



Incontinence in Zambia: initial investigation into the coping strategies of sufferers and carers

Claire A. Rosato-Scott and Dani J. Barrington

Abstract: *There is little information on the management of incontinence in low-income settings. This article provides some initial insights, of particular relevance to water, sanitation, and hygiene (WASH) and health practitioners, into the coping strategies used by sufferers and carers in Zambia. Incontinence is rarely reported to medical professionals in Zambia, possibly due to a reluctance to disclose as a result of the stigma associated with the condition. Management and treatment of incontinence is subsequently limited, and both coping strategies and treatment received are determined by affordability and accessibility. If the global community is to achieve the Sustainable Development Goals of universal sanitation (Goal 6) and well-being (Goal 3), future studies and programmes on incontinence in Zambia will need to involve collaborations between WASH and health practitioners that investigate how to reduce the stigma associated with the condition and increase awareness, and how to improve the availability and affordability of management and treatment, considering the potential preference for traditional medicine in rural communities.*

Keywords: disability, elderly, health, water and sanitation, fistula

Introduction

Incontinence is a global healthcare challenge that has a significant impact on the quality of life of both sufferers and carers. In higher-income countries with well-developed healthcare systems, experience shows that simple behavioural changes and technologies can bring dramatic improvements to the quality of life of those who endure the condition daily (Dumoulin et al., 2014). If the global community is to achieve the Sustainable Development Goals, particularly those relating to universal sanitation (Goal 6) and well-being (Goal 3), translating such methods for managing incontinence to low-income settings could benefit resident sufferers and carers. However, doing this requires an understanding of local challenges to inform and drive effective innovation.

Prevalence

Incontinence affects a wide variety of people, and commonly those typically identified as vulnerable: children, new and expectant mothers, the elderly, and those with

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Box 1 Definitions

The International Continence Society (ICS) defines faecal incontinence (FI) as an involuntary loss of faeces (ICS, 2016). Urinary incontinence (UI) is defined as an involuntary loss of urine (Haylen et al., 2012). More specific symptoms include stress urinary incontinence (SUI), defined as the involuntary loss of urine on effort or physical exertion or on sneezing or coughing, and urgency urinary incontinence (UUI), defined as the involuntary loss of urine associated with urgency (Haylen et al., 2012). Incontinence can range from being inconvenient to debilitating. For the purposes of this article, incontinence is defined as the involuntary loss of urine and/or faeces.

physical and/or cognitive disabilities (Giles-Hansen, 2015). Estimating the prevalence of incontinence is challenging due to variable definitions and the dynamic nature of the condition: significant incidence rates are associated with equally significant remission rates (Minassian et al., 2008).

Systematic reviews using research from developed and developing countries found that studies tend to report a prevalence of any UI in females in the range of 25% to 45%; UI in men in the range of 1% to 39% (increasing with age); and FI frequencies in adults lower than 15% (Abrams et al., 2013). Walker and Gunasekera conducted a systematic review of research from only low- and lower-middle-income countries (LICs and LMICs) and found that, of the 83000 women who have given birth surveyed (women who have given birth), the mean prevalence of UI was 28.7%, and FI 7% (Walker and Gunasekera, 2011).

Incontinence in men is usually related to disability, injury, or surgery. Incontinence in women is typically related to reproductive history, with pregnancy, labour, and vaginal deliveries established risk factors for UI and FI (Wood and Anger, 2014; Walker and Gunasekera, 2011). The prevalence of incontinence is likely to be high in Zambia as the total fertility rate is 5.7 children per woman, compared with an African average of 5.2 children and a global average of 3.0 children (WHO, 2017). Regular heavy physical work has also been identified as a risk factor for UI; this is a particular concern as, for example, almost half of men and women aged 15 to 49 in Zambia are engaged in agricultural occupations (Central Statistical Office, 2015; Walker and Gunasekera, 2011).

A severe form of incontinence can result from a fistula, which is an abnormal opening between the bladder and vagina, and/or between the rectum and vagina. A fistula is usually the result of an obstructed (prolonged) childbirth, which is more likely to occur in young girls due to pelvic immaturity (House et al., 2012). The 2013–14 Zambia Demographic and Health Survey (DHS) found that the median age at first marriage (a proxy for first exposure to the risk of pregnancy) among women aged 20 to 49 years (at the time of the survey) was 18.7 years. It also found that, among women aged 15 to 49 years, one in three had heard of fistula with less than 1% experiencing fistula-like symptoms (Central Statistical Office, 2015). With 46.2% of the 2016 female population in Zambia aged 15 to 49 years (3.8 million), this suggests that up to 38,400 will experience fistula-like symptoms (World Bank, 2017).

Consequences

It is difficult to quantify the personal and economic costs of living with incontinence, not least due to the broad spectrum of consequences caused by the condition. 'Direct' costs are defined as the value of goods, services, and other resources used to treat or manage incontinence (Hu et al., 2005). The majority of direct costs are classified as routine care, including absorbent pads and laundry expenses. 'Indirect' costs are defined as the value of lost productivity or employment due to morbidity and mortality (Hu et al., 2005). Such costs are difficult to calculate, as are the 'intangible' costs, which are defined as the monetary value of pain and suffering (Hu et al., 2005).

Little is known about the implications of living with incontinence for sufferers and carers in LICs and LMICs, and a 2016 article in *Waterlines* specifically called for more research in this area (Hafskjold et al., 2016). The few studies that have been completed have found that the personal consequences of incontinence in LICs and LMICs are often more severe than for people with similar symptoms in high-income settings. This is often due to limited opportunities to keep clean (as a result of restricted access to water, soap, pads, and/or spare clothes), to disclose (often related to a fear of discrimination), and to access health education and/or facilities (Gjerde et al., 2013; Walker and Gunasekera, 2011).

Management

The coping strategies of incontinence sufferers and carers will be influenced by cultural, practical, and structural conditions (Gjerde et al., 2013). Initially, incontinence products and aids, such as disposable inserts, pads or diapers, and reusable diapers, can be used to manage symptoms. Behavioural changes that could be advised include weight loss (if applicable) and dietary adjustments. Conservative management measures include the use of pessaries and pelvic floor exercises. If unsuccessful, treatment can progress to pharmacological interventions and also to surgery.

The availability and/or affordability of interventions to improve the prevention and management of incontinence may be restricted in LICs and LMICs (Giles-Hansen, 2015; Wood and Anger, 2014). Further, it appears that only a minority of sufferers ask for help: of 15 studies conducted in higher-income countries, the median percentage of UI sufferers seeking help was 23% (Minassian et al., 2003). Reasons for not seeking help included embarrassment, fear of alienation, a belief that UI is a normal part of the ageing process, and a lack of knowledge about or expectations of the treatment options available (Minassian et al., 2003).

Methodology

The initial research plan was to conduct semi-structured interviews with male and female adult (aged 18 and over) incontinence sufferers and carers in Central Province, Zambia. As there is no central repository of medical data in Zambia to

determine a population of current and historic incontinence sufferers, convenience sampling was to be used, with potential informants identified through working with colleagues from Plan International Zambia to establish collaborations with medical practitioners in rural health centres. The intention was that such interviews would provide in-depth, qualitative information on the coping strategies of incontinence sufferers and carers, and generate ideas to improve their quality of life.

The research began by holding informal conversations with rural health workers (Table 1). Although these did yield valuable information on Zambian culture, and on the local and national health systems, they did not result in the identification of potential informants. As such, the study area was expanded to Lusaka Province, and the study population was expanded to include conventional and traditional medical practitioners (as carers of incontinence sufferers). The semi-structured interview questions were refined based on these conversations. For example, once it became clear that the term 'incontinence' was not known, the questions were refined using local language ('leakage') to describe symptoms. The questions therefore became more applicable to the Zambian context.

In Lusaka, potential informants were identified through collaboration with health workers at University Teaching Hospital (UTH). Formal interviews were held with both incontinence sufferers and their carers (Table 2), and informal conversations also continued with a variety of stakeholders (Table 1). The semi-structured interview questions were refined as more knowledge became available, particularly around the use of traditional medicine, but also to explore academic work that we learned had been completed. Once it became clear that obstetric

Table 1 Details of informal conversations

	<i>Zambia resident (female)</i>	<i>Zambia resident (male)</i>	<i>Medical professional</i>	<i>Pharmacist</i>	<i>Academic</i>	<i>NGO worker</i>	<i>Total</i>
Central Province		1	6			1	8
Lusaka Province	1	1	2	1	2		7
Total	1	2	8	1	2	1	15

Table 2 Details of semi-structured interviews

	<i>Incontinence sufferer</i>		<i>Carer of an incontinence sufferer</i>		<i>Medical professional</i>		<i>Total</i>
	<i>M</i>	<i>F</i>	<i>M</i>	<i>F</i>	<i>M</i>	<i>F</i>	
Copperbelt Province		1					1
Lusaka Province	1				5	1	7
Southern Province			1				1
Total	1	1	1	0	5	1	9

Notes: Residential (rather than treatment) location shown. M = male; F = female.

fistulas were perceived and treated differently to 'mild' incontinence, this area was explored separately. Daily field notes were also taken throughout the study period (Figure 1).

Semi-structured interviews

Interviews were held in the hospital, at the informant's office, or over the telephone, as these were confidential settings and also convenient for the interviewees. A research collaborator familiar with Zambian culture and fluent in Nyanja assisted with the data collection, and an interpreter was also used when necessary. An informed consent form was read out loud; this included information outlining the aim and purpose of the study. Consent to participate was documented by a signature, or with a cross (allowing for illiterate participants to be interviewed), or given verbally and witnessed by the research collaborator. Interviews were digitally recorded when permission was granted, with data transcribed in the spoken language and then translated into English for analysis.

Analysis

A system of codes and memos was used to inductively analyse interview transcripts and daily field notes. The codes (Table 3) assigned a summative attribute to a portion of data, with a corresponding memo to succinctly summarize the data. This system was used to identify emerging themes and to highlight pertinent excerpts. The validity of these emerging explanations was tested and improved as the fieldwork progressed, and this iterative process refined the analysis (Gjerde et al., 2013).

Table 3 Codebook

<i>Code</i>	<i>Definition of the discussion to which the code relates</i>
Definition	How the term 'incontinence' is understood by the interviewee
Prevalence	The perceived and/or reported prevalence of incontinence
Fistula	The causation, incidence, and treatment of obstetric fistulas
Diagnosis	The diagnosis of incontinence by both conventional and traditional medical practitioners
Management	The management of incontinence (at home and in the hospital)
Treatment	The treatment options available (traditional and conventional)
Culture	Zambian culture (in general and in relation to incontinence)

Ethics

Ethical approval for the study was obtained from the Human Research Ethics Committee at Cranfield University, United Kingdom (3499 and 4231), the Excellence in Research Ethics and Science (ERES) Converge IRB, Zambia (2017-June-033), and the Zambian Ministry of Health (MoH) (no approval number provided, but approval documentation can be produced if requested).

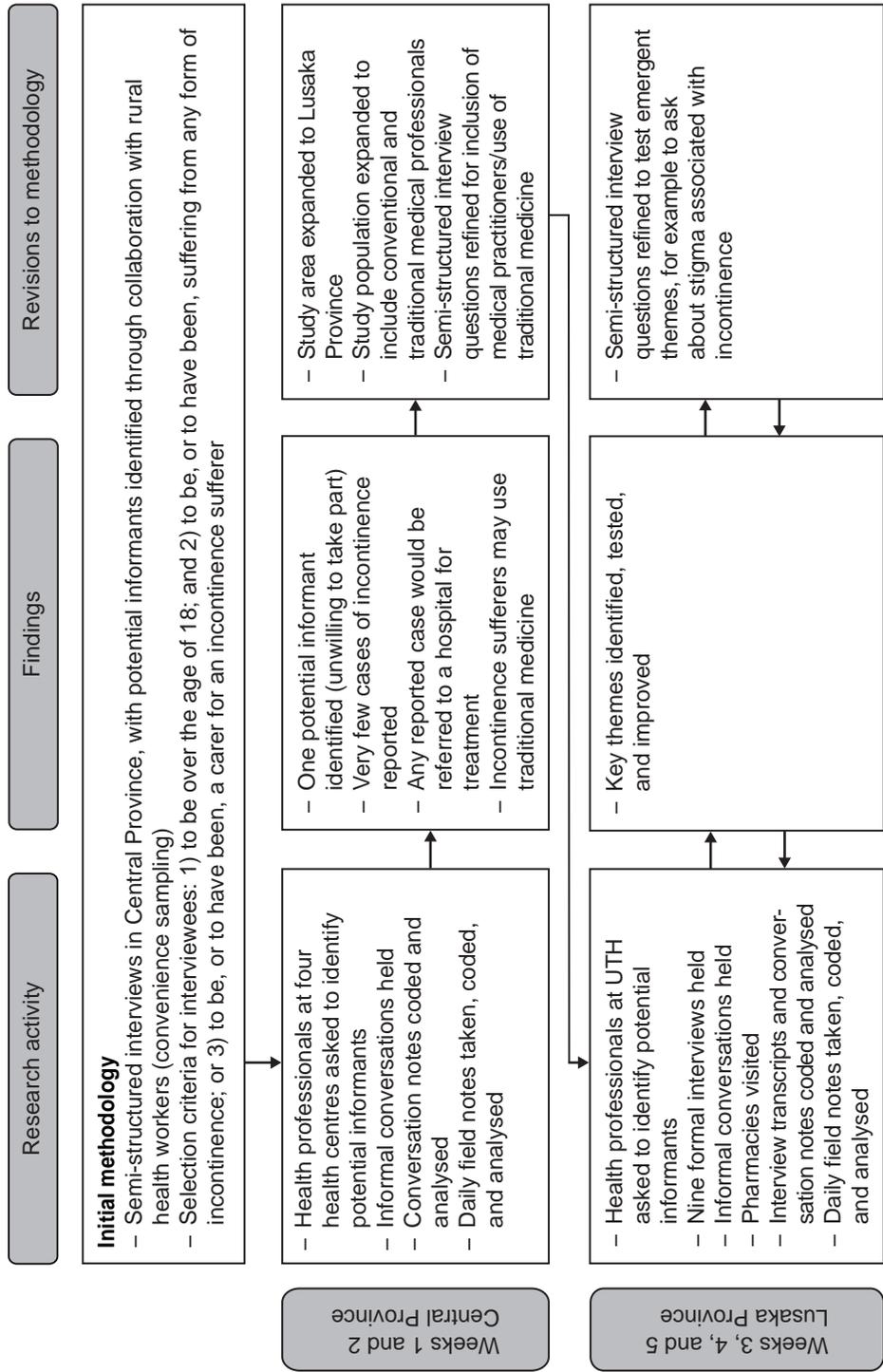


Figure 1 Iterative development of the methodology

Findings and discussion

'Incontinent? I hadn't heard before' (incontinence sufferer)

The term 'incontinence' was not commonly understood within the study population, including by those suffering from the condition or caring for those with the condition. Outside UTH, the term was not even recognized among medical professionals. Where it was not understood, the symptoms were explained using such terminology as 'loss of control' or 'involuntary passage' of urine or faeces. The condition was then usually recognized but often only in relation to obstetric fistulas and commonly referred to as 'leakage'.

'Incontinence is not an issue' (medical professional)

Incontinence as a stand-alone condition (that is, not due to an underlying illness) was not considered to be a medical issue for men or women by the health centre workers in Central Province. Of four rural health centres in the province serving a population of over 40,000, only one case of UI had been reported within memory; this was diagnosed retrospectively following conversations related to this study (tenure of the health centre workers varied from two to ten years). Incontinence as a stand-alone condition was also not perceived to be a common complaint by the traditional health practitioner interviewed, or by health workers at UTH, where incontinence patients not suffering from other conditions are seen only 'once in a while' (medical professional).

No cases of incontinence due to an underlying illness had been reported within memory at the rural health centres either. One health worker did remember that when previously working at a local hospital there were usually two or three incontinence patients per month: all of these patients were girls under the age of 16 suffering from incontinence as a consequence of an obstetric fistula. The traditional health practitioner noted that the majority of incontinence cases were seen in men, and were due to illnesses including prostate cancer. At UTH, most cases of incontinence were believed to be due to patients being bedridden as a result of an underlying illness (e.g., paralysis) or following surgery, although there was also usually one fistula case every one or two weeks. Incontinence (either as a stand-alone condition or due to an underlying illness) appears to be reported rarely, even at the community level, with one long-term (10 years plus) sufferer noting that they had not met anyone else with incontinence symptoms prior to being admitted to UTH.

Why might there appear to be so few incontinence sufferers in Zambia?

The lack of reported cases of incontinence both at rural health centres in Central Province and at UTH was surprising given that the literature suggests around a third of women who have given birth will suffer from the condition at some point (Walker and Gunasekera, 2011). It is possible that incontinence might not be a problem in Zambia. Some interviewees discussed the role of traditional marriage counsellors, known as *alangizi*, who hold counselling sessions for adolescent girls

before marriage. The education provided can cover, for example, sexual practices, home management, and health messages, and can include raising cervical cancer awareness (Kapambwe et al., 2013). It was suggested that a traditional emphasis on vagina tightening, consequently strengthening the pelvic floor muscles, could prevent or cure UI. It is unlikely, however, that such practices would reduce the prevalence of incontinence in Zambia seemingly to zero, resulting in a quandary over a lack of reported cases versus an expected prevalence.

It could be that incontinence as a stand-alone condition is not perceived by Zambians to be a medical issue, which may be a reflection of Zambian culture. Some interviewees suggested that a high level of resilience to pain and suffering is expected, particularly among women. Individuals who would therefore be medically diagnosed as incontinent may simply regard the symptoms as a challenge – among others – to be silently managed, perhaps in the same way that the menstrual cycle must be managed. However, a distinction must be made between mild (or intermittent, such as UUI or SUI) and severe (or constant) incontinence, as it is mild incontinence that appears not to be perceived as a medical issue. This could also be due to toilet habits and accessibility. For example, a SUI sufferer noted that management at home ‘wasn’t easy’, but ‘I was ok [because] I could get to the toilet’, and medical help was sought only for the persistent cough causing the SUI. UUI is likely to be considered more of an issue for sufferers who need time to find a toilet than for those who urinate in public and/or those who do not travel far from the household or community latrine; it is estimated that in 2015 only 25% of the population in rural Zambia had access to improved sanitation (versus 69% of the urban population), with 25% openly defecating (versus 1% of the urban population) (WHO/UNICEF JMP, 2017).

For those who recognize incontinence symptoms as an issue requiring medical treatment, many may not visit a health centre due to a lack of awareness that there are treatment options available. Interviewees noted that this was particularly true for those in rural areas and for obstetric fistula sufferers who ‘do not believe that anything can be done’ (medical professional).

Preferred management and treatment options may also explain the lack of reported incontinence cases. The one reported case of UI in Central Province had undergone six months of treatment using traditional medicine prior to visiting the rural health centre. This suggests that the successful treatment of incontinence at the community level results in a lack of disclosure to conventional medical centres. Some interviewees noted that, for a culture that places an emphasis on a woman being able to fulfil her traditional duties as a wife, priority would be given to resolving any issues that may negatively impact sexual relationships. A female sufferer’s first step in managing incontinence would therefore be to consult trusted female family and/or community members who would be able to offer advice on how best to treat the symptoms, and the healthcare path described by many included visiting either a religious adviser and/or a traditional medical practitioner before attending a conventional medical centre.

For both mild and severe incontinence as stand-alone conditions, the lack of reported cases may also be due to misdiagnosis. The one case of incontinence reported

in Central Province was initially treated as a urinary tract infection (UTI). It was only retrospectively re-diagnosed as UI after the health centre worker was reminded of the condition following questions related to this study. For incontinence that is the result of an underlying medical condition, the paucity of reported cases could be due to a lack of recognition of incontinence symptoms as a (priority) issue and/or a lack of full documentation of symptoms presented. The UI patient misdiagnosed with a UTI in Central Province claimed that the UI symptoms had been reported during a visit six months earlier. However, no record of such symptoms could be found and treatment was provided for a different medical condition, suggesting that the incontinence had not been recognized as an issue requiring separate treatment (which, in this instance, was necessary), or perhaps had not been seen as a priority given that health centres can be over-burdened.

A final explanation for the lack of reported cases is a reluctance to disclose: that is, those with incontinence suffer in silence.

The stigma associated with incontinence is 'a mixed picture' (medical professional)

Many study participants discussed a Zambian culture that was open to discussing rare and private issues, including obstetric fistulas. All those spoken to in Central Province therefore claimed that an incontinence sufferer would be willing to discuss their symptoms with someone (whether a family or community member, or a healthcare professional). Despite such claims, others regarded a lack of disclosure at both rural health centres and UTH as a reflection of the stigma associated with the condition; one interviewee noted that even the nurse in charge of a hospital ward may not know which patient is incontinent due to them disclosing to only one of their team of medical professionals.

There appear to be many myths and misconceptions about incontinence in Zambia, which can be viewed as 'supernatural' or a 'curse', so campaigns are in place to address this (e.g. Figure 2). Sufferers can therefore view themselves as 'abnormal' and 'less human' (medical professional) and can be ostracized by those who share this perception. As a result, few may disclose their suffering, even within their family.

The picture is mixed, however, and attitudes to incontinence seem to be dependent on an understanding of the cause. For male sufferers of UI and/or FI, both family and community members tend to be supportive as the incontinence is usually clearly the result of an underlying illness or injury: 'You can never feel embarrassed or disgusted by your own child having such a condition' (incontinence carer). Another male interviewee claimed that, although he had been embarrassed to discuss the SUI that he had suffered initially due to a cough, once it was clearly the result of paralysis (the illness progressed) there was no longer a need to be embarrassed. However, such a lack of embarrassment might not be applicable where it is believed that the cause of the incontinence is linked to sexual relations, which is a common opinion. The traditional medical practitioner noted that, as a man's 'happiness is dependent on virility', there is a lot of stigma associated with any sexual imbalance and/or dysfunction, therefore preventing disclosure.

FISTULA FOUNDATION
ZAMBIA

What is a fistula?

- Obstetric fistula is a hole between the vagina and bladder or rectum
- It is most often caused by prolonged obstructed labour when a woman labors for hours or days without medical intervention

What are the symptoms of fistula?

- A woman who has fistula leaks urine or feces continuously all day and night and she cannot stop it nor control it
- She wets or soils her clothes frequently and has a strong smell associated with the leaking

Fistula is stigmatizing

- Many women with fistula are isolated due to the shame caused by the condition
- Fistula is not a curse and women should be supported to seek treatment

Fistula can be treated

- Fistula can be treated by a trained doctor. You don't need herbs to cure fistula.
- A woman with fistula should seek medical care immediately at a hospital that offers fistula treatment services, including:
 - Chilonga Mission Hospital
 - Kabwe General Hospital
 - Mansa General Hospital
 - Monze Mission Hospital
 - University Teaching Hospital

Fistula Foundation supports women with fistula to be treated free of charge and pays for transport to and from the facility. Women with fistula will also receive essential items such as soap, chitenge, and body lotion.

After fistula repair, a woman can return to a normal life.

**Call this number for free screening and referral:
096 9 934410**

Figure 2 A fistula poster at University Teaching Hospital, Lusaka, Zambia

For women, incontinence can rarely be discussed freely, particularly when it is a result of childbirth and/or the cause is not understood. Again, this may be due to the condition being associated with sexual promiscuity, imbalance, and/or dysfunction. Support within the family can be variable: although many noted that parents tend to be supportive, the husband of the female sufferer interviewed left her due to the condition.

Home management is 'dependent on income' (medical professional)

Initially, incontinence sufferers tend to seek to manage the condition through concealment: all of those interviewed reported the use of disposable pads and/or reusable cloths by sufferers, with both found to be effective. A sufferer does not need to disclose the condition to use incontinence aids and products such as disposable diapers, although the ability to purchase such items discreetly may be appreciated.

Such aids and products can be found in pharmacies and supermarkets in Zambian towns (as witnessed in Lusaka and Kafue) and include the South African brands Active and National Pride (Figure 3).

Choice was dependent on the ability to afford and access incontinence products and/or washing powder. The Clemens 14 pull-up briefs with super absorbency (Figure 3) are priced at 229.99 kwacha (around US\$1.80) for each pair of briefs; this compares to a 2015 adjusted net income per capita of \$2.65 per day in Zambia (World Bank, 2017). The affordability of incontinence products can therefore be limited, particularly as the incontinence sufferers and carers of incontinence sufferers interviewed could no longer work due to the condition. Even a hospital may struggle to maintain a supply of incontinence products, with one sufferer interviewed noting that their only complaint about having to use a diaper was that ‘sometimes they do finish [run out]’.

For those who cannot afford disposable products, management is often dependent on the use of reusable cloths (in a manner similar to the management of the menstrual cycle). Maintaining a sufficient level of hygiene and an acceptable level of smell when using cloths can be a challenge. This was not found to be due to the unavailability of water, even though in 2015 only 61.2% of the Zambian population had access to an improved source of drinking water within 30 minutes, and only 44.4% had access in rural areas (WHO/UNICEF JMP, 2017). Instead, the challenge



Figure 3 Incontinence products from a Pick'n'Pay supermarket, Lusaka, Zambia

appears to be the ability to purchase soap powder. One carer interviewed noted that: 'I just don't like it when we run out of money to buy washing powder and only use water. In this case the beddings usually have a bad smell.' A lack of sufficient cleanliness can also result in recurrent bowel and urinary tract infections.

In those cases where a high level of stigmatization prevents disclosure by incontinence sufferers, management may be focused on concealment and possibly restricting their intake of water; this was also reported to be a common coping strategy for sufferers of UI. The use of community support groups as a coping strategy was also discussed by one interviewee familiar with the work of the Fistula Foundation. It was claimed that these groups form as sufferers look for 'people less human than them' (medical professional). Such groups can help break down the stigmatization associated with the condition, which will have many benefits, including encouraging disclosure to medical professionals in order to seek treatment.

***For those who do disclose, 'it is a long process to reach hospital'
(medical professional)***

A health worker at UTH claimed that around 80% of the Zambian population use traditional medical practitioners. In the one case of UI reported in Central Province, the patient had undergone six months of treatment using traditional medicine prior to visiting the health centre, and one sufferer interviewed mentioned trying a traditional treatment prior to visiting a conventional medical centre. It was unclear what this treatment had entailed, however, and the traditional practitioner consulted in this study advised that all cases of incontinence would need to be referred to a health centre.

Suggested traditional treatment methods included prayers, the ingestion of herbs, the topical application of herbs, insertion of the same herbs that are used to dry vaginas prior to having sexual intercourse, and the use of iced salt baths post-birth. The insertion of herbs can result in infections (Phiri, 2016), and in conventional medicine ice baths and cleansing with warm salt water can be recommended to help care for the perineum post-birth but are not recognized as a treatment for incontinence.

Multiple reasons were provided for preferring to visit traditional medical practitioners before seeking conventional treatment. The strongest were: proximity (reducing transportation costs and the time needed to make a visit); the ability to pay using a bartering system; and a lack of awareness of conventional treatment options, as traditional practices are well-known and traditional medical practitioners have the funds to advertise. One conventional medical practitioner interviewed believed that the 'holistic service' offered by traditional medical practitioners was also a driving factor: that is, they have the time to listen and will offer treatment for most health conditions. In contrast, a hospital visit will probably require long waiting times, appointments with several doctors and nurses across multiple departments, and rushed conversations requiring the repetition of embarrassing details.

The two sufferers interviewed who had initially used traditional medicine turned to conventional practices after it was clear that traditional approaches were not working. Unfortunately, there are limited treatment options available in rural health centres; all four of the rural health centres in Central Province stated that, should there be any reported cases of incontinence, they were ill-equipped to treat the condition. This reflects the fact that the rural health workers associated incontinence with obstetric fistula, for which surgery is the necessary treatment.

There are more treatment options available at UTH, including physiotherapy (although this is believed to be effective only for young patients), surgery (seemingly limited to the repair of fistulas), and pessaries for those who are too frail for surgery. The use of pharmacological interventions was not reported. The provision of emotional support for those suffering from incontinence and for their carers was found to be limited and provided only by the patient's doctor subject to time constraints. In terms of preventing incontinence, health workers at UTH noted that, although antenatal care can play a role in reducing the incidence of UI post-birth, pelvic floor exercises (known as Kegel exercises in Zambia) are not advised systematically.

For those requiring hospital treatment, many noted that a lack of transportation limits accessibility for patients: for example, the closest hospital to the Malombe health centre, located in Central Province, is Litete, which is a 60-kilometre round trip. One medical professional interviewed claimed that even outreach programmes 'struggle to reach patients', as the areas served are so vast. Accessibility to hospital treatment can therefore be limited by affordability, particularly if patients require repeat visits to, for example, replace pessaries or undergo further surgery. For such reasons, even those who have disclosed to conventional medical practitioners may continue to also use traditional approaches as they seek to manage their condition.

Interviewee suggestions to improve the quality of life for incontinence sufferers and carers in Zambia

Some medical practitioners interviewed believed that the medical service for incontinence sufferers has 'moved a step further' in Zambia in recent years, which has resulted in fewer incontinence cases being reported at UTH. Improvements in provincial care were cited as the reason for this, including better training provided to rural health workers and more specialists located in rural areas or visiting them via outreach programmes. All those interviewed believed that the service could be improved further, however.

It was widely felt that increasing awareness of the condition, including both the causes and the treatment options available, is a necessary first step to improving the quality of life of incontinence sufferers and carers. It is hoped that, by increasing such awareness, the stigma associated with the condition will be lessened and sufferers will no longer perceive that nothing can be done to treat their symptoms. Disclosure levels would then rise and sufferers would be a step closer to receiving the treatment needed.

Increasing awareness will take time, however; as one conventional medical practitioner interviewed noted: 'It needs to come with positive change'. Given the limitations of the care that can be provided by rural health centres, despite recent improvements, this doctor believed that the continuation and expansion of outreach programmes and the subsequent (successful) surgery performed by 'flying doctors' have a crucial role to play in changing perceptions.

Traditional medical practitioners could also have a role. The traditional medical practitioner consulted believed that all cases of incontinence should be referred to conventional medical centres as there was little that traditional medicine could do to improve symptoms. Yet some interviewees described trying traditional approaches for a period of time before realizing that it wasn't working and subsequently turning to conventional medicine. Other sufferers may simply give up at this stage of the care pathway. Encouraging traditional medical practitioners to refer incontinence cases to conventional medical centres rather than prescribe treatment that cannot result in a positive change would therefore also help reduce perceptions that nothing can be done.

Some of the struggles that sufferers face, even once they do disclose, are reflective of systemic issues within the wider conventional healthcare system, specifically a lack of accessible hospital care.

Implications for further research and programming

This article is an exploratory study into some of the coping mechanisms of incontinence sufferers and carers in Zambia. It is anticipated that the findings will be used to guide questions for further research and the development of future water, sanitation, and hygiene (WASH) and health programmes that address incontinence. We recommend an exploration of the myriad themes identified as being important to improvements in incontinence care: a lack of awareness of it as a medical issue, particularly by sufferers and rural health workers; the stigma, particularly for women; the affordability of management, particularly of cleaning products and the cost of travel to urban centres; and the preference for traditional medicine and sexual counselling.

Due to the small size of the study, we do not make specific suggestions for WASH and health practitioners working in Zambia (or elsewhere), but instead hope that this work highlights the need to collaborate across the sectors. For example, a WASH programme may provide additional soap for sufferers in humanitarian disasters or low-resource contexts, but the life of the sufferer could be significantly improved if this were paired with appropriate medical treatment. Furthermore, collaborations between WASH and health practitioners will assist in ensuring that no harm is done in attempts to help sufferers: for example, the provision of inappropriate pads by WASH practitioners (or others), particularly to bed-ridden sufferers, may promote bacterial infections. Although WASH practitioners have a role to play in addressing incontinence, health practitioners may be required to advise on management strategies in some contexts.

Study limitations that could be addressed in future work

The study was designed to interview participants to gather sensitive personal and confidential data, and therefore it was deemed to be most ethically appropriate to collaborate with conventional medical professionals to identify potential interviewees. This limited the number of potential interviewees to those who had disclosed current incontinence symptoms to medical professionals. The study found a high level of stigmatization associated with incontinence and subsequently a low level of disclosure, particularly of mild incontinence symptoms. The study also found evidence that incontinence sufferers use community support groups and can receive treatment at the community level. It is therefore recommended that future studies collaborate with such community support groups to identify potential interviewees who may not have disclosed current or historic incontinence symptoms to conventional medical professionals, ensuring that an ethical approach is used.

A low level of disclosure at rural health centres within Central Province resulted in the study having to collaborate with medical professionals at UTH to identify potential interviewees. This further limited potential interviewees to those who: 1) had disclosed incontinence symptoms that were severe enough to require hospital treatment from conventional medical professionals; or 2) had incontinence symptoms as a consequence of another illness that was severe enough to require hospital treatment. Note that those patients who had incontinence as a result of hospital treatment, for example due to being bed-ridden, were excluded from the study as the incontinence was being managed by the hospital. This limited the depth of analysis that defines a qualitative study, as only the coping strategies of severe incontinence sufferers (as opposed to mild incontinence sufferers) have been well-understood. It is recommended that future studies look at a larger study area and collaborate simultaneously with community groups, rural health centres, and hospitals to increase the sample size.

Conclusion

The term 'incontinence' is not commonly understood in Zambia, and the condition is rarely reported. A likely explanation for this is a reluctance to disclose due to the stigma associated with the condition, with attitudes to incontinence seemingly influenced by perceptions about causation. For those who are reluctant to disclose, management is limited to concealment, with the method used (disposable versus reusable products) determined by income levels. For those who do disclose, the treatment received is dependent on accessibility, which in turn is also largely a function of affordability. The first step in treatment is usually a traditional medical practitioner, mainly due to proximity and the ability to pay using a bartering system. Some will eventually turn to conventional approaches, with treatment available in Zambia limited to pessaries, physiotherapy, and surgery. If the global community is to improve the experiences of incontinence sufferers and carers, ultimately contributing to the achievement of universal sanitation and well-being, WASH and health practitioners will need to collaborate to conduct further studies

and programmes that increase awareness, address stigmas, and improve the accessibility and affordability of management and treatment.

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