Rode Kruis

Case Study

Living with incontinence in refugee camps
(Gedaref, Sudan)

SUMMARY

This study has found that displaced people from the Tigray region in Eastern Sudan experience extreme challenges to manage incontinence. They lack access to the right hygiene products and commodities, sanitation facilities and right amount of water. They also experience isolation and discrimination, and lack proper health care. The study showed that addressing incontinence requires integrated health care, MHPSS and WASH services to ensure dignity and wellbeing.

Incontinence can be investigated within wider WASH and health assessments, with tailored and tested tools that include the right language. Incontinence is a sensitive matter to be discussed in privacy, preferably in separate discussion groups or individual interviews. It is widely unknown by most of the population, so staff engaged in assessments may need to provide careful explanations without adding a bias effect to the responses.

This study found that standard hygiene kits alleviated the condition of incontinence in some groups, mainly women and girls at the age of menstruation who received Menstrual Hygiene Management kits. Other groups such as older men and women and people living with disability had less access to essential hygiene products such as soap and detergent and absorbent pads, aggravating their discomfort.

Meaningful consultations with people in displacement settings about preferred ways to receive items are essential to diversify methods of distributions. This study proved that specific items for managing incontinence such as mattress protectors, adult diapers, urine catheters and hand-held urine containers are difficult to find in local markets near by the camps, so cash and vouchers modalities might not be suitable to respond to the needs of people suffering incontinence. In-kind distribution of items was the preferred choice of people suffering incontinence in this study. They strongly asked for their hygiene needs to be covered, considering the difficulty they experience accessing distribution points, standing in long queues and bringing heavy hygiene kits back home.

Hygiene products for handling incontinence such as pads, diapers and bed covers are present in reusable or disposable forms. In this study, people suffering from incontinence did not have strong preferences, but they highlighted the challenges of being dependent on aid distribution and lack of solid waste disposal facilities when given disposable items, while facing the problem of not having enough water and detergent to wash reusable items.

A review of current hygiene products, better profiling of people's needs, and a rethinking of the modality to distribute are essential steps to ensure hygiene kits provided are tailored to the needs of people suffering from incontinence. This is a challenge that WASH actors need to take up to ensure the fulfillment of the right to the highest attainable standard of physical and mental health, and the right to life and human dignity.

The people portrayed in the photos in this report do not represent necessarily people suffering from incontinence


Photo: Rita Nyaga (IFRC)

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1. What is this case study about?

In Sudan, refugees fleeing the conflict and armed violence in Tigray have settled mostly in Kassala and Gedaref states. Um Rakuba and Tunaydbah are the major camps for refugees from Tigray in Gedaref State. During 2021, investment in WASH in these two refugee camps by Sudanese Red Cross (SRCS) with Netherlands Red Cross (NLRC) funding was rapid and focused on sanitation and hygiene promotion. Assessments conducted in 2022 by SRCS and partners described that, despite the progress made in 2021, the population in these two camps were under increasing strain to meet their basic sanitation and hygiene needs, especially vulnerable groups such as those suffering from incontinence. In 2022, SRCS continued with investments in hygiene promotion in both camps. These activities were coupled with an in-depth assessment conducted in November 2022. At the time of the study, in November 2022, 50,100 Tigray refugees lived in Gedaref State. Um Rakuba camp hosted 19,189 individuals, and Tunaydbah camp hosted 23,257 individuals. This case study aims to deepen the understanding about the WASH needs of People suffering from incontinence (PsI) and especially those needs related to the access to hygiene items and facilities in displacement and refugees' settings.

> Incontinence in this paper is defined as *the involuntary loss of urine and/or feces by people of any gender, age, or ability*. This group is referred to as People suffering from incontinence (PsI) in this case study.

2. Research methods

Based on reported difficulties to openly address this sensitive topic in previous studies, the data collection process was carefully designed. A variety of data collection techniques were used in this study, including observations, key informant interviews (KIIs), focus group discussions (FGDs), surveys at HH level, in-depth interviews with people suffering from incontinence and literature review.

The household survey collected data from 437 households (426 women and 11 men), refugees in both camps - 217 household in Tunaydba and 160 household in Um Rakuba. With thoughtful consideration to avoid any possible harm, the team carried out 8 in-depth interviews directly with People suffering from incontinence (PsI) in private spaces and with a limited number of people involved.

In addition to direct interviews with PsI, in-depth interviews with other members of the community were carried out. The study conducted 18 KIIs in total: 10 KIIs in Um Rakuba and 8 KIIs Tunaydbah with local leaders, health staff, officials from Ministry of Health, Commission for Refugees, and INGOs. The study conducted 19 FGDs in total, 8 KIIs in Um Rakuba and 11 KIIs in Tunaydbah. The discussions were held with older male refugees (65+ years) and Persons with Disabilities (PwDs); older female refugees (50+ years) and PwDs; refugees of mixed age (disaggregate by sex); female refugees (20-50 years) and refugees that are girls (16-20 years). The study also conducted 12 KIIs in total with market owners and traders in local markets on both camps.


Photo: IFRC

3. Findings overview

What is the Demographic profile of people suffering from incontinence in Gedaref Refugees Camps?

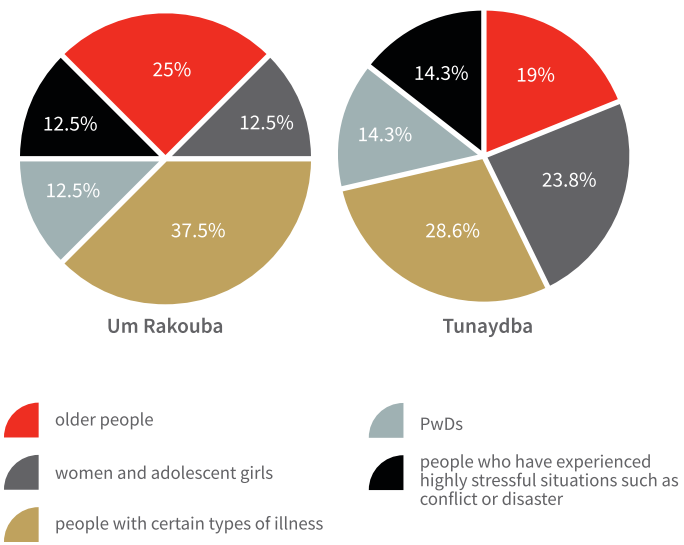
The picture portraying the group of people that self-reported to suffer from incontinence or caretakers that disclosed a familiar case, shows a very diversified group of people.

The household survey showed that the (self-reported) prevalence of incontinence in the camps was 9% in Um Rakuba and 8.1% in Tunaydbah. This was experienced by persons with and without disabilities and from different age and sex groups.

It is acknowledged that 97.2% of respondents in Um Rakuba and 93.3% in Tunaydbah said they think there is stigma or taboo around the topic. This may also indicate that figures of prevalence above might be higher.

‘I am a widowed man of 62 years old, living in Um Rakuba refugee camp for more than 2 years. I am suffering from urine incontinence for 20 years, but it is getting worse after forced migration and being a refugee living at the camp’

Percentage of people who responded to the question: ‘to your knowledge, who are those suffering incontinence?’



What knowledge is there about incontinence in Gedaref Refugees camps?

In Um Rakuba camp, 35% of survey respondents indicated they have heard about incontinence before, while 42.9% indicated this in Tunaydbah camp. FGD participants however, revealed a substantial lack of knowledge on what incontinence is and its causes, and shared some of the misconceptions about this condition. As reported directly by PsI:

> ‘My community fellows have different views on acceptance of people suffering incontinence. Some people accept, and some people feel that this is God curse for being a bad person’.

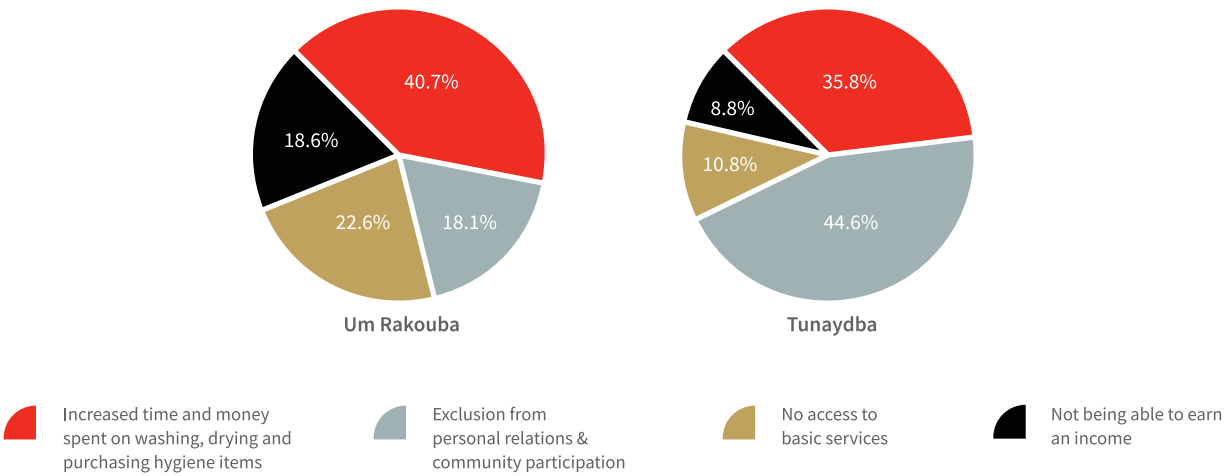
> ‘Due to the age factor, I am not able to clean myself or the mattress I use. Sometimes, the neighbors assist me but sometimes they refuse due to the urine smell, or they are afraid to be contagious and get the same problem’.

Among FGD participants, PwDs and older people (men over 60 years of age and women over 50 years of age) were those with better awareness about this topic. Older women (50+) at the age of menopause were also well aware of the topic, but they did not report incontinence as a symptom of menopause. In general, they showed poor knowledge about menopausal symptoms and the effects on their life.

What are the main challenges people experience?

In the household interviews, the highest-rated challenge reported was increased time and money spent on washing, drying and purchasing of hygiene items, followed by exclusion from personal relations and community participation, no access to basic services, and not being able to earn an income.

Percentage of people who responded to the question: 'what are the main challenges faced by people suffering from incontinence?'



WASH needs

The lack of household latrines was reported as the main challenge among older men (+65) and (male) PwD (FGDs participants). They reported need to often wait and stand in queues. Older men suffering from incontinence reported using water empty bottles as alternatives to handle pressing needs of urination.

Survey respondents reported that there was not enough water, especially in Um Rakuba, where 62% of respondents indicated that water was a strong challenge, while only 1.7% of respondents indicated that Tunaydba camp seemed better served in terms of water supply. In addition, 37.5% in Um Rakuba and 98.3% in Tunaydbah reported that toilets were dirty, full, or insufficient to handle incontinence.

During the FGDs, older women (+65), and female PwD participants reported similar issues as men, emphasizing the need of access to hygiene materials such as pads and soap.

> ‘The main challenge I faced when handling urine incontinence was that the distributed hygiene materials were inadequate and very limited. There is a lack of available incontinence items such as mattress protectors (to stop liquids and fluids soaking into the mattress), bed sheets, and re-usable male underwear. Also, I am not able to work and have no money to purchase hygiene specific items to handle urine incontinence. Moreover, the bad urine smell is very annoying’.

‘I am suffering social isolation. I avoid drinking water. I am unable to work and have no money to purchase the incontinence hygiene items. Due to movement disability, I am not able to use the latrine, as I need a special mobile chair that has a hole to place over a latrine hole. Due to the use of ash for a long period of time, I developed ulcers and have bleedings. I am not able to sit down and feel embarrassed when any person comes to visit me’.

Health needs

Health facilities located near the two camps confirmed receiving cases of people suffering with heavy forms of incontinence due to prostate tumors, urinary tract problems and being victims of rape. Also, in this case, the age, sex, and background of the people affected was very diversified. During KIIs with health staff working in health facilities in both camps, it was reported that no staff have knowledge or special medical training to support PsI. Staff also lack medical supplies and equipment to help patients to manage incontinence. Also, for outpatient consultations, they reported not having any knowledge and supply to help people handling better their incontinence when going home. It was observed as well that both health facilities did not have specific protocols to support people suffering incontinence.

Photo: IFRC

Psycho-social needs

The results of the study are consistent with patterns seen in previous studies carried out in relation to personal conditions of isolation and impact on mental health and negative coping strategies such as eating or drinking less and sleeping on the floor. All people interviewed that suffered from incontinence reported to be in a condition of social isolation, lacking proper means of livelihoods, and feeling unable to work.

> ‘The Ethiopian community is famous for supporting each other, but there is internal fear of incontinence and bad smell. Some community members didn’t accept my case and were running away of me. This mistreatment pushed me to isolate myself and keep distance with people to avoid any disrespect or embarrassment.’

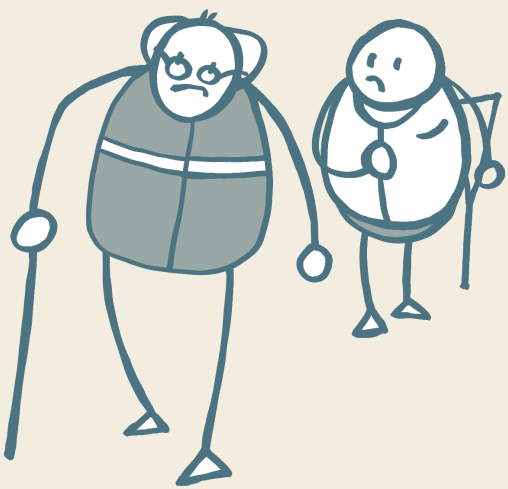
There were some isolated cases of physical mistreatment toward PsI. One reported,

> ‘The main challenge I face is lack of hygiene materials and mistreatment from my husband’

The most common feeling was the sense of social marginalization due to uncontrolled odors and shame. Those who, like old men, need to move around carrying an empty plastic bottle to be used as catheter, reported cases of mockery and feelings of humiliation. Family members and sometimes neighbors are key actors in supporting PsI. They help with bathing and cleaning clothes, despite, in many cases, having limited access to water and detergents.

Did PsI receive any hygiene items via in-kind or CVA in the last year? Were those items appropriate? Were they satisfied?

All FGD participants reported being targeted in hygiene distributions in the last 6 months via in-kind donations or via cash or voucher assistance (CVA). All age and sex categories reported that the items received were not sufficient and not distributed on a regular basis (only 2 piece of soap per month for instance), and they hardly felt satisfied with the aid received.



Among the different groups, it was clear that older men (60+) including men living with disabilities are those receiving less or no items compared to other categories. In Um Rakuba camp, FGD participants reported not being targeted with in-kind donations, and some reported accessing soap and bathing liquid in the local market, either from their personal money or CVA activities under way. In Tunaydbah camp, the same age and sex group reported having 2 pieces of washing soap distributed per month. In the 6 months leading up to the study, they used to receive washing/ laundry soap, water containers and hand sanitizers as part of the Covid-19 and monkey pox response.

Older women (50+), including women living with disabilities, received more compared with previous categories, and still less if compared with other women (the category of women ages 20-50) which received MHM Kit via distributions. Older women (50+) were not targeted with MHM kits, and pads were not available despite some reporting suffering from incontinence.

Four out of the eight PsI interviewed reported that items such as pads were not appropriate to handle the involuntary loss (they were missing the elastic or not having enough absorption). Three of them reported not having received any hygiene kit at all. The lack of or reduced mobility has been one of the main barriers to access to the distribution sites where hygiene kits were handed over.

‘I am dissatisfied. Products received were inadequate to my needs and I need more items that are neither affordable nor available in the local market, such as bathing soap and disposable incontinence pads (diapers) with elastic sides’

What kind of hygiene items would people suffering from incontinence like to receive?

People suffering from incontinence who participated in FGDs or in-depth interviews had a clear idea of what their preferences were with regards to hygiene items. Most of them indicated preferring hygiene items such as in-kind donations instead of CVA, since they fear that items cannot be found in local markets. Some products are reported to be available in Gedaref Market, but this is far, therefore making the items inaccessible for people that cannot walk long distances.

Items needed to handle incontinence reported by PsI are

- mattress protector,
- hand-held urine containers,
- disposable incontinence pads with elastic sides
- commode chairs or potties.

The items that were ranked as more important

- **In Um Rakouba:** underwear, and adult diapers or pads for incontinence
- **In Tunaydba:** hand-held urine containers, bed pads and pads with elastics

The same items were confirmed by caretakers or participants of FGD from the categories 50+ and PwDs.

In Um Rakuba, in general, survey respondents preferred reusable hygiene items, and in Tunaydbah, they identified disposable items as their preferred choice. Those preferring reusable products in Um Rakuba pointed out reasons such as avoiding dependence on the relief distributions. Those selecting disposable in Tunaydbah referred to the burden of washing the reusable items, not being familiar with them, lack of water, and not knowing how to wash soiled items in a safe way.

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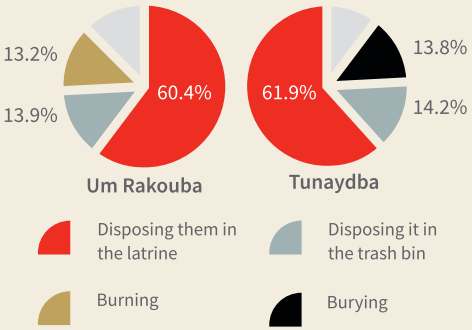
‘I also prefer to use reusable products, because I can keep them as long as I can, but the disposable products are not guaranteed for regular supply and sometimes they are not available’.



Being asked how they plan to dispose of the soiled items like menstruation pads and diapers, respondents in both camps reported disposing them in the latrine as their planned choice, followed by disposing it in the trash bin, and burning in Um Rakuba and burying in Tunaydbah. This explains the current situation of latrine getting full very fast in both camps.

Through observation and reporting in FGDs, the study team could verify and confirm that safe solid waste disposal methods are lacking in both camps. Burning and burying are currently the main methods for disposing of solid waste in general.

What relief distribution modality do PsI prefer?

FGD participants (men 65+, women 50+, including men and women with disability) strongly reported their preference to receive hygiene material as in-kind donations, since all of them fear not finding appropriate items in the market when given cash or vouchers. FGD participants and other stakeholders interviewed expressed concerns on how distribution is organized. They also provided some tips to better organize the distribution that could be summarized as follows:

'If targeting would be accurate, access to the distribution site would be easier. Waiting time to get the items would be shorter, allowing persons with reduced mobility to participate. Tension would be reduced among beneficiaries while waiting, and PsI would be treated fairly and with respect'.

Despite the strong pattern on preferring in-Kind donations in the older people groups and in depth interviews, FGD participants in groups of mixed age and sex preferred cash or vouchers, as they would be free to choose the items needed in the market and would avoid the waiting time in distribution lines. They referred to the mother in the household as the one making decisions on how to spend money in hygiene items, but they shared their concern on whether the money would be spent on hygiene items if cash is provided unconditionally considering other dire needs in these groups with little or no income.

FGD participants and other stakeholders interviewed fully recognized that the main challenge for cash-based intervention would be finding the right items in the local market, as those are non-existent (some items are only available in Gedaref market or not available at all). Some expressed concerns about being robbed when cash is disbursed, or not being able to stand in long queues for registration and receiving the cash.

> 'I would prefer to receive in-kind incontinence hygiene kits, I think it is better than vouchers or cash, because if I get cash, I may not find the items available in the market'.

Market assessment

The market assessment showed that existing markets within Tunaydbah and Um Rakuba camps and host communities are functional, and they have the capacity to supply basic goods for managing incontinence at any time. More specific items that are not available in the camps and host communities can be found in larger markets in nearby towns, like Gedaref town.

Markets in the camps and host communities are accessible to most of the population, but might be difficult for the groups of concern, especially older men and women and PwD. Markets in nearby towns can be even more difficult, as these requires an extra cost in transport. All FGDs pointed out that very few hygiene items, especially for women, were available in the local market. This was also reported directly by PsI in interviews, but also other stakeholders including NGOs. They also reported that the Aburakham market, located 2-3 km from the Tunaydbah camp, is the nearby market where they can access washing basins, buckets, bathing soap and latrine cleaning material.

Inflation has impacted the prices, as they are changing frequently, and this has affected the refugees and host community purchasing power, therefore transfer values need to be adjusted in case of regular payments and prices closely monitored.

Small-scale interventions might be done with the traders inside the camps for certain basic items, but cannot sustain a large-scale cash transfer intervention alone as they lack the capacity to supply large quantities and with the quality desired. However, for small scale intervention, host community traders play an important role in provision of the selected items. Based on the preferences of PsI in the camps, and the findings of the market assessment, an intervention to respond to incontinence in both camps could include a mixed modality 'in kind' and 'cash' assistance, with physical cash being the only mode of trading that is acceptable in local currency.

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