington, D. J., Bhakta, A., House, S. J., Mactaggart, I. & Wilbur, J. 2020 Incontinence: We need to talk about leaks. Frontiers of Sanitation: Innovations and Insights 16. Institute of Development Studies, Brighton, United Kingdom. doi:10.19088/SLH.2020.005.

Rosato-Scott, C., Alam, M.-U., Evans, B. E., Rose, J., Wozei, E. & Barrington, D. J. 2023 Understanding children's experiences of self-wetting in humanitarian contexts: An evaluation of the Story Book methodology. *PLOS Global Public Health* **3** (5), e0001194. doi:10.1371/journal.pgph.0001194.

Ryan, F. 2018 'It's horrifically painful': The disabled women forced into unnecessary surgery. *The Guardian*. Available from: https://www.theguardian.com/society/2018/aug/06/disabled-women-surgery-catheter-accessible-toilets (accessed 13 June 2023).

Sphere Association 2018 *The Sphere Handbook: Humanitarian Charter and Minimum Standards in Humanitarian Response*, 4th edn. Sphere Association, Geneva, Switzerland. Available from: https://spherestandards.org/handbook-2018/ (accessed 22 May 2023).

Whiting, D., Shane, A. I., Pope, R., Payne, S. & Venn, S. 2022 Female urinary incontinence in sub-Saharan Africa *BJU International* **130**(5). doi:10.1111/bju.15903.

Wilbur, J., Morrison, C., Bambery, L., Tanguay, J., Baker, S., Sheppard, P., Shem, J., Iakavai, J., Poilapa, R. & Mactaggart, I. 2021 'I'm scared to talk about it': Exploring experiences of incontinence for people with and without disabilities in Vanuatu, using mixed methods. *The Lancet Regional Health – Western Pacific* **14**, 100237. doi:10.1016/j.lanwpc.2021.100237.

Wozei, E., Barrington, D., Kizza-Nkambwe, S., Nassaka, B. & Rose, J. forthcoming tbc Children's experiences of self-wetting (including incontinence) in Adjumani district refugee settlements, Uganda.

First received 21 August 2023; accepted in revised form 7 February 2024. Available online 21 August 2024