Urinary Incontinence in Sub-Saharan Africa: Experiences of Women and Healthcare Workers in Nigeria and Kenya and Opportunities for Expanding Care

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Including Female Pelvic Floor Disorders in the Global Women's Health Agenda: Insights from Kenya and Nigeria

Several recent reports in the global women's health sector powerfully describe longstanding gaps in research, healthcare access and delivery, and health-related innovation that disadvantage women across the lifespan and across the world. [1-3] Closing the women's health gap represents a $1 trillion USD opportunity for the global economy with untold benefits to women and societies.[1]

Women's health conditions include those that affect women uniquely, disproportionately, or differently than men.

Pelvic floor disorders, including urinary incontinence, fecal incontinence, and pelvic organ prolapse are among the health conditions that affect women uniquely, differently, **and** disproportionately. Pelvic floor disorders affect at least 1-in-3 women, with a global prevalence of approximately **1 billion women**. Most women with these conditions will never access treatment due to individual, societal, and structural barriers. These barriers remain in place due to lack of consideration, prioritization, and collective will. Pelvic floor disorders are burdensome and associated with negative physical, psychosocial, economic, and quality of life impacts. These conditions become chronic or progressive largely because they are not treated—not because they cannot be treated. Despite their burden and ubiquity, pelvic floor disorders are un- or underrepresented in the global women's health agenda.

This report provides perspectives from 175 individuals, comprising healthcare workers and women with urinary incontinence in Kenya and Nigeria, who describe influences on healthcare decision-making and the experiences and impact of urinary incontinence.

Key findings include:

- Women with incontinence are bothered by their symptoms and desire education, treatment, and dismantling of the stigma associated with bladder leakage.
- Lack of awareness of urinary incontinence as a health condition is pervasive and is a major contributor to extremely low care-seeking behaviors.
- Healthcare workers highlight data gaps including prevalence studies and the need to differentiate fistulous and non-fistulous incontinence.
- Both healthcare workers and women with incontinence are eager for innovation, education, and policy changes to set the path for capacity-building in pelvic floor disorders management.

The strong relationship between incontinence and other marquis women's health issues, such as pregnancy, childbirth, and menopause, affords a synergistic platform for the integration of research, advocacy, and awareness. This report aids our understanding of the challenges to accessing healthcare and how this is changing in response to a rise in healthtech and innovation in sub-Saharan Africa. Concerted effort is required to scale evidence-based treatment for pelvic floor disorders, and opportunities abound for innovative care delivery that leverages technology and the burgeoning digital health sector. This is a moment for multiple partners in global women's health to come together to impact the lives of women across the lifecourse and across generations.

Acronyms and Abbreviations

FDA	Food And Drug Administration
HCD	Human-Centred Design
HCW	Health Care Worker
LMICs	Low-and-Middle-Income Countries
MUI	Mixed Urinary Incontinence
NCD	Non-Communicable Diseases
PFD	Pelvic Floor Disorders
PFME	Pelvic Floor Muscle Exercises
SSA	Sub-Saharan Africa
STD/STI	Sexually Transmitted Diseases/Sexually Transmitted Infections
SUI	Stress Urinary Incontinence
UI	Urinary Incontinence
UUI	Urgency Urinary Incontinence
UN	United Nations
UTI	Urinary Tract Infection
WHO	World Health Organization

About us

Axena Health, Inc. is a women-led company dedicated to improving the lives of women with pelvic floor disorders. Axena Health's flagship product, the Leva® Pelvic Health System (Leva), offers a novel, effective, first-line treatment for urinary incontinence (UI) and chronic fecal incontinence. Leva is a medical device that combines hardware with a smartphone app and is cleared by the U.S. Food and Drug Administration (FDA) for the treatment of stress, mixed, and mild to moderate urgency urinary incontinence, including overactive bladder in women; treatment of chronic fecal incontinence in women; and strengthening of weak pelvic floor muscles in women. Leva is a Class II medical device and was authorized by the FDA through a 510(k) Pre-Market filing. Leva also received Breakthrough Device designation from the FDA for the treatment of chronic fecal incontinence.

In line with Axena Health's commitment to women's health, the company has established a workstream focused on lower- and middle-income countries (LMICs), aiming to develop a Leva-informed solution to address pelvic floor disorders among women in LMICs. This investment is aligned with UN Sustainable Development Goals 1 – No Poverty, 3 – Good Health & Well-Being, 5 – Gender Equality, and 10 – Reduced Inequalities. The social mission of Axena Health is to provide all women with accessible and effective treatment to address their pelvic floor symptoms.

ThinkPlace is a global strategic design and innovation consultancy driven by its mission to have a positive impact on society. ThinkPlace's purpose is tied directly to the UN Sustainable Development Goals. ThinkPlace aims to provoke, to disrupt, to unthink the way global humanitarian and development challenges have been approached in the past.

ThinkPlace specializes in deeply understanding the drivers of human behavior and co-designing interventions (products, services, strategies, programs) that reach a desired behavioral outcome. The company does so by integrating human-centred design, behavioral science, and complex systems design to transform communities, workplaces, and government structures around the world. Comprised of 14 studios across 5 continents, ThinkPlace has conducted hundreds of projects in more than 25 countries and over 10 languages. Through the company's work, ThinkPlace has supported clients to rethink some of the worlds most complex challenges and has been recognized by numerous prestigious design awards, including the Design Management Institute, WHO, Core 77 and Dezeen.

This research was conducted by the ThinkPlace Kenya Limited Team and Axena Health, Inc. The report was prepared by: Oliver Muchiri, Michelle Angwenyi, Eliud Luutsa, Jacinta Ochoro, Collins Juma and Michael Ngigi from ThinkPlace Kenya Limited, and Dr. Laura Keyser, and Dr. Jessica McKinney from Axena Health, Inc. Special thanks to Dr. Fatimat Akinlusi and to the many stakeholders engaged during this study.

Project Background

Background

1 in 5 Women have UI in SSA

122+ Million

Women with UI in Sub-Saharan Africa

Pelvic floor disorders (PFDs) include urinary incontinence, fecal incontinence, and pelvic organ prolapse, and are estimated to affect approximately one third of women globally.[4] Urinary incontinence (UI) is the most prevalent of these disorders and involves the involuntary loss of urine, typically with physical activity (stress UI), with a strong and sudden urge to urinate (urgency UI), or both (mixed UI).[5] Risk factors for UI are similar worldwide and include pregnancy, childbirth, chronic cough, aging, chronic constipation, and overweight or obesity.[6]

UI is associated with a multitude of negative psychosocial, economic, and physical impacts on women's lives. It is highly stigmatized, can be costly to manage with absorbent products, and may negatively impact a woman's ability to participate in the workforce, society, and family life.[7–9] Treatment of UI is limited by several factors ranging from lack of access to medical facilities and expertise within the healthcare workforce to stigma and self-isolation faced by those women who experience this condition.

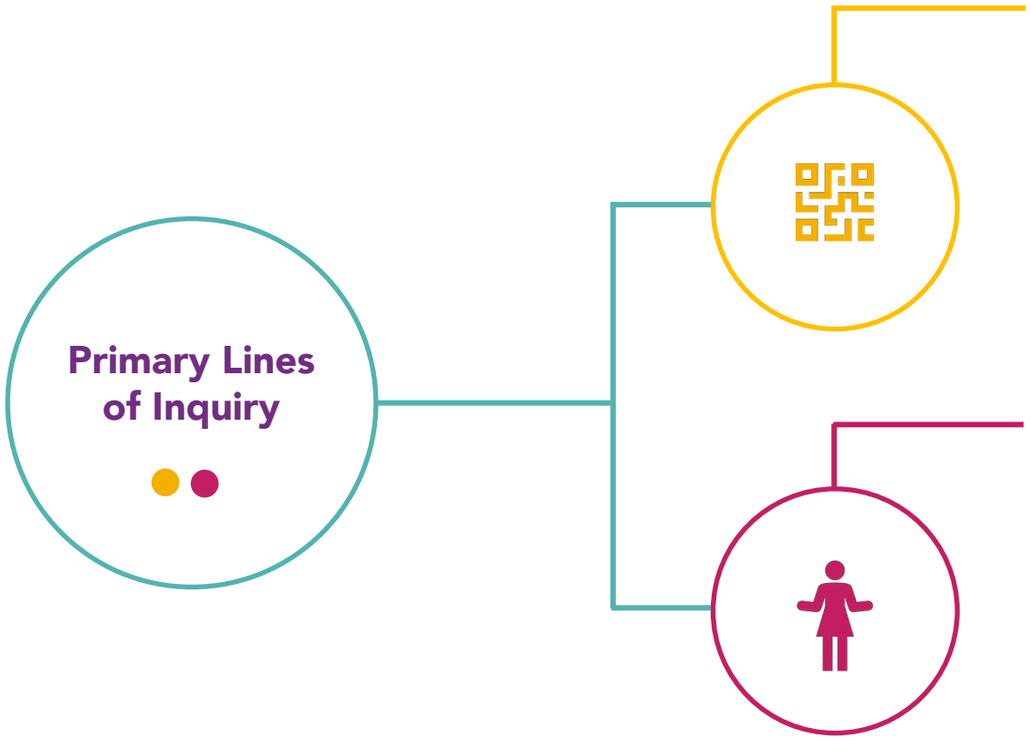
Gaps exist in the literature related to the lived experiences of women with UI in low-and-middle-income countries (LMICs) and particularly in sub-Saharan Africa (SSA), as understood through the lens of the women themselves, their family members, clinicians, and other local leaders and key stakeholders. A better understanding of this will inform effective, accessible, and patient-centered education and treatment, as well as the need for such treatment.

The purpose of this research is to explore the UI landscape in SSA and specifically to understand the experiences and needs of women and healthcare workers in urban centers in Kenya and Nigeria in this context.

Project Objectives

The objective of this study was to understand the beliefs, perceptions, experiences, and preferences of women with UI and HCWs regarding the healthcare environment broadly and UI specifically.

This included the existing context of UI care, management, and treatment options in LMICs. Given the growth in digital health worldwide and the rapid pace of this growth specifically in SSA, included in the objective was a goal to derive insights pertaining to digital health as related to general health, women's reproductive health, and UI.



Influences on Healthcare Decision-making and Care-seeking:

- Individual to community level factors affecting health-seeking behaviors
- Awareness and understanding of general health issues and those specific to women's health (e.g., sexual and reproductive health, pelvic health)
- Cultural and social norms and religious beliefs
- Experiences with the healthcare system
- Awareness of and engagement with digital health (e.g., telehealth, mHealth apps)

Perceptions and Experiences of Urinary Incontinence:

- Prevalence and awareness
- Women's experiences and associations
- Healthcare workers' perceptions of UI
- Health and quality of life effects of UI
- UI treatment landscape, including home vs. clinic-based first-line care
- Awareness of and engagement with digital health specific to UI

A second report, *A Digital Health Solution for Urinary Incontinence in Sub-Saharan Africa: User-centered Research Using a Targeted Design Approach*, may be available on request. Those findings detail feedback and insights related to adapting the Leva Pelvic Health System for clinical use in this setting.

Key Approach

A mixed-methods approach rooted in human-centered design (HCD) was employed.

The primary qualitative research component included in-depth interviews and focus group discussions, using semi-structured interview guides to collect information from women with UI, clinicians engaged in women's healthcare, and other key stakeholders. Secondarily, quantitative data collection included online questionnaires that incorporated standardized UI-specific survey questions, in addition to information about UI management. These were administered to in-person participants, as well as to women who self-identified as having UI through various online platforms.

The report presents research findings from women with UI and healthcare workers (HCWs) involved in women's healthcare delivery.

Research Methods

Primary:
- One-on-one interviews
- Focus group discussions
- Desktop reviews and expert sessions

Secondary:
- Quantitative surveys

HCD is a widely adopted approach to improve and conceptualize healthcare interventions. The HCD approach promotes the idea that the needs of the end-user(s) lie at the center of the design process.

It encourages empathy for the end-users by including them in the design process. It is centered around the active participation and consultation of multiple stakeholders, including the beneficiary/user of the healthcare intervention (patient, healthcare worker, caregiver, community member) using a mixed-methods research approach.

Research Study Locations

Lagos, Nigeria

- Nigeria is the **most populous country in Africa** with a growing healthcare market, including digital health and healthcare services[10]
- Lagos is **Nigeria's commercial capital** and is considered a **major economic hub in West Africa**

Nairobi, Kenya

- Kenya is widely recognized as a **hub of healthcare and health tech innovation in East Africa** and on the continent[10]
- Nairobi is Kenya's capital & the **largest city in East Africa**

Both regions are culturally, religiously, and ethnically diverse with a predominantly urban population, a high concentration of middle- and high-income earners, and **high smartphone market penetration**

Key Inclusion Criteria:

Women with stress, urgency, or mixed UI (screened using 3-Incontinence Questions (3IQ) survey[11])

- 18-65 years old
- Ambulatory
- Speak English or Swahili
- Have a phone for personal use (may be a shared phone)

Healthcare workers engaged in women's health service provision

- Physicians, nurses, physiotherapists, community health workers

Mixed Methods Approach

Mobilization

In Nairobi, local healthcare professionals and community health volunteers helped to identify, engage, and mobilize participants. In Lagos, a co-investigator and research assistant at Lagos State University Teaching Hospital (LASUTH) worked to enlist participants within the LASUTH facility. An online recruitment process was also utilized in both settings to mobilize women from the community. This included sharing a study description and online link in various social media groups that focus on women's health issues (e.g., WhatsApp™, Facebook™).

Informed consent process

All participants provided written informed consent prior to engaging in the research process.

Data collection locations

Interviews were conducted in private rooms. In Kenya, office space at the ThinkPlace headquarters was used, and in Nigeria, dedicated space was reserved within the LASUTH facility.

For the few interviews where participants could not meet in-person, these discussions were conducted via video conference.

Whether in-person or virtual, the location provided a safe space for the interviewees to express themselves freely.

Data collection process

Qualitative data collection

Qualitative interviews were completed over a period of two weeks in Nairobi and one week in Lagos (August – September 2023).

Quantitative data collection

Online surveys, including standardized UI-specific questionnaires, were administered to qualitative study participants and to women recruited online for online participation only.

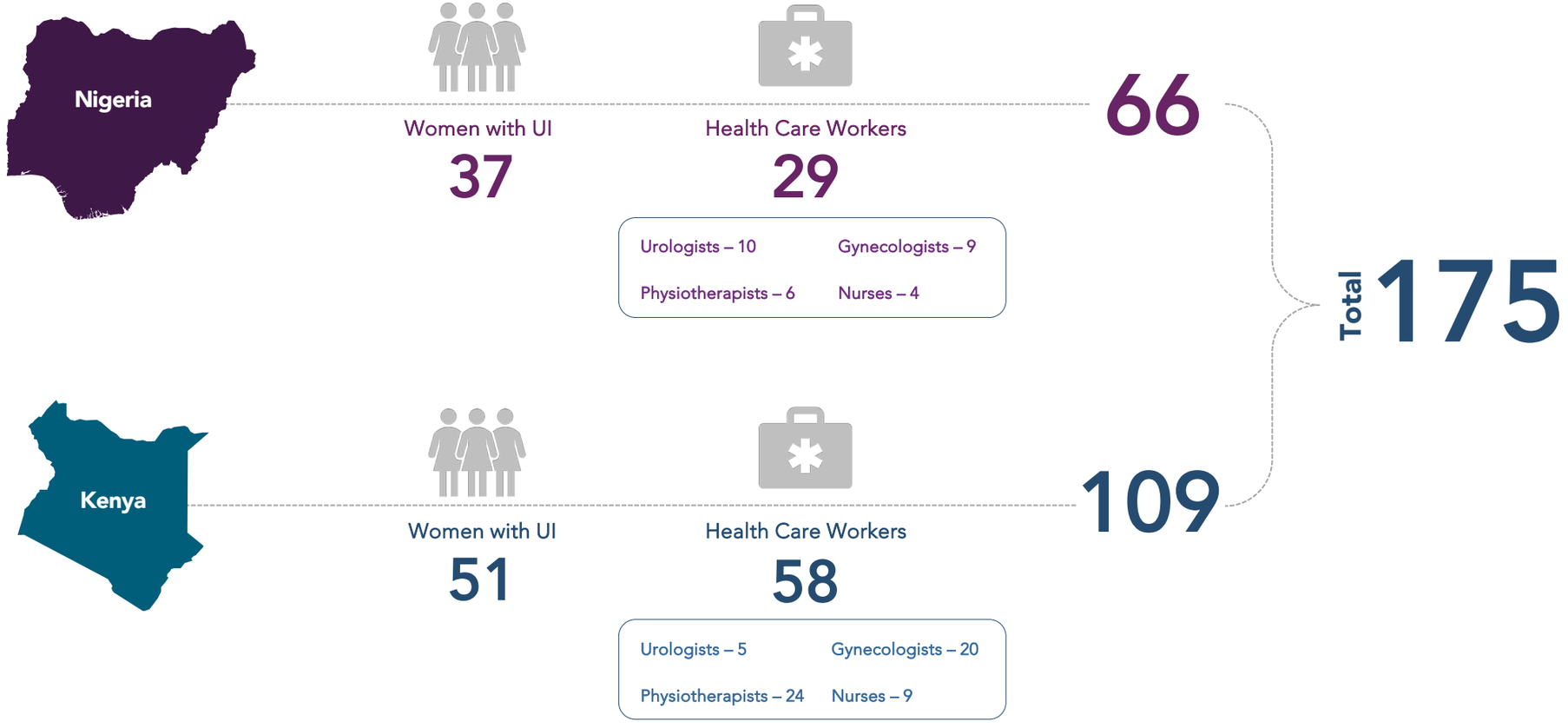
Participant Information

The following slides summarize information about the individuals who participated in interviews and focus group discussions, including demographics and other characteristics.

Participants Interviewed

A total of 175 women and HCWs comprised the primary participants. **88 women with UI** participated in focus group discussions or in-depth interviews – 37 Nigerian women and 51 Kenyan women. **87 HCWs** participated in focus group discussions and in-depth interviews – 29 Nigerian HCWs and 58 Kenyan HCWs. This included urologists, gynecologists, nurses, and physiotherapists.

Additional participants included nine key informants, representing two religious leaders, one political leader, one women's rights advocate and one data specialist in Nigeria, and three community health volunteers and one data and technology lawyer in Kenya. Family members of women with UI were also engaged, including 5 husbands in Nigeria.



Participant Demographics – Women with UI

The table below describes the demographics of women with UI who participated in interviews and focus group discussions. **This cohort represents a relatively young and well-educated group that may be a receptive audience for future work to promote pelvic health awareness and to pursue UI treatment.**

Demographics		Kenya, n (%)	Nigeria, n (%)	Total, n (%)
Age	18-29 years	30 (60.0%)	5 (14.7%)	**35 (41.7%)**
	30-45 years	15 (30.0%)	24 (70.6%)	**39 (46.4%)**
	45-65 years	5 (10.0%)	5 (14.7%)	**10 (11.9%)**
Education Level	Primary School	4 (8.0%)	0 (0.0%)	**4 (4.8%)**
	Secondary School	6 (12.0%)	2 (5.9%)	**8 (9.5%)**
	College/University	40 (80.0%)	32 (94.1%)	**72 (85.7%)**
Income Source	Employed	21 (42.0%)	18 (52.9%)	**39 (46.4)%**
	Self-employed	26 (52.0%)	15 (44.1%)	**41 (48.8%)**
	Unemployed	1 (2.0%)	1 (2.9%)	**2 (2.4%)**
	Other	2 (4.0%)	0 (0.0%)	**2 (2.4%)**
Childbirth History	Given birth	28 (56.0%)	23 (67.6%)	**51 (60.7)%**
	Not given birth	22 (44.0%)	11 (32.4%)	**33 (39.3)%**

Of the 51 Kenyan participants, one chose not to share biodata. Of the 37 Nigerian participants, three chose not to share biodata.

Study Findings

Healthcare Decision-Making & Care-Seeking

Participants provided key insights about the factors that influence healthcare decision-making and care-seeking in Kenya and Nigeria. These influences may be organized into the following themes: **health literacy, cultural and religious beliefs, and previous health system interactions.** Taken together, these factors drive how women engage in healthcare and wellness services.

This section provides further detail about these spheres of influence and draws conclusions about healthcare decision-making among this cohort of women.

Health Literacy

Health literacy refers to "the ability of individuals 'to gain access to, understand and use information in ways which promote and maintain good health' for themselves, their families and their communities." [12]

Individuals in Kenya and Nigeria take a keen interest in understanding the root causes of various health conditions. An individual's knowledge and understanding of what is troubling them serves as a gentle nudge to seek appropriate health interventions.

- Across Kenya and Nigeria, both women and HCWs emphasized the importance of understanding the causes and risk factors for various health conditions. **This knowledge is considered essential to cultivate positive health-seeking behaviors,** including prevention and early treatment.
- HCWs in Kenya and Nigeria indicated that when people have knowledge about various health conditions, they are more inclined to seek appropriate healthcare services, adopt preventive measures, and identify early warning signs. **This knowledge empowers individuals to take charge of their health**, make informed decisions, and ultimately improve health outcomes.
- One HCW in Kenya observed a noteworthy trend: a **growing interest in general well-being** among women in the country. They attribute this to ongoing concerns related to COVID-19 and heightened fears surrounding conditions like cervical cancer.
- HCWs and women perceive a general **surge in awareness and use of health and fitness mobile apps**, including period-tracking, wellness, and fertility apps, as well as online clinics and e-pharmacies.

> ***"Awareness and access to healthcare is a problem for most."***
> *HCW, Lagos*

> ***"Pregnant women as well as those with sexual and reproductive health issues are better health seekers than the rest."***
> *HCW, Nairobi*

> ***"Regarding women's health, information should flow from a reliable place."***
> *HCW, Lagos*

> ***"Education is a critical part of the treatment offered to patients."***
> *HCW, Lagos*

Health Literacy

> ***Compared to the 90's, women are now more intentional about driving health awareness and seeking information from friends and digital platforms."***
>
> *HCW, Lagos*

> ***These days we have mothers we refer to as digital mothers, who have so much information from online sources and can always challenge you if your information doesn't match what they obtained online."***
>
> *HCW, Nairobi*

Health Literacy

Women in both Kenya and Nigeria seek health information from online and offline sources before making the decision to access healthcare.

- Kenyan women living in urban areas access health information from online sources and in particular, social channels, such as WhatsApp™ and Facebook™ groups.
- Some women turn to reputable medical websites, such as Medscape and Mayo Clinic. Younger women reported seeking reproductive health information from video platforms, such as YouTube and TikTok™.
- By contrast, in Nigeria the utilization of online platforms for women's reproductive health information is less prevalent. Many Nigerian women indicated they rely on family and peer networks for such health information.
- This difference between the two countries may be attributed in part to concerns raised about the trustworthiness of digital sources, due to the perceived greater prevalence of misinformation and conspiracy theories in Nigeria, even on topics unrelated to health.

It is important to note that, even in Kenya where online sources are more widely used, a significant number of women validate the information they gather online by discussing it with peers, family members, and HCWs, either in WhatsApp groups or in person. This underscores a shared trend of cautious skepticism about the reliability of online platforms in both countries and habits around verifying information obtained online with known resources.

> ***You know, we go to the Google doctor."***
>
> *29yr old woman, Nairobi*

> ***Google is my best friend; its always up to date on information."***
>
> *22yr old woman, Nairobi*

> ***I am scared of searching things from Google fearing misinformation and revelations of much bigger health problems."***
>
> *28yr old woman, Lagos*

> ***Women now seek health information from Google and WhatsApp groups. Now we have communities on social media platforms. A lot is posted that educates women on their health."***
>
> *30yr old woman, Nairobi*

Health Literacy

> ***When I need any clarifications [on wellbeing], I go online."***

25yr old woman, Lagos

> ***Technology has taken over virtually everything, and so I have to be present and active on digital platforms so that I don't miss out on key information."-***

28yr old woman, Lagos

Cultural and Religious Beliefs

HCWs observed that men often hold most of the power in determining a family's health-seeking options and behaviours.

- It is well-known in these settings that gender-based power dynamics play a significant role in determining women's healthcare access and decisions.
- In many families in Kenya and Nigeria, men hold more economic power than women, contributing to gendered power dynamics.
- With the male as head of household and typically the family's primary breadwinner, mothers often customarily consult with the father to secure funds for the mother's and children's healthcare needs.
- Of note, HCWs reflected these sentiments, though, women participants did not categorically describe these dynamics in their own lived experiences. **HCWs see women from varied cultural, religious, and socioeconomic backgrounds and thus, expressed the breadth of their views and experiences.**
- **The women interviewed represent a relatively young, educated, and employed demographic. Most women expressed that they do not need permission or financial support from their husbands to seek healthcare services. Additionally, the male partners interviewed showed a high level of support and considered any treatment for a health condition their partners are struggling with acceptable in any shape or form.**

> ***I believe health conditions are not things you should be shy about."***
>
> *Husband, Lagos*

> ***Women sometimes cannot come to the clinic without their husbands as they are not economically empowered."***
>
> *HCW, Lagos*

> ***My wife is hesitant to visit the hospital sometimes for fear of finding a male gynecologist."***
>
> *Husband, Lagos*

Cultural and Religious Beliefs

> ***Having conversations with men [to increase awareness and healthcare-seeking] is important.”***
>
> *HCW, Nairobi*

> ***Yorubaland (Lagos) is deeply rooted in culture and difficult to break societal norms such as restrictions on men and women interacting freely. Therefore, since most specialists are male, some women don't feel comfortable being seen by them.”***
>
> *HCW, Lagos*

Cultural and Religious Beliefs

Some women in both Kenya and Nigeria cited varying levels of distrust of conventional medicine, associating it with adverse side effects, addiction, and dependence.

- Women also described a prevailing belief that, during childbirth, failure to deliver vaginally is viewed as failure of motherhood. Thus, some women are resistant to medical interventions during delivery, including Cesarean section.
- For most women in Nigeria, healthcare is sought when a condition becomes severe or causes significant pain. Women believe the body is well-poised to deal with mild illnesses, and there is no need to seek healthcare within a hospital setting.
- A few women in Nigeria mentioned a traditional healer and prayers as their first intervention whenever they feel unwell. **These women had the perception that some illnesses were best suited to being treated by medical doctors, while other diseases were most suited to treatment by traditional healers**. For example, malaria, typhoid and fever caused by 'natural causes' may best be treated by biomedicine, whereas conditions, such as those with mental health symptoms and stigma, appeared to be uniquely suited to traditional healing outside of health facilities.
- In both countries, cultural and religious beliefs about sexual purity, which is highly valued and emphasized in communities, churches, and mosques cause some women to feel uncomfortable seeing a male HCW or to decline an intra-vaginal examination or treatment.
- Women in both countries noted that they sought **immediate treatment for certain reproductive health conditions, where typical symptoms were better known**, such as bladder infections, sexually transmitted infections (STIs), and anemia. A gynecologist in Nairobi suggested that early seeking of reproductive healthcare is **motivated by the value women attach to bearing children.** He indicated that most women derive a sense of fulfillment from having children and would therefore be eager to address any issues that may be perceived to compromise their fertility.

> ***Most patients present themselves to hospitals late after having tried many other local options."***
>
> *HCW, Lagos*

> ***I'm very afraid of the side effects of all these modern medicines."***
>
> *32yr old woman, Nairobi*

> ***Mwanamke ni mwanamke, Mungu alisema upush." [A woman is a woman, God said you must persevere.]***
>
> *HCW, Nairobi [regarding labor in pursuit of vaginal birth]*

> ***I avoid hospitals because modern medicine weakens my immune system and causes addiction. There are also many cases of misdiagnosis."***
>
> *40yr old woman, Lagos*

Cultural and Religious Beliefs

> ***Women prefer to be treated by women on matters that touch on their reproductive health."***
>
> *HCW, Nairobi*

> ***Anything to do with that part of the body [female genitalia] always has that negative connotation."***
>
> *HCW, Lagos*

> ***I don't like going to hospital, my first 3 babies were delivered at church. It's my triplets that brought me to hospital."***
>
> *39yr old woman, Lagos*

Cultural and Religious Beliefs

Stigma around conditions related to women's reproductive health discourage many women from seeking healthcare. Women fear a diagnosis that would not only lead to losing out on the sense of belonging, but that would be life-threatening, such as cervical cancer.

Cultural and Religious Beliefs

Peer and community influences serve as a force for good in spreading health information, dismantling stigma, and encouraging others to seek medical attention.

- Women draw **inspiration from communal spaces** that expose them to other women's stories, and this increases their chances of seeking healthcare.
- In Nigeria, **religious organizations and their programs play a critical role** in reinforcing health messages through collaboration with health institutions. This joint programming enables members to access specialized and sometimes subsidized health services. This approval and collaboration helps many to embrace and experience the benefits of modern healthcare.
- A woman's decision-making in both Kenya and Nigeria is influenced not only by her individual needs, but also by those of her family. Beyond the influence and role that male partners play in determining whether a woman seeks health services or not, women spoke of being **driven by the love, care and concern they have for their children and their role as mothers**. This positively influences them to seek healthcare and wellness services so as to be healthy and to be able to take care of their children.

> ***When you have children, you can't afford to relax. I need to remain healthy for their sake."***
>
> *34yr old woman, Lagos*

> ***You know, as women, we gather together, we discuss."***
>
> *29yr old woman, Lagos*

> ***I have been supporting my wife throughout her journey, and I'm always willing to try out new treatments for her."***
>
> *Husband, Lagos*

> ***When you bring the husband or spouse into the picture, it changes the recovery rate in a good way, as women feel supported [not judged]."***
>
> *HCW, Nairobi*

Cultural and Religious Beliefs

In both countries, and in the face of formidable barriers that challenge women's agency in making informed choices about their health, the empowering influence of peer and community support emerges as an unwavering force for positive change.

Women, driven by their shared experiences, play a pivotal role in encouraging one another to access essential women's health services.

Healthcare System

Healthcare workers are perceived as custodians of quality healthcare and can positively or negatively influence healthcare decision-making.

- The healthcare system in both countries plays a critical role in determining how people generally experience healthcare and ultimately, whether they seek health services or not. **The influence of HCWs in healthcare seeking behaviors cannot be overstated.**
- HCWs in Kenya highlighted an **evolving practice of women engaging in routine gynecologic care.** Historically, gynecologic services were accessed predominantly by wealthy women, and seeking such services was associated with class status rather than a necessary service for women's reproductive health. Today, women are increasingly seeking the services of gynecologists not only when unwell, but also for routine check-ups, underscoring a growing proactive approach to women's health.
- Women in both Kenya and Nigeria noted that HCW attitudes influence their decision on whether to access healthcare and wellness services. For most, **positive experiences and language from HCWs incentivize them to access healthcare services even where distance to the health facility is long or cost is considered high.**
- In Nigeria, women noted that where HCWs have positive attitudes, they would seek health services in general facilities because they **trust in doctors and hospitals**. Even where a facility may be considered expensive, women's desire to access personalized care may lead her to still seek care despite the expense.

> ***The focus of Nigerian healthcare has been communicable diseases, with a recent move to NCDs."***
> *HCW, Lagos*

> ***General hospitals are the best because they have different doctors for different problems."***
> *29yr old woman, Lagos*

> ***What brings most Nigerians to hospital is discomfort and pain."***
> *HCW, Lagos*

> ***If you want the best treatment, at times you have to travel far."***
> *33yr old woman, Nairobi*

Healthcare System

Both ease of access and cost influence a woman's point of entry into the health system.

- The **quality, variety, and availability of treatment influence women's willingness to seek healthcare.** In Kenya, for example, women would rather not deal with their health condition, if seeking health services takes too much time away from work and social activities.
- For most people in both Kenya and Nigeria, their first point of contact with the health system is in pharmacies or small clinics near their home. Private clinics and large hospitals are accessed when people are dealing with conditions that they deem sensitive or severe and hence, worth the investment of time and financial resources.
- Other touchpoints include digital pharmaceutical platforms or self-management based on medical advice from social media channels. In Nigeria, informal touchpoints, such as seeking the services of traditional healers remain rife.
- **Many urban women in both countries have access to medical insurance,** easing access to formal medical care at well-established health facilities with minimal additional cost.
- In Kenya, it is common for women with medical insurance to access healthcare from private hospitals due to the perception of better care and advanced medical equipment and drugs. In Nigeria, however, there is a preference for public hospitals due to perception of greater availability of medical personnel and credible treatment options as compared to private ones.

> ***"Cost of healthcare, distance to hospital and attitudes of health workers have hindered me from accessing the best healthcare."***
>
> *32yr old woman, Lagos*

> ***"Anything related to health is usually expensive."***
>
> *29yr old woman, Lagos*

Healthcare System

Online platforms allow for instant interactions with the healthcare system.

- Online healthcare platforms that allow patients to consult a doctor online and order prescriptions through the same digital platform are well-regarded by urban women for their convenience and affordability. Additionally, several women indicate that **these platforms are preferred when they do not feel comfortable speaking to a doctor in-person about sensitive health matters as they guarantee privacy.**

- In Kenya, HCWs belong to certain social channels where members seek information about different medical conditions. HCWs provide answers to questions raised within these groups. This is described as an **opportunity to provide education and promote awareness about diverse health matters, including UI.**

> ***"If you are sick and can stay at home and monitor yourself [using online platforms], then there is no need to access hospital care."***
>
> *35yr old woman, Nairobi*

> ***"Working in an environment surrounded by professionals or with access to professionals in the health sector, reaching out and seeking consulting services from the comfort of my phone is easy."***
>
> *33yr old woman, Nairobi [In reference to the benefits of online health services such as e-pharmacies in Kenya]*

> ***"Some physiotherapists are already raising awareness around UI and PFMs through written blogs...this is especially targeted at urban women."***
>
> *HCW, Nairobi*

Healthcare System

Certain infrastructure and personnel limitations in the healthcare system negatively influence women's healthcare seeking.

- In both Kenya and Nigeria, HCWs reported **inadequate medical equipment and healthcare personnel** leading to strained health systems and frustration for patients.
- Due to healthcare workforce shortages, many women feel that HCWs should be consulted only if one's situation is dire. General check-ups, such as the 6-week postnatal visit, are perceived as less important, not life-threatening, and potentially very time-consuming, and thus, do not warrant medical attention.
- Additionally, **women cited privacy concerns** in public hospitals due to the high number of patients within a limited space. Nigerian women cast doubt on the ability of hospitals to keep their health information confidential and to provide safe space to speak about sensitive health issues.
- Unpleasant experiences, such as long queues, lack of medication, and disrespectful medics discourage some patients from seeking treatment from hospitals altogether. **Women in both countries noted traumatic hospital experiences during childbirth**, characterized by unfriendly and arrogant hospital staff. This creates a 'hospital phobia,' especially concerning reproductive healthcare.

> ***Trauma from [their] birth experience makes women less willing to go [to hospital].***"
>
> *32yr old woman, Nairobi*

> ***We don't have access to most of the equipment we need."***
>
> *HCW, Lagos*

Healthcare System

Both women and some HCWs described the lack of a clear and well-defined referral system.

They felt this was especially problematic for health conditions that were less understood and/or more intimate or stigmatized, such as various sexual and reproductive health conditions.

- Hospitals and clinics vary in their capacity to evaluate and treat different health conditions. In Nigeria, HCWs noted that they are not always well-trained in treating non-life-threatening conditions, including UI. This creates the need to refer patients to access specialized treatment.
- Most clinics, however, lack clinical guidelines defining when and where to refer patients. While some HCWs refer patients based on their personal knowledge and networks, many HCWs do not refer, leaving patients to navigate on their own.

> ***"It's like they learn medicine by prescribing medicine – [this is a] huge gap in our hospitals."***
>
> *HCW, Nairobi*

> ***When seeking healthcare for both UI and general health, people tend to go for the cheapest available option due to financial constraints. Quack doctors take advantage of this."***
>
> *HCW, Lagos*

Healthcare System

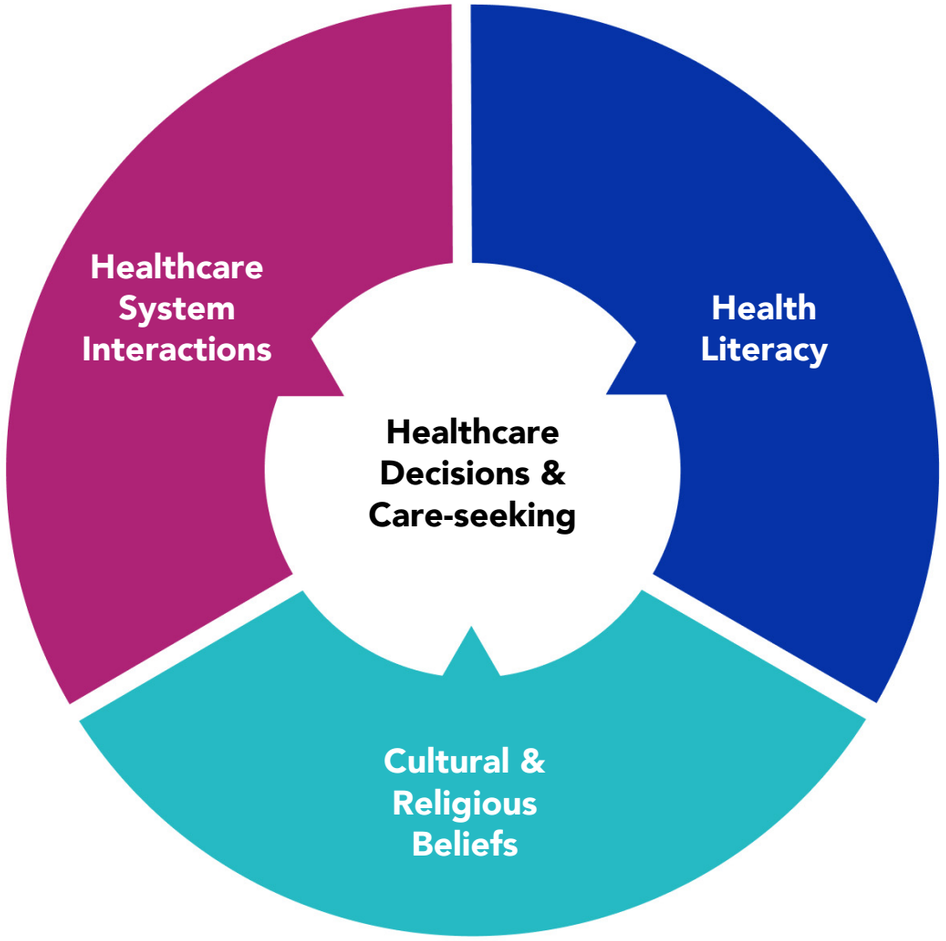
> ***The health workers' attitude at times can be frustrating."***
>
> *27yr old woman, Lagos*

> ***You wait for long before they can attend to you."***
>
> *27yr old woman, Lagos*

> ***Some of the challenges with the health system include lack of proper equipment, patients presenting themselves late for treatment, high cost of treatment and most patients lacking medical insurance coverage."***
>
> *HCW, Nairobi*

> ***Most hospitals in Kenya don't take women's care into consideration."***
>
> *38yr old woman, Nairobi*

Healthcare Decision-Making and Care-Seeking – Key Insights



The choice to access healthcare is anchored around the health knowledge and information a woman has and her perception of the severity of a particular health condition.

In both countries, several factors influence a woman's decision-making on whether to seek healthcare services. These include health awareness and access to information, peer influences, cultural & religious norms, stigma, lived and shared experiences from previous healthcare system interactions, cost, perception of severity of the health condition, as well as the likelihood of health issues interfering with a woman's social and work life.

Emerging digital health technologies may influence healthcare decision-making in the future, particularly for women's health conditions.

Women are embracing digital health, particularly telemedicine and digital pharmacy platforms, because of their convenience and assurance of privacy. As availability of these digital services expands, it is reasonable to consider their growing influence on women's healthcare decisions and care-seeking behaviors.

Perceptions and Experiences of Urinary Incontinence

This section summarizes what is known, experienced and spoken about regarding UI, from the perspective of both women with UI and HCWs in Kenya and Nigeria.

This includes women's experiences of UI, what they believe causes UI, the impact of UI on day-to-day life, and self-management and treatment options women employ. Standard treatments and the attitudes and preferences towards these are also described.

Women's Experiences of Urinary Incontinence

Women described their beliefs about the causes of UI. Many women associated the onset of UI symptoms with pregnancy and childbirth and described altered behavioural habits in relationship to their bladder symptoms.

- For many women in both countries, their experience of UI began during or soon after pregnancy. In some cases, they had been **told to expect it as a "normal consequence" of childbirth**. Some women were counseled during pregnancy about preventing UI.
- Some women with conditions, including fibroids and hernia, reported they developed UI symptoms alongside these health concerns. These women had leakage with laughing, sneezing, or coughing and perceived this to be linked to their experience of **increased abdominal pressure** as related to their respective health conditions.
- Several women shared a common experience of regularly holding urine for many hours, as they lacked access to toilets or avoided unclean public toilets and waited to use their personal ones at home. They believed that **holding in urine had caused their muscles to weaken, resulting in UI**. One woman reported holding her urine for a full workday, but on approaching her home, she often leaked before getting to the toilet.
- In Kenya, some women related their current incontinence to prior bedwetting as children. They had received treatment for it over the years, but still experienced leakage from time to time .
- One woman **linked her UI to feelings of anxiety or excitement.** She recounted that when she received shocking news, she would find that she had "wet herself."

> ***I just had a feeling it was due to heaviness of the baby."***
>
> *29yr old woman, Lagos*

> ***I raised my concerns about UI with fellow new mums, and they said my UI would go away but it did not."***
>
> *25yr old woman, Nairobi*

> ***I started leaking during pregnancy. I visited a doctor but was told the leakage was obviously due to the pregnancy, but it did not stop."***
>
> *25yr old woman, Nairobi*

Women's Experiences of UI

> ***I've seen that UI happens when someone is forcefully raped – I perhaps saw it in a movie."***
>
> *26yr old woman, Nairobi*

> ***I believe my urine leakage is caused by ageing, excess sugar, too much water intake, weak bladder and childbirth."***
>
> *33yr old woman, Lagos*

> ***I thought UI is experienced by everyone, so I didn't seek out healthcare services."***
>
> *29yr old woman, Nairobi*

> ***I started leaking a few years back and don't get to the restroom on time. I didn't do anything to control the leakage."***
>
> *25yr old woman, Lagos*

Women's Experiences of UI

> ***"The leakage started after giving birth and usually happens when I laugh, sneeze or cough. I tried Kegel exercises but found them very difficult, especially the holding part."***
>
> *27yr old woman, Lagos*

> ***"The involuntary leakage of urine started happening when I was pregnant. Urine passed without me noticing. I thought it was normal because I had heard from friends that weird things happen to women when pregnant."***
>
> *26yr old woman, Nairobi*

> ***"My spouse is very supportive, partly because he feels guilty for having made me pregnant and believing that pregnancy caused the leakage."***
>
> *25yr old woman, Nairobi*

Women's Experiences of Urinary Incontinence

Women also shared common myths and misconceptions about the causes of UI.

- In Kenya, there is **a notion that women with UI have been unfaithful to their husbands.**
- In Nigeria, women described the myth that UI is caused by witchcraft, demonic forces, or a spiritual attack.
- In both countries, there was **a belief that incontinence is caused by a sexually transmitted infection** (STI). This belief reinforced the fear that many women with UI feel around their partners, who may think they have been unfaithful.

> ***I think the awareness on UI is not there, and some women believe it is a result of witchcraft."***
> *35yr old woman, Lagos*

> ***People say that you've had a lot of abortions or contraceptives when you have UI. You have to be tactical when bringing UI conversations to society."***
> *28yr old woman, Lagos*

> ***The leakage happens when I am really pressed or when I am anxious. I didn't see it as a medical condition though. I thought it was my fault that I could not hold the urine."***
> *25yr old woman, Lagos*

Women's Experiences of UI

> ***When you start leaking, people can say your enemies are after you, or the devil has caused leakage after childbirth, yet all your peers are normal."***
>
> *30yr old woman, Lagos*

> ***Some women believe UI is an STD [STI] which is why they shy away from speaking about it."***
>
> *HCW, Nairobi*

> ***People around me do not commonly talk about UI as compared to yeast infections and UTIs [urinary tract infections]. I look at UI as a medical condition because people don't have control over it."***
>
> *25yr old woman, Nairobi*

Women's Experiences of Urinary Incontinence

Women describe both shame and normalization of UI and how this affects with whom they are willing to discuss their symptoms.

- Women are aware that leaking urine is a common experience, albeit one not spoken about openly and comprehensively.
- They explain that **UI is often normalized** – both within the medical community and in other channels they rely on for information, such as interactions with friends, family, and social media. Therefore, UI is not always considered a condition that requires medical attention.
- UI is also seen as **a normal part of old age and is stigmatized in younger women.**
- Women cite the **shame associated with UI**. While many are willing to speak to each other about their experiences, even then women with UI are discussed in **coded or dismissive terms** such as being promiscuous or having had abortions or having used contraceptives often.
- Social media offers an outlet for some women to learn about and discuss UI. The **relative anonymity offered by platforms, such as, WhatsApp™ allows for many women to speak about UI**, particularly within women-focused groups on the platform.

> ***When it started, I never saw it as a big thing."***
> *26yr old woman, Lagos*

> ***I didn't even know it was called UI. We need to have the basics and to have more people talk about it."***
> *27yr old woman, Nairobi*

> ***I see people talking about it on social media … Instead of looking for solutions, they are grumbling."***
> *28yr old woman, Lagos*

> ***The society is not as friendly as it should be towards women with UI, as people still don't know much about it."***
> *31yr old woman, Lagos*

> ***My mum is also like that [has urine leakage], and she has been holding in pee since her school days."***
> *30yr old woman, Lagos*

Women's Experiences of UI

> ***I honestly didn't think it was a medical issue."***
> *30yr old woman, Lagos*

> ***Maybe even our mothers have not told us."***
> *27yr old woman, Nairobi*

> ***Most women seek information from fellow women who have the condition. We walk the journey together."***
> *29yr old woman, Nairobi*

> ***After the third leakage instance, I went online to do my own research as I did not believe what friends were telling me about my urine leakage."***
> *26yr old woman, Nairobi*

Healthcare Worker's Perspective of Urinary Incontinence

Healthcare workers in Kenya and Nigeria believe the prevalence of UI in SSA is very high and highlight the need for awareness and education targeted at the general public and medical community.

- Even though prevalence data about UI in SSA is limited, HCWs believe that there are many community-dwelling women living with UI. As an example, they cite **high fertility rates in SSA and the role of parity as a risk factor for UI.**
- They describe that when women attend gynecology clinics, they often must be prompted to confirm the presence of UI; it is not information they will volunteer willingly.
- HCWs describe the common assumption that UI is not a condition requiring medical attention and is something to be managed rather than treated. They report that most women do not seek treatment. The HCWs describe **a prevailing belief among women that UI is a condition that has been survived by many generations of women, therefore they, too, can withstand it.**
- HCWs mentioned that many patients associate UI with poverty, yet the HCWs emphasize that **UI cuts across socio-economic strata.**

> ***We may be shocked to see the amount of UI that exists.***
>
> *HCW, Lagos*

> ***This is a developing country, we have more of them [UI cases] than in the developed world."***
>
> *HCW, Lagos*

> ***Pelvic floor disorders such as UI are common in the country but are not well researched."***
>
> *HCW, Nairobi*

> ***There is limited data on prevalence of most conditions as this is based on who complains and seeks treatment - most patients do not seek treatment."***
>
> *HCW, Lagos*

> ***We know the prevalence of UI in Nigeria is very high. We may not have the data but when you look at the high number of women giving birth to many children, you will know. Labor exposes them to UI. However, since this is very common, they see UI as normal and don't report."***
>
> *HCW, Lagos*

Healthcare Worker's Perspective of UI

> ***Some people won't volunteer that information, so you have to ask."-***
>
> *HCW, Nairobi*

> ***Speaking about UI is taboo due to factors such as religion where women may not speak about matters relating to their private parts."***
>
> *HCW, Lagos*

> ***UI is not just for the rich, or the poor."***
>
> *HCW, Lagos*

> ***Women take it as one of the many other things they have to cope with in their lives."***
>
> *HCW, Lagos*

> ***Some people perceive these issues as part of womanhood. They think everyone is going through this."***
>
> *HCW, Lagos*

Healthcare Worker's Perspective of UI

> ***UI has been normalized through generations; from mother to daughter and we need to create awareness on large scale to get beyond this as no one is talking about UI."***
>
> *HCW, Nairobi*

> ***A lot of our Nigerian culture, people say 'na God', let it be. They may not even see it as a problem."***
>
> *HCW, Lagos*

> ***Sincerely I will say many of them don't see it as a problem...They are not empowered medical wise."***
>
> *HCW, Lagos*

> ***Some patients don't really understand what is going on down there, and they get information from the wrong place."***
>
> *HCW, Nairobi*

> ***It is incidentally picked up when they come for other conditions."***
>
> *HCW, Lagos*

Fistulous and Non-fistulous Incontinence

An estimated 0.5-2 million women worldwide experience continuous urinary and/or fecal incontinence secondary to gynecologic and obstetric fistula.

Fistulous incontinence is most commonly a devastating consequence of prolonged obstructed labor. It disproportionately affects women who lack economic, structural, and agentic means to access antenatal and emergency obstetric care, including safe surgery. It is unquestionably a severe and disabling health condition that warrants treatment and prevention. Successful treatment nearly always requires surgery. Rehabilitation and reintegration activities for women with fistula are increasingly part of holistic care for women with this condition.[13]

Non-fistulous UI is classically episodic and affects women in exponentially greater numbers; an estimated 122+ million women in SSA, alone. The care pathway for non-fistulous UI, though minimally described in LMICs, is well established globally and results in cure or meaningful improvement in symptoms for most who engage in treatment. It begins with rehabilitative exercise, health education, and behavioral modification, followed by, or implemented in conjunction with, more advanced interventions, such as medications, procedures, and surgeries.[14]

Fistulous and Non-Fistulous Incontinence

In SSA, incontinence related to gynecologic or obstetric fistula has been the focus of awareness campaigns, governmental and non-governmental organization programming and funding, contributing to widespread perceptions that only fistulous UI is problematic.

- HCWs indicate that awareness campaigns related to fistula are common in both countries. They suggest that as fistula is the only context in which UI is highlighted in such public health campaigns, it **leads the public and the medical community to think of fistula as the primary or only cause of UI.**
- There are also women who believe that UI can only be caused by fistula. This is how some doctors have identified non-fistulous UI patients – through camps for fistula screening and treatment.
- Several HCWs expressed an explicit need to engage in awareness efforts and research to help the public and the healthcare community understand the differentiated burdens of fistulous and non-fistulous UI. They express a belief that **there is opportunity to promote education and awareness of all causes of UI, especially given non-fistulous UI is significantly more common.**

.

> ***On the policy side, there seems to be more structures on fistula and none for UI."***
>
> *HCW, Nairobi*

> ***We currently have poor UI data reporting tools and fistula is what has made UI to be known."***
>
> *HCW, Nairobi*

> ***The first thing would be to establish the burden of non-fistulous UI."***
>
> *HCW, Lagos*

> ***Generally, non-fistulous UI is under-treated because of the perception that it is less common. The condition is masked by other more "serious" illnesses."***
>
> *HCW, Lagos*

Fistulous and Non-Fistulous Incontinence

> ***There are few things that get attention in Nigeria, anyway. The focus is on fistulous incontinence, especially in the northern part of the country where the majority of cases are."***
>
> *HCW, Lagos*

> ***UI is stigmatized, and they think it [any UI] is equivalent to fistula."***
>
> *HCW, Nairobi*

> ***The ones who come to the [fistula] camps are the bold ones."***
>
> *HCW, Nairobi*

Effects of Urinary Incontinence on Health and Quality of Life

Women describe self-management strategies and significant lifestyle changes related to their incontinence.

- Many women manage their condition by wearing **protective garments**, such as pads, panty liners or diapers, which comes at a financial cost to them.
- Other women report **hyper-vigilance**; they are always aware of where the bathroom is whenever they are in a new location and frequently empty their bladder to avoid any embarrassing leaks. They also convey significant **worry about odor** due to leakage and describe **frequent cleaning and changing clothes**, as a result.
- On long journeys, some women **refrain from drinking water**, as they would need to stop several times to use the toilet to avoid leaking.
- One woman shared she keeps a bucket by the side of her bed into which she can urinate. When she awakes with a strong urge to urinate, she sometimes uses the bucket so that she doesn't leak on the way to the toilet.

> ***The UI condition has turned my life upside down; I use diapers to manage the condition and can't go out without diapers."***
>
> *32yr old woman, Lagos*

> ***I normally avoid water; I also use pads and I carry extra clothing in case [I have leakage]."***
>
> *33yr old woman, Nairobi*

> ***Because of UI, my timing has changed, and I now have to wake up at 3am, ensure I am clean so as to leave by 6am and I also have babies to take care of."***
>
> *27yr old woman, Lagos*

> ***With UI, I have reduced my water intake and I walk around with a urinating bottle to manage the leakage."***
>
> *25yr old woman, Lagos*

Health and Quality of Life

> ***My UI has been active during my practice (exercise sessions) and when lifting things. I have had to cut down on my practice hours."***
>
> *34yr old woman, Nairobi*

> ***It impacted how much water I take, which has impacted my skin and gut health."***
>
> *27yr old woman, Nairobi*

> ***I keep a bucket in my bedroom in case I don't make it to the loo in time."***
>
> *27yr old woman, Nairobi*

> ***Due to UI, I constantly change my innerwear and I use pantyliners to manage. I also wear pads and this is expensive."***
>
> *23yr old woman, Nairobi*

> ***I have had the UI condition since I was in school. This subjected me to bullying by others who frequently made fun of me."***
>
> *27yr old woman, Nairobi*

Effects of Urinary Incontinence on Health and Quality of Life

Social interactions also suffer, and a significant driver of this is the fear women have of odor related to their UI.

- This includes limiting sex with one's partner, going to work and meeting friends and family.
- Some women indicate they have **reduced their active lifestyle**, decreasing the amount of time spent playing sports or being in the gym. Instead, they spend more time **sedentary and in relative isolation** at home.
- In Nigeria, it was mentioned by women, HCWs, and a religious leader (e.g., an imam) that Muslim women with UI experience a **sense of alienation from their religious community**, as leakage deems them unclean and thus unsuitable for prayers. Women must attend prayers when 'clean', after performing ablutions. This is not possible when there is leakage you are unable to control and even with infrequent leakage creates a significant challenge.

> ***When there was leakage, I could not go out."***
> *26yr old woman, Lagos*

> ***I can't stay with people for long periods of time due to urine leakage and smelling."***
> *33yr old woman, Nairobi*

> ***The leakage has affected my self-esteem and confidence making me avoid social groups for fear of being judged harshly."***
> *23yr old woman, Nairobi*

> ***It is quite embarrassing to be going to the washroom frequently when you're in the midst of people."***
> *24yr old woman, Lagos*

> ***There is a large population with UI. UI hinders women from prayer, ablution, being clean – but people rarely discuss it."***
> *HCW, Lagos*

Health and Quality of Life

> ***It's not life-threatening, but it has psychological effects and eats into their finances."***
>
> *HCW, Lagos*

> ***For all these women, UI has been a shameful experience. Some have had to not go outside and have a social life as they are scared of being judged for leaking and smelling urine."***
>
> *HCW, Nairobi*

> ***We know incontinence causes social and hygienic challenges."***
>
> *HCW, Lagos*

> ***My wife's leakage has gotten so bad that she rarely goes far from the house. She doesn't even go to pray anymore."***
>
> *Husband/Caregiver, Lagos*

Urinary Incontinence Treatment

Most women seek treatment for UI when symptoms significantly interfere with their day-to-day life.

- In both Kenya and Nigeria, most women do not seek treatment for UI due to **low awareness of UI as a health condition that could improve with treatment.** Women cope with their leakage and seek treatment once symptoms impact their life in a severe way.
- Many women in both countries express that they, and they believe other women, **would seek treatment earlier if they knew more about the health condition and about potential treatments**. HCWs endorsed this sentiment.
- HCWs in Nigeria noted that women may have more pressing needs, and thus, choose to live with UI.

> ***I have been experiencing UI for 2-3 years, but I've never known that there is a treatment for it."***
>
> *32yr old woman, Lagos*

> ***Treatment of UI amongst women depends on severity of UI. Rarely do we seek treatment if we think that the leakage is not severe."***
>
> *33yr old woman, Lagos*

> ***There was a recent video on Instagram that showed a woman sneezing and leaking urine and this was promoted as a cool thing. This definitely normalizes UI and women will not seek treatment."***
>
> *HCW, Nairobi*

> ***UI is only managed when it becomes a huge problem, when a woman can no longer hide the fact that she is leaking urine."***
>
> *HCW, Nairobi*

Urinary Incontinence Treatment

- **HCWs also tend to prioritize more serious and life-threatening conditions,** such as eclampsia, preeclampsia, and diabetes over UI. This is also due, in part, to the notion that UI is not a health condition that requires medical attention.
- Low rates of treatment may also be due to strained referral systems for women experiencing UI. There are a very limited number of specialists, who remain relatively inaccessible for most patients. There are few HCWs, for example, who are specialists in pelvic floor disorders in both Kenya and Nigeria.
- **Having few specialists contributes to lower awareness, and other HCWs are not well trained to recognize UI and know how to initiate treatment.** An example of the outcome of this is that UI ends up being confused with UTIs.
- Additionally, seeking out healthcare is generally time-consuming and expensive, and even more so, given the limited availability of HCWs skilled in treating UI.

> ***The patients that come to ask about UI always have one critical question, will the leakage stop? Most of them come after they have consulted their friends and tried local options to no avail."***
>
> *HCW, Lagos*

> ***When I saw a doctor concerning the leakage, the doctor said I didn't have a problem. He administered drugs that never worked but only changed the color of the urine."***
>
> *32yr old woman, Lagos*

> ***I sought treatment and medication for my urine leakage, but the doctors told me it was part of menopause."***
>
> *41yr old woman, Nairobi*

UI Treatment

> ***I talked to a doctor who could not identify what was wrong with me when I had UI. He never put a name to it. He however prescribed some drugs that didn't make a difference."***

27yr old woman, Nairobi

> ***The willingness to pay by most patients is influenced by the severity of the condition and the affordability of the treatment. The odor resulting from urine leakage is also a major motivation to seek treatment."***

HCW, Lagos

Urinary Incontinence Treatment

Most women were familiar with Pelvic Floor Muscle Exercises (PFME), or 'Kegels' as a treatment for UI, but they expressed that these exercises are not always useful or done well.

- For a significant number of women, they **first learn about PFME to control their leakage through online sources**, such as YouTube and Facebook and social media platforms, such as WhatsApp™ groups.
- Though there are various sources for women to learn how to do PFME, most HCWs reported that many **women struggle with doing them well**.
- Women in both countries believed that UI may be treated with medications or surgical interventions, and this pressures HCWs to default to advanced treatments rather than recommending PFME.
- Both women and HCWs indicated a **lack of digital health tools, particularly PFME training devices and smartphone apps to guide exercise**, support adherence to daily training, and track progress over time.
- Most women seek treatment from gynecologists, many of whom may not be well versed in UI management, and thus, the treatment options offered may not follow best practices. An example of this may be offering medication to all women with UI.
- HCWs in Nigeria noted that UI treatment is not as expensive as treatment for other health conditions. The affordability is a result of integration of UI treatment with antenatal and postnatal care services at some institutions.

> ***The first thing that you run to [with health questions] is YouTube, and they recommend Kegels."***
> *25yr old woman, Nairobi*

> ***Most of the information the UI patient has on UI including how to perform PFMEs/Kegels was got from YouTube™."***
> *29yr old woman, Lagos*

> ***I was introduced to PFM exercises by an influencer on TikTok™."***
> *25yr old woman, Lagos*

> ***I was introduced to Kegel exercises from an online YouTube source. I have tried doing the exercises using Kegel balls and seen some progress."***
> *27yr old woman, Nairobi*

> ***Many patients find it difficult to identify the muscles they are to exercise."***
> *HCW, Lagos*

UI Treatment

> ***Whilst I do Kegel exercises, I can't tell if I do them correctly, and this might be the reason I am not getting better sooner."***
>
> *29yr old woman, Nairobi*

> ***Emotional and pelvic health are connected. It's therefore important to take care of patient's mental health together with pelvic health."***
>
> *HCW, Lagos*

> ***They come to us with a mindset of surgery."***
>
> *HCW, Nairobi*

> ***I haven't come across any digital treatment options for UI yet, we only rely on PFM exercises - rule of 10*3 [10 reps, 3 sets]."***
>
> *HCW, Nairobi*

UI Treatment

> ***Kegel exercises remain the most common form of conducting PFMEs, but unfortunately, even most doctors do not know how to perform these. So, a doctor will prescribe these exercises to a woman with UI but not show them how to perform them."***
>
> *HCW, Nairobi*

> ***Doctors teach the pelvic floor exercises themselves to those women who do not respond to UI medication."***
>
> *HCW, Lagos*

> ***The biggest treatment gap we have in the UI field is lack of digital devices that can help track progress. For now, we rely on women doing Kegel exercises correctly which is not always the case."***
>
> *HCW, Nairobi*

Urinary Incontinence Treatment

Though most women do not receive treatment for UI, HCWs describe the various treatment options available in their settings.

- There are several treatment options that HCWs in both countries put forward for female patients experiencing UI. Treatment may include pelvic floor muscle exercises/training (PFME/T), pessaries, 'Kegel balls' (e.g., vaginal weights), medications or surgery.
- **Many HCWs noted the important role of physiotherapy in UI treatment, including PFME supervision. They cited the limited number of physiotherapists as a major barrier to implementing first-line care for UI.**
- In Kenya, electrical stimulation and other modalities were was also mentioned as a treatment option, including Emsella® - an in-office electromagnetic simulation machine perceived as very costly.

.

> ***"The biggest challenge we have is where to send women experiencing UI for physiotherapy when they come to us urologists, as we don't have many specialists for physiotherapy."***
>
> *HCW, Nairobi*

> ***"We use pessaries for UI treatment as there are no digital/technological treatment methods used."***
>
> *HCW, Lagos*

> ***"During UI treatment, patients may be uncomfortable with some procedures such as catheterization. Some of them are afraid for nothing."***
>
> *HCW, Lagos*

Urinary Incontinence Treatment

HCWs are aware of interventions for specific UI subtypes and describe limitations in providing evidence-based treatment for UI.

- HCWs explained that the treatment recommended depends on the type of UI being experienced; for example, medications (i.e., anticholinergics) are prescribed in the case of incontinence associated with overactive bladder.
- HCWs use bladder diaries kept by the patient to determine the type of UI. In some facilities, urodynamic studies may be completed, though this is rare due to the high cost and limited availability of this technology at most institutions.
- Additionally, HCWs in Kenya indicated significant issues with importing pelvic health products, such as vaginal weights or dilators. In the customs process, these products may be marked as 'sex toys', complicating their entry into the market, and thus further limiting the treatment landscape.

> ***"Like in most developing countries, we have made progress, but could be better."***
>
> *HCW, Nairobi*

Urinary Incontinence Treatment – Opportunities for Expanding Access

When asked about new treatment options, participants expressed strong interest in non-surgical and non-pharmacologic interventions and a preference for clinician-directed treatment at a health facility. Digital health technologies, including intravaginal devices and smartphone applications designed for women with UI appealed to all participants. Both HCWs and women with UI agreed that such treatment is best accessed in a clinic setting, where privacy and discretion is guaranteed.

- Generally, **HCWs are trusted** by patients in both Kenya and Nigeria, and their advice on any health condition is well-followed.
- Most women noted that they would prefer to access UI treatment at a clinic where they can have personal attention and time with their HCW. They noted the stigma associated with UI in LMICs and expressed the **importance of a private space, where they are not embarrassed or ashamed** to ask questions about UI.
- Women in both Kenya and Nigeria noted that one of the reasons they don't seek UI treatment is due to the lack of information, and they would thus prefer a treatment option that is **accompanied by dynamic UI information** to sensitize them on the condition.
- Women also preferred a clinic-based treatment, including an intravaginal device that may be sterilized and reused amongst women to **reduce costs**. They felt it would be expensive to purchase a home-use product that is only used for a limited amount of time.
- Women expressed a **sense of community and collective responsibility,** desiring as many women as possible to access UI treatment by recognizing that a clinic-based treatment solution would be least costly and more accessible for all women.

> ***I prefer a clinical model as I am likely to be more consistent with the training guided in a hospital."***
> *28yr old woman, Lagos*

> ***I would be open to using a UI treatment solution with a HCW just to monitor how strong my pelvic muscles are."***
> *25yr old woman, Lagos*

> ***So long as the digital solution is proposed by a HCW, women will have no problem as people in Kenya and Africa tend to trust their doctors wholly."***
> *HCW, Nairobi*

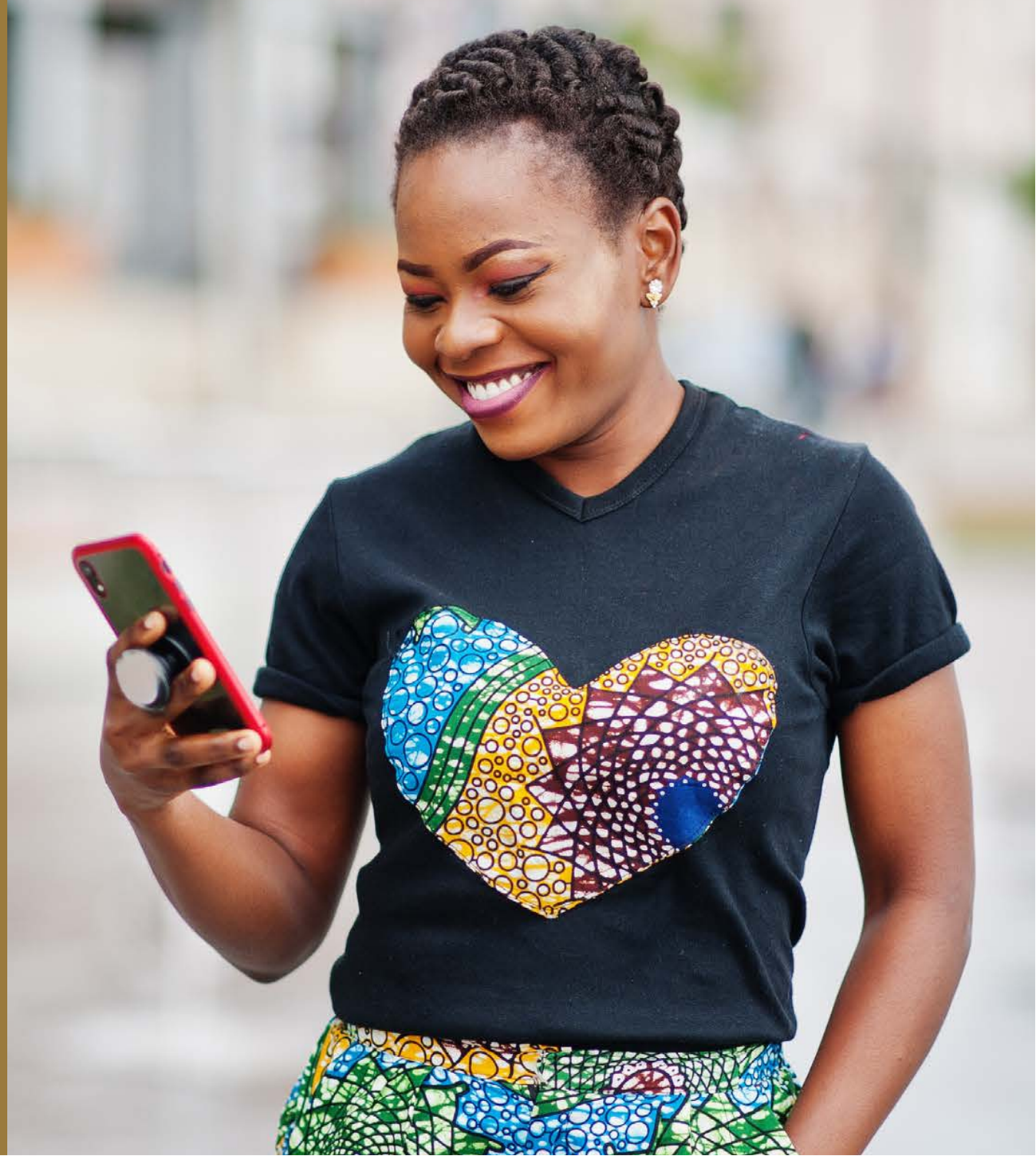
> ***I prefer a hospital UI treatment model because of the ability to monitor and advise patients and this can also guarantee privacy."***
> *HCW, Lagos*

> ***I prefer a clinical model for UI treatment because of the trust I have for medical providers."***
> *26yr old woman, Lagos*

Quantitative Analysis of UI Survey Data

In addition to qualitative interviews and focus group discussions, participants completed a series of questionnaires designed to quantify UI symptom severity and its effect on quality of life. To expand the available information about UI, questionnaires were also administered to online participants, who were screened for UI symptoms, and if positive, were prompted to complete the same questionnaires as those completed by in-person participants.

Questionnaires included the International Consultation on Incontinence Short Form (ICIQ-SF) and the ICIQ Lower Urinary Tract Symptoms Quality of Life measure (ICIQ-LUTS-QoL).[15,16] Both survey tools are standardized and validated in the context of high- and middle-income countries. Importantly, these surveys have not been validated in the Nigerian or Kenyan populations, and so this represents an early effort to apply these tools and understand participant responses.

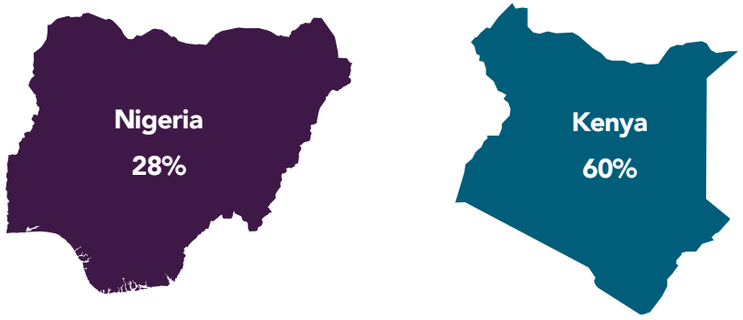


Urinary Incontinence Prevalence

Online survey respondents were screened for UI symptoms using the 3 Incontinence Questionnaire – 3IQ, the same survey employed to screen in-person participants.

Among 352 screened, 44% (155/352) reported UI symptoms – 104/173 women in Kenya and 51/179 women in Nigeria.

UI Prevalence by Country:



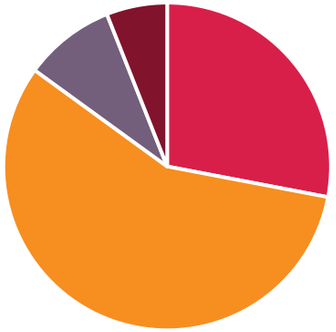
Online respondents provided demographics data, including age, childbirth history, education level and employment status. These respondents were similar to those who participated in interviews and focus group discussions with regard to these characteristics. Survey data from in-person and online participants was combined and analysed as a group, by country.

Urinary Incontinence Subtype

UI subtypes include stress, urgency, and mixed UI, defined by the activity with which leakage occurs. These three subtypes comprise most UI cases globally and among this cohort of community-dwelling women. The ICIQ-SF enables classification of UI subtype.

According to these results, the majority of participants report urgency UI (121/235, 51%), followed by mixed UI (55/219, 23%) and stress UI (48/235, 20%). The breakdown by country is illustrated in the pie charts.

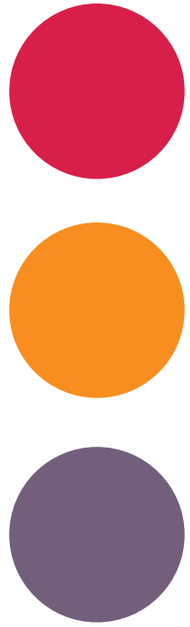
Nigeria



- Stress- 28%
- Urgency-57%
- Mixed- 9%
- Other- 6%

Kenya

- Stress- 22%
- Urgency-47%
- Mixed-25%
- Other- 10%



Stress urinary incontinence (SUI)
Involuntary urine loss that occurs with coughing or sneezing, physical activity or exertion

Urgency urinary incontinence (UUI)
Involuntary loss that occurs with the urge to urinate

Mixed urinary incontinence (MUI)
A combination of symptoms of stress and urgency urinary incontinence

Urinary Incontinence Symptom Severity and Quality of Life

Participants reported a range of UI severity from mild to severe symptoms and bother. The total average ICIQ-SF score was 8 points (range 3-20), which indicates **moderate UI severity** and is associated with symptoms bothersome enough to seek treatment among women in high- and middle-income settings.[17] Kenyan women reported greater UI symptom severity and bother than Nigerian women with average scores of 9 and 6 points, respectively.

Similarly, quality of life scores indicate **moderate effect of UI on various aspects of daily activities, social participation, and feelings of shame or embarrassment**.[18] The average ICIQ-LUTS-QoL was 36 points (range 16-73). Kenyan women indicated greater effects of UI on quality of life compared to Nigerian women with respective average scores of 40 and 26 points.

Of note, in Nigeria, women who were interviewed reported more severe quality-of-life effects compared to online participants, with average ICIQ-LUTS-QoL scores of 30 versus 26 points.

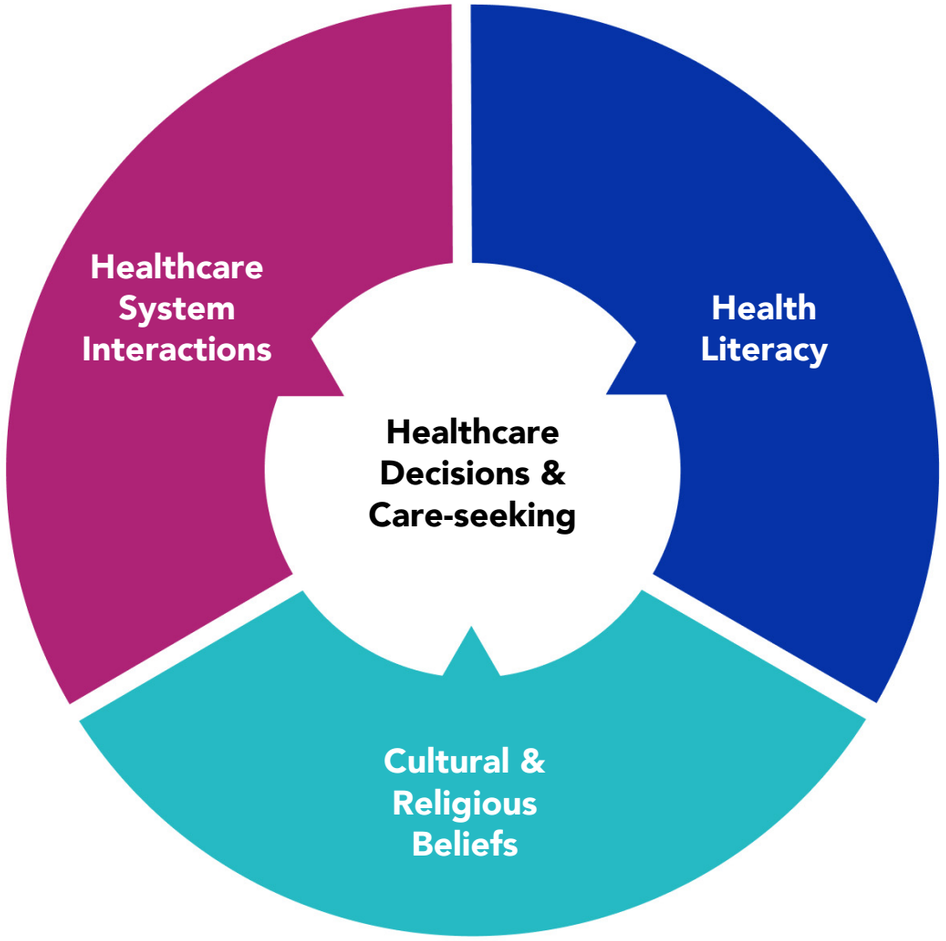
This discrepancy was not noted among Kenyan women; both in-person and online participants reported similar average scores. While this may represent a true difference in the effects of UI across these two populations, it is possible these differences may be attributed to language, cultural, or other barriers to understanding and responding to the survey questions. Future work to translate and/or validate these tools in the Nigerian and Kenyan populations is warranted.

The ICIQ-LUTS-QoL questionnaire asks respondents about UI management, such as pad usage, fluid restrictions, and clothing changes, as well as how often they worry about the smell associated with urine leakage and feel embarrassed by their condition. **In both countries, fluid restriction, frequent clothing changes, and significant worry about odour associated with UI characterize the primary effects of UI on women's lives. Of note, pad usage is especially low in Nigeria, perhaps due to availability and affordability of absorbent products.**

Number of respondents who report the following behaviours or concerns

	Kenya (154)	Nigeria (68)
Pad Usage	91 (59%)	12 (18%)
Restrict fluids	133 (86%)	34 (50%)
Change Clothes	143 (93%)	43 (63%)
Worry about smell	141 (92%)	34 (50%)
Feel embarrassed	122 (79%)	22 (32%)

Expanding Urinary Incontinence Care in Sub-Saharan Africa – Key Insights



Understanding key influences on healthcare decision-making and care-seeking elucidate multiple paths forward to expand care for women with urinary incontinence and other pelvic floor disorders.

Sensitization focused on pelvic health and urinary incontinence can promote **health literacy** of women and communities. Health education efforts may leverage digital platforms and existing local and international women's health organizations to enhance impact and reach.

Cultural values related to community, belonging, and a sense of collective responsibility can serve as enablers for women to learn about UI and to seek treatment. Partnerships with social and religious institutions can further promote awareness and care-seeking and dismantle stigma and embarrassment associated with UI.

Research and training in UI management and expanding available treatment options can strengthen **healthcare systems** in these settings. There is strong interest amongst HCWs in UI-related research and education, as well as a desire from both HCWs and women with UI to embrace new technologies that facilitate treatment and enhance the clinician-patient relationship.

Conclusion

Conclusion

In conclusion, this research, incorporating both qualitative and quantitative methodologies, underscores the pervasive and bothersome nature of UI among women in SSA. While the prevalence of UI is notably high, a significant impediment lies in the low health-seeking behaviors exhibited by affected women. This reluctance stems from factors such as a lack of awareness, the normalization of UI, UI myths and misconceptions, and a broader trend of non-health-seeking behaviors within the population.

Compounding this challenge is the constrained treatment landscape observed in both Kenya and Nigeria. Women who actively seek treatment encounter limited treatment options, with cost emerging as a key barrier, as well. Moreover, HCWs face limited training opportunities in UI diagnosis and treatment, resulting in a scarcity of professionals dedicated to addressing UI concerns.

Noting the normalization of UI and the perception of UI as a less serious condition amongst women and HCWs, women often downplay the resultant effects of UI on their lives, as noted in the quantitative survey analysis. However, the lived experiences of women and HCWs shared during qualitative interviews sheds light on the extent to which UI affects women in LMICs. **Most women described UI as having a significant impact on their daily lives, including activity restrictions and negative effects on their social lives and feelings about themselves.**

A critical imperative emerges from this research: the urgent need to enhance awareness of UI as a health condition. Despite its wide-ranging implications on lifestyle, livelihood, and general well-being, UI receives inadequate attention from HCWs, policymakers, and, consequently, the affected women.

Furthermore, a substantial gap in the treatment and management of UI is evident. The lack of awareness, coupled with competing healthcare priorities, indicates the **need for improvement in the provision of effective, safe, and affordable UI treatment services. Findings from this research demonstrate strong interest amongst women and HCWs to engage in new UI treatment options.**

Addressing these challenges requires a concerted effort to elevate the understanding of UI and other PFDs, both within the healthcare sector and society at large, in order to foster a more responsive and supportive environment for women grappling with this significant health issue.

> ***Lack of a government policy streamlining UI treatment limits alignment among healthcare providers, including physiotherapists, with different institutions adopting different methodologies of managing the condition."***
>
> *HCW, Lagos*

> ***With data, the enormity of the problem stares into your face."***
>
> *HCW, Lagos*

Conclusion

> ***UI has been normalized through generations; from mother to daughter and we need to create awareness on large scale to get beyond this as no one is talking about UI."***
>
> *HCW, Lagos*

> ***Awareness must be created to end the associated stigma."***
>
> *HCW, Nairobi*

> ***To get health interventions adopted by communities, you'll need to work with community influencers that are part of them."***
>
> *Key Informant, Nairobi*

> ***I hope you'll make a lot of noise about it."***
>
> *27yr old woman, Nairobi*

Conclusion

Given the prevalence and impact of UI in Kenya and Nigeria, future efforts within women's health in SSA should include pelvic floor disorders. Key areas of need include building awareness, fostering research, and targeted healthcare capacity-building for UI and other PFDs. Digital communities and innovations in digital health hold promise for facilitating progress in all areas and should be explored, especially given the rise of the digital health ecosystem in LMICs and especially in SSA and the desire amongst women and HCWs for such solutions.

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