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Incontinence in Zambia: Understanding the coping strategies of sufferers and carers

Supervisor: Dr Dani Barrington
September 2017

This thesis is submitted in partial fulfilment of the requirements for the degree of MSc Community Water and Sanitation

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GRAPHICAL ABSTRACT

1: Incontinence appears to be rare
   - Not a problem
   - Perceptions
   - Mid-diagnosis not recognised
   - Community-Level treatment

2: Associated stigma is a mixed picture
   - VS

3: Coping strategies are limited by income
   - Money
   - Leaf

4: Treatment is determined by accessibility
   - Hospital

Incontinence in Zambia
ABSTRACT

Incontinence is a prevalent worldwide healthcare challenge which significantly impacts upon the quality of life of both sufferers and carers. Simple behavioural changes and technologies can bring dramatic improvements for those who suffer from the condition, but for them to be successful first requires an understanding of local challenges. There is very little information on the management of incontinence in low income settings, and this study aims to reduce that knowledge gap by providing an understanding of the coping strategies used by sufferers and carers in Zambia.

Semi-structured interviews with a range of adult stakeholders were held in the Central Province and Lusaka Districts of Zambia to obtain in-depth, qualitative information. As it was not possible to determine a population of current and historic incontinence sufferers convenience sampling was used. Daily field notes, informed by a number of informal conversations held with a variety of informants, were also analysed and used to inform the findings.

The study found that the term ‘incontinence’ was not commonly understood within the research population, and that the condition is rarely reported to medical professionals. The most likely explanation for a lack of reported cases is a reluctance to disclose due to the stigma associated with the condition, with attitudes to incontinence largely influenced by perceptions about causation. The incontinence care process in Zambia is subsequently limited, and both coping strategies and treatment received are determined by affordability and accessibility.

Incontinence care is likely to remain limited until the stigma associated with the condition is addressed. Raising awareness is key, as successfully dispelling myths and misconceptions would encourage the development of treatment pathways for sufferers and support systems for carers, and stimulate the innovation needed to improve the daily management of the condition.

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I would also like to thank the IMPRESS Network, and in particular Dr Peter Culmer, for providing various opportunities to share the findings of this study with a wide audience to raise awareness of incontinence needs in low and lower-middle income countries.

Finally, and most importantly, I especially thank the many stakeholders who participated in both interviews and conversations for sharing their thoughts and experiences. Without you, this study would not have been possible.
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<td>Demographic and Health Survey</td>
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<td>Faecal incontinence</td>
</tr>
<tr>
<td>ICS</td>
<td>International Continence Society</td>
</tr>
<tr>
<td>K</td>
<td>Zambian kwacha</td>
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<tr>
<td>GNI</td>
<td>Gross national income</td>
</tr>
<tr>
<td>LICs</td>
<td>Lower income countries</td>
</tr>
<tr>
<td>LMICs</td>
<td>Lower-middle income countries</td>
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<td>MoH</td>
<td>(Zambian) Ministry of Health</td>
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<tr>
<td>MUI</td>
<td>Mixed urinary incontinence</td>
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<td>SUI</td>
<td>Stress urinary incontinence</td>
</tr>
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<td>UI</td>
<td>Urinary incontinence</td>
</tr>
<tr>
<td>UNFPA</td>
<td>United Nations Population Fund</td>
</tr>
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<td>US$</td>
<td>United States dollars</td>
</tr>
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<td>UTH</td>
<td>University Teaching Hospital (Lusaka, Zambia)</td>
</tr>
<tr>
<td>UTI</td>
<td>Urinary tract infection</td>
</tr>
<tr>
<td>UUI</td>
<td>Urgency urinary incontinence</td>
</tr>
<tr>
<td>WASH</td>
<td>Water, Sanitation and Hygiene</td>
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<td>WHO</td>
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Incontinence in Zambia: Understanding the coping strategies of sufferers and carers

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ABSTRACT

Incontinence is a prevalent worldwide healthcare challenge which significantly impacts upon the quality of life of both sufferers and carers. Simple behavioural changes and technologies can bring dramatic improvements for those who suffer from the condition, but for them to be successful first requires an understanding of local challenges. There is very little information on the management of incontinence in low income settings, and this study aims to reduce that knowledge gap by providing an understanding of the coping strategies used by sufferers and carers in Zambia.

Semi-structured interviews with a range of adult stakeholders were held in the Central Province and Lusaka Districts of Zambia to obtain in-depth, qualitative information. As it was not possible to determine a population of current and historic incontinence sufferers convenience sampling was used. Daily field notes, informed by a number of informal conversations held with a variety of informants, were also analysed and used to inform the findings.

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strategies and treatment received are determined by affordability and accessibility.

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Word count: 7,990

Keywords: Fistula; Hygiene; Low income; Lower-middle income; Sanitation
1 INTRODUCTION

Incontinence is a prevalent worldwide healthcare challenge which significantly impacts upon 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, Hay-Smith and Habée-Séguiin 2014). Translating such methods for managing incontinence to low income settings would benefit resident sufferers and carers, but to do so requires an understanding of local challenges to inform and drive effective innovation.

There is a paucity of information on the management of incontinence in low income settings (Hafskjold et al. 2016). This study aims to reduce the knowledge gap by providing an understanding of the coping strategies used by sufferers and carers in Zambia. The study also specifically aims to identify key stakeholders and define their roles in the incontinence care process; investigate synergies with other public health issues, particularly menstrual hygiene management, maternal health and others identified within the Water, Sanitation and Hygiene (WASH) sector; and identify gaps in the provision of incontinence management, particularly where an engineering innovation could make an improvement to the quality of lives of sufferers and carers.

1.1 Definitions

The International Continence Society (ICS) defines faecal incontinence (FI) as an involuntary loss of faeces, which can present in different forms, including passive or urge faecal leakage (ICS 2016). Urinary incontinence (UI) is defined as an involuntary loss of urine (Haylen at 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 complaint of involuntary loss of urine associated with urgency (Haylen at al. 2012).
SUI is uncommon in men, and the ICS estimates that around 30% of women with incontinence have mixed urinary incontinence (MUI), defined as the complaint of involuntary leakage associated with urgency and also with physical exertion, effort, or on sneezing or coughing (ICS 2013, ICS 2017, Haylen at al. 2012). For the purposes of this study, incontinence is defined as the involuntary loss of urine and/or faeces.

1.2 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 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, Stewart and Wood 2008).

The vast majority of studies that have attempted to estimate the prevalence of incontinence focus on populations in high income settings, and there are wide variations in findings. 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%; in men a UI prevalence of 1% to 39% (increasing with age) have been published; and FI frequencies in adults tend to be 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 LMICs1), and found that of 83,000 parous (have given birth) women surveyed the mean prevalence of UI was 28.7%, and of 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. In Zambia the total fertility rate is 5.7 children per woman, compared to an African average of

1 LICs are defined as those with a gross national income (GNI) per capita of $1,005 or less in 2016; LMICs are defined as those with a GNI per capita between $1,006 and $3,955 (World Bank 2017a).
5.2 children and a global average of 3.0 children (WHO 2017). Rates of antenatal care coverage and births attended by skilled health personnel are higher than the African average: 55.5% of women have at least four antenatal visits as recommended by the World Health organisation (WHO) (versus 54% in Africa and 64% globally), and 63.3% of births are attended by skilled health personnel (versus 53.1% in Africa and 77.7% globally) (WHO 2017).

The prevalence of incontinence is likely to be high in Zambia as pregnancy, labour and vaginal deliveries are established risk factors for UI and FI (Wood and Anger 2014, Walker and Gunasekera 2011). Regular heavy physical work has also been identified as a risk factor for UI, and 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). Irwin et al. estimate that by 2018, 40.5 million people will be affected by UI in Africa (7.3 % of the population, up from 31 million in 2008) (Irwin et al. 2011). Applying this percentage to the 2016 Zambian population of 16.6 million suggests that at least 1.2 million people will be affected by urinary incontinence by 2018 (World Bank 2017b).

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, Mahon and Cavill 2012). The World Health Organisation (WHO) estimates up to 100,000 new cases per year (with rare incidence in high-income countries) and this is likely to be a gross underestimate given the stigma surrounding the condition (Semere and Nour 2008).

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; and that of 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 around 38,400 will experience fistula-like symptoms, although the United Nations Population Fund (UNFPA) reported that 208 Zambian women with obstetric fistula were repaired in 2016 (World Bank 2017b, UNFPA 2017).

1.3 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 at al. 2005). The most recent study calculated the direct costs of incontinence for men and women over the age of 18 in the United States at US$19.5 billion (in 2000 US dollar terms, Hu et al. 2004). The majority of direct costs are classified as routine care, which includes absorbent pads and laundry expenses. A study of 293 female UI sufferers in the United States found that the weekly cost of UI for women ranges from US$1 to US$20, increasing with frequency, severity, and UUI versus SUI (Subak et al. 2006). To the author’s knowledge, no similar studies in LICs or LMICs have been conducted.

‘Indirect’ costs are defined as the value of lost productivity or employment due to morbidity and mortality (Hu at al. 2005). Such costs are difficult to calculate, as are the ‘intangible’ costs defined as the monetary value of pain and suffering (Hu at al. 2005). Incontinence can have a profound personal impact on sufferers and carers. Associations between UI and both depression and anxiety have been found, with the psychological impact of FI believed to be greater (Miner 2004). Quality of life can also be impacted by, for example, diminished self-esteem (due to feeling a loss of control and/or issues related to cleanliness which can be accompanied by isolation), and an inability to undertake daily activities and partake in social relationships (Hafskjold et al. 2016).

Little is known about the implications of living with incontinence for sufferers and carers in LICs and LMICs (Hafskjold et al. 2016). The few studies that have been completed found that the personal consequences of incontinence are often more severe than for those 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).

1.4 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 or pads, disposable diapers, reusable/washable diapers, reusable pull-up pants and bedpans, can be used to control symptoms. However, although these can commonly be found in higher-income countries, availability and/or affordability may be restricted in LICs and LMICs (Giles-Hansen 2015).

There are a number of possible interventions to improve the prevention and management of incontinence, but 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, Drutz and Al-Badr 2003). Reasons included embarrassment, fear of alienation, a belief that UI is a normal part of the aging process, and a lack of knowledge about or expectation of the treatment options available (Minassian, Drutz and Al-Badr 2003).

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: a systematic review of sufferers with UUI, SUI and MUI found that pelvic floor muscle training should be included in first-line conservative management programmes for women with UI (Dumoulin, Hay-Smith and Habée-Séguin 2014). If unsuccessful, treatment can progress to pharmacological interventions and also to surgery, but again availability and/or affordability may be restricted in lower-income countries (Wood and Anger 2014).
2 MATERIALS AND METHODS

The study was conducted in Zambia in June and July 2017. The initial research plan was to hold semi-structured interviews with male and female adult (aged 18 and over) incontinence sufferers and carers in Central Province. 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 collaboration with medical practitioners at 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 2). Although these did yield valuable information on Zambian culture, and 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 also refined.

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 1), and informal conversations also continued with a variety of stakeholders (Table 2). The semi-structured interview questions were refined as more knowledge became available, and daily field notes were also taken throughout the study period (Figure 1).
Figure 1 Iterative development of the methodology

Table 1 Semi-structured interviews held

Note: Residential location shown. M=male. F=female.

<table>
<thead>
<tr>
<th>Incontinence sufferer</th>
<th>Carer of an incontinence sufferer</th>
<th>Medical professional</th>
<th>Total</th>
</tr>
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<tbody>
<tr>
<td></td>
<td>M</td>
<td>F</td>
<td>M</td>
</tr>
<tr>
<td>Copperbelt Province</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lusaka Province</td>
<td>1</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Southern Province</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 2 Informal conversations held

<table>
<thead>
<tr>
<th>Zambia resident (female)</th>
<th>Zambia resident (male)</th>
<th>Medical professional</th>
<th>Pharmacist</th>
<th>Academic</th>
<th>NGO worker</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Central Province</td>
<td>1</td>
<td>6</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Lusaka Province</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>7</td>
</tr>
<tr>
<td>Total</td>
<td>1</td>
<td>2</td>
<td>8</td>
<td>1</td>
<td>2</td>
<td>15</td>
</tr>
</tbody>
</table>

2.1 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 interviewee. A research collaborator familiar with Zambian culture and fluent in Nyanja assisted with the data collection, and an interpreter was also used when
necessary. For those interviewees providing personal and confidential information, an Informed Consent Form (Appendices A, B and C) was read out loud which 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 to English if required.

2.2 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 summarise 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 (Corbin and Strauss 2008, Gjerde et al. 2013).

Table 3 Codes system used

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

2.3 Ethics

Ethical approval for the study was obtained from the Cranfield University Human Research Ethics Committee (CUHREC), United Kingdom (3499 and 4231), the Excellence in Research Ethics and Science (ERES) Converge Institutional Review Board, Zambia (2017-June-033) and the Ministry of Health (MoH), Zambia (no number provided but proof of approval is available on request).
3 RESULTS

3.1 “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 of UTH, the term was not even recognised amongst 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 (or stools). The condition was then usually recognised but often only in relation to obstetric fistulas and commonly referred to as ‘leakage’.

3.2 “Incontinence is not an issue” (Medical professional)

Incontinence as a standalone 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 the Central Province District. Of four rural health centres in the district serving a population of over 40,000, only one case of UI had been reported within memory which was diagnosed retrospectively following conversations related to this study (tenure of the health centre workers varied from two to ten years). Incontinence as a standalone 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. One interviewee familiar with the work of the Fistula Foundation in Zambia commented that although social workers were identifying obstetric fistula patients in the Northern Province, they were not finding many. 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 (for example, paralysis) or following surgery, although there was also usually one fistula case every one or two weeks. Incontinence (either as a standalone condition or due to an underlying illness) appears to be rarely reported even at the community level, with one long-term (ten-years plus) sufferer noting that they had not met anyone else with incontinence symptoms prior to being admitted to UTH.

3.3 The stigma associated with incontinence is “a mixed picture” (Medical professional)

Many 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 (be it 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. This stigma has even been recognised by the MoH as an issue. In 2014, the MoH in collaboration with UNFPA conducted a study to track the prevalence of UI in post-obstetric fistula surgery patients. An associated aim of the study was to understand the stigma surrounding incontinence as a means to inform a public health programme to dispel myths and misconceptions associated with the condition.

3.4 Home management is “dependent on income” (Medical professional)

All of those interviewed reported the use of both disposable pads and reusable cloths by sufferers, with both found to be effective. Choice was dependent on the ability to afford and access incontinence products and/or washing powder. Affordability levels were noted to be low as the incontinence sufferers and the carers of incontinence sufferers interviewed could no longer work due to the condition. For the female sufferer, incontinence symptoms are managed in the same way that the menstrual cycle is managed (being the income-dependent
use of pads or cloths). Restricting the intake of water was also reported to be a common coping strategy for sufferers of UI. A lack of water supply to maintain hygiene levels was not found to be an issue.

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 stigmatisation associated with the condition which will have many benefits, including encouraging disclosure to medical professionals to seek treatment.

2.5 For those that 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. Reasons for this include proximity and the ability to pay using a bartering system. Of the one case of UI reported in the Central Province district, the patient had undergone six months of treatment using traditional medicine prior to visiting the health centre and one sufferer interviewed noted 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 advised that all cases of incontinence would need to be referred to a health centre.

All four of the rural health centres in the Central Province district stated that should there be any reported cases of incontinence, they were ill-equipped to treat the condition. This was based on the assumption that a patient would require surgery and would therefore need to be referred to a hospital. There are more treatment options available at UTH which include physiotherapy (albeit this is only believed to be effective for young patients), surgery (seemingly limited to the repair of fistulas) and pessaries for those that are too frail for surgery. The use of pharmacological interventions was not reported. As referral is usually a long process and visiting a hospital requires long travel times for many, accessibility can be limited.
It was noted that for obstetric fistula sufferers, incontinence was one of many issues faced including vaginal infection (resulting in painful sexual intercourse), nerve pressure injuries, pelvic inflammation, infertility and the emotional distress associated with losing a baby. However, the provision of emotional support for obstetric fistula patients, and indeed all those suffering from incontinence and 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 there is a role to play for antenatal care in reducing the incidence of UI post-birth, pelvic floor exercises (known as Kegel exercises in Zambia) are not systematically advised.
4 DISCUSSION

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

Obstetric fistulas (and associated incontinence) are more likely to occur in young girls that do not have sufficient medical assistance during delivery. Few reported cases would be expected at rural health centres in the Central Province District as a) nationally less than 1% of women aged 15 to 49 years report experiencing fistula-like symptoms (Central Statistical Office 2015); b) traditional birth attendants are advised to refer all births to health centres; and c) it is the policy of rural health centres to refer all under-18 births to the local hospital. Unfortunately obstetric fistula cases do still occur: UTH reported one fistula case every one or two weeks and a surgeon that takes part in an outreach programme to repair obstetric fistula damage noted that there were 100 patients waiting for treatment across Zambia (as at mid-July 2017).

The lack of reported cases of incontinence at both rural health centres in the Central Province District and at UTH was surprising given that the literature suggests around a third of parous women 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 spoken to discussed the role of traditional marriage counsellors, known as alangizi, who hold counselling sessions for adolescent girls before marriage. The education provided can include, for example, sexual practices, home management and health messages including raising cervical cancer awareness (Kapambwe et al. 2013). It was suggested that a traditional emphasis on vagina tightening, and 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 to seemingly zero, resulting in a quandary of a lack of reported cases versus an expected prevalence.

It could be that incontinence as a standalone condition is not perceived by Zambians to be a medical issue, which may be a reflection of Zambian culture. Some spoken to suggested a high level of resilience to pain and
suffering is expected, particularly by women. Individuals that would therefore be medically diagnosed as incontinent may simply regard the symptoms as an(other) challenge to be silently managed, perhaps in the same way 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 to not 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 felt to be more of an issue for sufferers that need time to find a toilet than for those that urinate in public, and/or those that 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 that recognise 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 care pathways may also explain a lack of reported incontinence cases. The one reported case of UI in the Central Province District 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 spoken to 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 that would be able to advise how best to treat the symptoms, and the healthcare
path described by many included either a religious advisor and/or a traditional medical practitioner before visiting a conventional medical centre.

For both mild and severe incontinence as standalone conditions, a lack of reported cases may also be due to misdiagnosis. The one case of incontinence reported in the Central Province District 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, a 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 the Central Province District claimed that the UI symptoms had been reported during a visit six months earlier. No record of such symptoms could be found and treatment was provided for a different medical condition, suggesting that the incontinence had not been recognised as an issue requiring separate treatment (which in this instance was needed), or perhaps as a priority given that health centres can be over-burdened.

A final explanation for the lack of reported cases, and the most likely, is a reluctance to disclose. That is, those with incontinence suffer in silence. Many claimed a Zambian culture that does not shy away from discussing even the most private and rare health issues, but this may not seem to apply to incontinence.

4.2 How stigmatised is incontinence in Zambia?

One interviewee noted that there was such a stigma in Zambia associated with incontinence 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. This is attributable to a high level of embarrassment associated with the condition. There do appear to be many myths and misconceptions about incontinence in Zambia, which can be viewed as ‘supernatural’ or a ‘curse’ (Figure 2). Sufferers can therefore view themselves as “abnormal” and “less human” (Medical professional,) and can be ostracised
by those that 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 they had been embarrassed to discuss the SUI 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 may also not be applicable where it is believed that the cause of the incontinence is related 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, preventing disclosure.

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

4.3 Why does income determine coping strategies?

It was found that initially all incontinence sufferers will seek to manage the condition through concealment. A sufferer does not need to disclose the condition to use incontinence aids and products such as disposable diapers, although the ability to purchase 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).

Affordability is limited however. The Clemens 14 pull-up briefs with super absorbency shown in Figure 3 are priced at K229.99, or around US$1.79 for each pair of briefs, which compares to a 2015 adjusted net income per capita (current US$) of US$2.65 per day in Zambia (World Bank 2017b). Even a hospital may struggle to maintain a supply of incontinence products, with one sufferer interviewed noting that their only complaint with regards to having to use a diaper was that “sometimes they do finish [run out]”.

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In those cases where a high level of stigmatisation prevents disclosure by incontinence sufferers, management will be limited to concealment. Those with a low income (or no income if forced to stop working due to the condition, as for the sufferers and carers interviewed) are likely to therefore be more affected by a reluctance to seek treatment than those that can afford both disposable incontinence products and the transport to purchase them. For those that cannot afford disposable products, management is 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 an availability 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% in rural areas (WHO/UNICEF JMP 2017). Instead the challenge is 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.

4.4 Why do rural patients use traditional medical practitioners?

Suggested traditional treatment methods included prayers; the digestion 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. It should be noted that 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 recognised as a treatment for incontinence.

Multiple reasons were provided for a preference 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 whereas traditional practices are well-known and practitioners also have the funds to advertise. One conventional medical practitioner interviewed believes 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 conditions suffered. This compares to a hospital visit that will most likely 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 that 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, as the rural health workers spoken to believe that incontinence can only be treated by surgery, which must be conducted at a hospital. This is a reflection of the association (and known occurrence) of incontinence with obstetric fistula, for which surgery is the necessary treatment. 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 the Central Province district 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 due to, for example, pessary replacement or further surgery. For such reasons, even those that have disclosed to conventional medical practitioners may continue to also use traditional approaches as they seek to get better.

4.5 What can be done to improve the quality of life for incontinence sufferers and carers?

Some medical practitioners interviewed believed that the medical service for incontinence sufferers has “moved a step further” in Zambia in recent years, which was reflected in fewer incontinence cases being reported at the hospital. Improvements in provincial care were cited as the reason, including better training provided to rural health workers and there being more specialists located in, or visiting (via outreach programmes), rural areas. All spoken to however believed that the service could be improved further.

It was widely felt that increasing awareness of the condition, including both the causes and 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. As such, disclosure levels would rise and sufferers would be a step closer to receiving the treatment needed. Dispelling myths and perceptions associated with the condition will also provide further benefits for incontinence sufferers and carers, and opportunities for many. These include the development of sustainable and scalable businesses to manufacture and distribute locally produced, affordable and environmentally-friendly incontinence products and aids, as seen in menstrual hygiene management (House, Mahon and Cavill 2012).
Documentaries have been shown in Zambia by the MoH, UNFPA and the Fistula Foundation to raise awareness regarding obstetric fistulas as part of the global Campaign to End Fistula launched by UNFPA and partners in 2003. Widening the focus of such documentaries to include incontinence caused by other factors is recommended. Increasing awareness will take time however, and as one conventional medical practitioner interviewed noted, “it needs to come with positive change”. Given the limitations to 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’ therefore have a crucial role to play in changing perceptions.

Traditional medical practitioners 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. However, some interviewees described trying traditional approaches for a period of time before realising 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 to 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, most specifically a lack of accessible hospital care. Addressing such issues are outside the scope of this paper. However, it could be possible to widen the care package available to sufferers and their carers. In the first instance, developing preventative care practices such as systematically including guidance to strengthen the pelvic floor as part of routine antenatal care could benefit women post-birth. Ensuring the inclusion of emotional support in treatment plans, for
both the sufferer and carers, could also improve the quality of life of those affected by the condition by, for example, establishing official support networks.

With regards to an engineering innovation that could make an improvement to the quality of lives of sufferers and carers, by understanding the difficulties that incontinence sufferers and carers face this study has revealed the key demands that an engineering innovation would need to satisfy. Affordability is critical and therefore reusability would be recommended to reduce the need for time, transportation (and the associated costs) and repurchasing costs. A further benefit of limiting the number of times that a purchase needs to be made is to reduce the opportunities for embarrassment. With reusability as a requirement, being able to clean the product becomes an issue, particularly given the struggles that many face to afford washing powder. Innovation within menstrual management, for example disinfection of products such as menstrual cups by using boiling water, could provide ideas to address this requirement.

On reflection, there is perhaps a larger role for pessaries to play in Zambia in managing mild incontinence cases for which surgery is not required. Although pessaries are currently prescribed, use is limited to those too frail for surgery. However, if a patient is capable of mastering self-management, distribution through community health workers (reducing embarrassment and increasing accessibility) and the ability to reuse through disinfection could be of benefit to both sufferers and carers. A reluctance to use pessaries is unlikely to be an issue, with one medical practitioner interviewed noting that patients were “more than happy to try anything”.

4.6 Limitations

The study was designed to interview human 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 potential interviewees to those that had disclosed current incontinence symptoms to medical professionals. The study found a high level of stigmatisation 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 that 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 the Central Province district resulted in the study having to collaborate with medical professionals at the University Teaching Hospital in Lusaka to identify potential interviewees. This further limited potential interviewees to those that had a) disclosed incontinence symptoms that were severe enough to require hospital treatment to conventional medical professionals, or b) had incontinence symptoms as a consequence of another illness that was severe enough to require hospital treatment. Note that those patients that 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.
5 CONCLUSIONS AND RECOMMENDATIONS

As there is little information on the management of incontinence in LICs and LMICs this study aimed to reduce the knowledge gap by providing an understanding of the coping strategies used by incontinence sufferers and carers in Zambia. The conversations held and the interviews conducted revealed that the term ‘incontinence’ is not commonly understood, and that the condition is rarely reported. The most likely explanation for a lack of reported cases is a reluctance to disclose due to the stigma associated with the condition, with attitudes to incontinence seemingly influenced by perceptions about causation. Further research is recommended at the community level to further understand perceptions of incontinence, with the findings used to inform the design and implementation of a national-level health promotion campaign to dispel myths and misconceptions associated with the condition, including treatment options available.

For those that are reluctant to disclose, management is limited to concealment with the method used (disposable versus reusable) determined by income levels. For those that do disclose, the treatment received is dependent on accessibility, which in turn is also largely a function of affordability. The first step in preferred care pathways is usually a traditional healer, mainly due to proximity and the ability to pay using a bartering system. Yet most will eventually turn to conventional approaches with treatment available in Zambia limited to pessaries, physiotherapy and surgery.

The study has highlighted key stakeholders in the incontinence care process; family members, community group leaders (including the *alangizi*), traditional healers and conventional medical practitioners (at both rural health centres and at hospitals). Unfortunately, the study has also found that these stakeholders are largely unaware of the incontinence care process, and therefore their role within it. This is fundamentally due to a lack of awareness about the condition, in terms of both its causation and the treatment options available. This subsequently limits the provision of incontinence management for those that overcome the first hurdle of disclosure, and particularly restricts diagnosis,
preventative guidance and emotional support. It is therefore recommended that culturally specific incontinence education and training materials for both diagnosis and treatment are designed and distributed to both conventional and traditional medical professionals. Other culturally appropriate groups, for example, the alangizi, should also be supported to integrate incontinence education into their messaging.

Parallels can be drawn between the challenges faced in managing incontinence and menstrual health, particularly given the similarities in associated stigma and coping strategies used. Should incontinence become the next frontier for humanitarian and development practitioners, there are many lessons that can be learned in both increasing awareness and encouraging innovative approaches to improve the quality of life for both sufferers and carers. By understanding the difficulties faced in managing the condition, this study has revealed the key demands that an engineering innovation would need to satisfy, namely affordability and reusability. But as found in menstrual health management, for innovation to flourish, stigma and taboo must first be dispelled. This would unlock treatment pathways and support their development, and it would also create opportunities to facilitate and improve the daily management of incontinence, for example, through the local manufacture of affordable and culturally appropriate products and aids.
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APPENDICES

A.1 Informed Consent Form for an Incontinence Sufferer located in Zambia

Principle Investigator: Claire Scott
Organization: School of Water, Energy and Environment, Cranfield University (United Kingdom)
Local Researcher: Mr Samuel Tembo (Plan International Zambia)
Project title: Incontinence in Zambia: Understanding the coping strategies of sufferers and carers

This Informed Consent Form has two parts:
1. An Information Sheet (to share information about the study with you)
2. A Certificate of Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form.

Information sheet

I am Claire Scott, a student at Cranfield University studying for an MSc in Community Water and Sanitation. I am doing research to understand the coping strategies for incontinence in low income countries like Zambia.

I am going to give you information and invite you to be part of this research. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research.

This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me or of another researcher.

Purpose of the research

Incontinence is a widespread worldwide healthcare challenge which impacts significantly on people’s quality of life, their health and their income.

Experiences show that simple technologies can bring dramatic improvements for those who endure daily life with this condition. However, there is a lack of information on incontinence in low income countries like Zambia. To determine if technologies could make an improvement to the lives of sufferers and carers in low income countries, first the local challenges of incontinence need to be understood.

The study would like to talk to incontinence sufferers and those that care for incontinence sufferers to understand their experiences of living with incontinence. These can include the challenges faced in managing incontinence, the support received to manage incontinence, and the support still needed.
Therefore, we would like to ask you some questions about your own experiences of managing long-term incontinence. Your answers may identify opportunities to improve the quality of life of incontinence sufferers.

Your participation in this study is entirely voluntary, and if you do not wish to take part that is fine. If you are willing to take part I will interview you with an interpreter present if required. The interview will take as much time as you are happy to talk to me for.

Interview process

The interview can take place in a location where you are comfortable and that will be confidential. An interpreter may be present if required, and you may also wish to have someone else present. I am asking you to share with me some very personal and confidential information, and you may feel uncomfortable answering some of the questions. You do not have to answer any question that you don’t wish to, and that is fine. You do not have to give me any reason for not responding to any question.

As a guide the questions could include:

- What does ‘incontinence’ mean to you?
- Can you tell me about when your incontinence started?
- Can you tell me how incontinence affects your everyday life?
- How do you manage your incontinence in your everyday life?
- What are the main challenges that you face in managing your incontinence?
- Can you tell me about the support and assistance that you have had for your incontinence?
- What type of assistance or support would you like to receive to help you manage your incontinence?

Your answers will remain confidential. A research paper will be published but names will not be used in communicating research findings and it will not be possible to link the answers back to you. I will only make handwritten notes of the interview if you give permission. I will only record the interview if you give permission. After the interview, handwritten notes will be kept in a locked room that only I have access to, and destroyed once converted into an electronic format. I am the only person that will keep an electronic copy of the notes and the recording of the interview (if applicable). These will be kept securely on a password protected computer for up to ten years. As the interview may take time, you will be reimbursed 100 kwacha for lunch expenses.

Contact Information

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Mobile: +44 7743 508 140

This proposal has been reviewed and approved by ERES Converge IRB, which is a committee whose task it is to make sure that research participants are protected from harm. If you wish to find out more about ERES Converge IRB, please contact 33 Joseph Mwilwa Road, Rhodes Park, Lusaka, Zambia (eresconverge@yahoo.co.uk / Mobile: +260 966 765 503)

Do you have any more questions?
Certificate of consent

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

Print Name of Participant: ______________________

Signature of Participant: ______________________

Date: ______________________
   Day/month/year

If required:

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness: ______________________

Signature of witness: ______________________

Date: ______________________
   Day/month/year

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands the purpose of the research and the interview process.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this informed consent form has been provided to the participant.

Print Name of Researcher/person taking the consent: ______________________

Signature of Researcher/person taking the consent: ______________________

Date: ______________________
   Day/month/year
A.2 Informed Consent Form for an Incontinence Carer located in Zambia

Principle Investigator: Claire Scott
Organization: School of Water, Energy and Environment, Cranfield University (United Kingdom)
Local Researcher: Mr Samuel Tembo (Plan International Zambia)
Project title: Incontinence in Zambia: Understanding the coping strategies of sufferers and carers

This Informed Consent Form has two parts:
1. An Information Sheet (to share information about the study with you)
2. A Certificate of Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form.

Information sheet

I am Claire Scott, a student at Cranfield University studying for an MSc in Community Water and Sanitation. I am doing research to understand the coping strategies for incontinence in low income countries like Zambia.

I am going to give you information and invite you to be part of this research. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research.

This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me or of another researcher.

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Incontinence is a widespread worldwide healthcare challenge which impacts significantly on people’s quality of life, their health and their income.

Experiences show that simple technologies can bring dramatic improvements for those who endure daily life with this condition. However, there is a lack of information on incontinence in low income countries like Zambia. To determine if technologies could make an improvement to the lives of sufferers and carers in low income countries, first the local challenges of incontinence need to be understood.

The study would like to talk to incontinence sufferers and those that care for incontinence sufferers to understand their experiences of living with incontinence. These can include the challenges faced in managing incontinence, the support received to manage incontinence, and the support still needed.

Therefore, we would like to ask you some questions about your own experiences of caring for a sufferer of incontinence. Your answers may identify opportunities to improve the quality of life of incontinence sufferers.
Your participation in this study is entirely voluntary, and if you do not wish to take part that is fine. If you are willing to take part I will interview you with an interpreter present if required. The interview will take as much time as you are happy to talk to me for.

**Interview process**

The interview can take place in a location where you are comfortable and that will be confidential. An interpreter may be present if required, and you may also wish to have someone else present. I am asking you to share with me some very personal and confidential information, and you may feel uncomfortable answering some of the questions. You do not have to answer any question that you don’t wish to, and that is fine. You do not have to give me any reason for not responding to any question.

As a guide the questions could include:
- What does ‘incontinence’ mean to you?
- Can you tell me about when [sufferers name] incontinence started?
- Can you tell me how [sufferers name] incontinence affects your everyday life?
- How do you manage [sufferers name] incontinence in your everyday life?
- What are the main challenges that you face in managing [sufferers name] incontinence?
- Can you tell me about the support and assistance that you have had for [sufferers name] incontinence?
- What type of assistance or support would you like to receive to help [sufferers name] manage their incontinence?

Your answers will remain confidential. A research paper will be published but names will not be used in communicating research findings and it will not be possible to link the answers back to you. I will only make handwritten notes of the interview if you give permission. I will only record the interview if you give permission. After the interview, handwritten notes will be kept in a locked room that only I have access to, and destroyed once converted into an electronic format. I am the only person that will keep an electronic copy of the notes and the recording of the interview (if applicable). These will be kept securely on a password protected computer for up to ten years. As the interview may take time, you will be reimbursed 100 kwacha for lunch expenses.

**Contact Information**

Lead Researcher: Claire Scott (MSc Student, Cranfield Water Science Institute)  
Address: Cranfield University, Bedfordshire, MK43 0AL, United Kingdom  
Email: c.a.scott@cranfield.ac.uk  
Mobile: +44 7984 622 164

Local Researcher: Mr Samuel Tembo (Plan International Zambia)  
Address: Plot 87A Kabulonga Road, Kabulonga, Lusaka, Zambia  
Email: Samuel.tembo@plan-international.org  
Mobile: +260 968 848 534

Supervisor: Dr Dani Barrington (Research Fellow in Water Engineering for Developing Countries, Cranfield Water Science Institute)  
Address: Cranfield University, Bedfordshire, MK43 0AL, United Kingdom  
Email: d.j.barrington@cranfield.ac.uk  
Mobile: +44 7743 508 140
This proposal has been reviewed and approved by ERES Converge IRB, which is a committee whose task it is to make sure that research participants are protected from harm. If you wish to find out more about ERES Converge IRB, please contact 33 Joseph Mwilwa Road, Rhodes Park, Lusaka, Zambia (eresconverge@yahoo.co.uk / Mobile: +260 966 765 503)

Do you have any more questions?
Certificate of consent

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have been asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study.

Print Name of Participant: ____________________

Signature of Participant: ____________________

Date: ____________________

Day/month/year

If required:

I have witnessed the accurate reading of the consent form to the potential participant, and the individual has had the opportunity to ask questions. I confirm that the individual has given consent freely.

Print name of witness: ____________________ Thumb print of participant

Signature of witness: ____________________

Date: ____________________

Day/month/year

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands the purpose of the research and the interview process.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this informed consent form has been provided to the participant.

Print Name of Researcher/person taking the consent: ____________________

Signature of Researcher/person taking the consent: ____________________

Date: ____________________

Day/month/year
A.3 Informed Consent Form for an Incontinence Sufferer located in Zambia

Principle Investigator: Claire Scott
Organization: School of Water, Energy and Environment, Cranfield University (United Kingdom)
Local Researcher: Mr Samuel Tembo (Plan International Zambia)
Project title: Incontinence in Zambia: Understanding the coping strategies of sufferers and carers

This Informed Consent Form has two parts:
3. An Information Sheet (to share information about the study with you)
4. A Certificate of Consent (for signatures if you choose to participate)

You will be given a copy of the full Informed Consent Form

Information sheet
I am Claire Scott, a student at Cranfield University studying for an MSc in Community Water and Sanitation. I am doing research to understand the coping strategies for incontinence in low income countries like Zambia.

I am going to give you information and invite you to be part of this research. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research.

This consent form may contain words that you do not understand. Please ask me to stop as we go through the information and I will take time to explain. If you have questions later, you can ask them of me or of another researcher.

Purpose of the research
Incontinence is a widespread worldwide healthcare challenge which impacts significantly on people’s quality of life, their health and their income.

Experiences show that simple technologies can bring dramatic improvements for those who endure daily life with this condition. However, there is a lack of information on incontinence in low income countries like Zambia. To determine if technologies could make an improvement to the lives of sufferers and carers in low income countries, first the local challenges of incontinence need to be understood.

The study would like to talk to incontinence sufferers and those that care for incontinence sufferers to understand their experiences of living with incontinence. These can include the challenges faced in managing incontinence, the support received to manage incontinence, and the support still needed.

Therefore, we would like to ask you some questions about your own experiences of caring for a sufferer of incontinence. Your answers may identify opportunities to improve the quality of life of incontinence sufferers.
Your participation in this study is entirely voluntary, and if you do not wish to take part that is fine. If you are willing to take part I will interview you with an interpreter present if required. The interview will take as much time as you are happy to talk to me for.

**Interview process**

The interview can take place in a location where you are comfortable and that will be confidential. An interpreter may be present if required, and you may also wish to have someone else present. I am asking you to share with me some very personal and confidential information, and you may feel uncomfortable answering some of the questions. You do not have to answer any question that you don’t wish to, and that is fine. You do not have to give me any reason for not responding to any question.

As a guide the questions could include:

- What does ‘incontinence’ mean to you?
- Do you think that incontinence is a problem for many people?
- Can you tell me about how you identify incontinence sufferers?
- Can you tell me about the care that is needed for incontinence sufferers?
- Can you tell me about the care that you are able to provide for incontinence sufferers?
- What are the main challenges that you face in caring for incontinence sufferers?
- Can you tell me about the support and assistance that could improve the quality of life for incontinence sufferers?

Your answers will remain confidential. A research paper will be published but names will not be used in communicating research findings and it will not be possible to link the answers back to you. I will only make handwritten notes of the interview if you give permission. I will only record the interview if you give permission. After the interview, hand written notes will be kept in a locked room that only I have access to, and destroyed once converted into an electronic format. I am the only person that will keep an electronic copy of the notes and the recording of the interview (if applicable). These will be kept securely on a password protected computer for up to ten years. As the interview may take time, you will be reimbursed 100 kwacha for lunch expenses.

**Contact Information**

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Address: Cranfield University, Bedfordshire, MK43 0AL, United Kingdom

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Do you have any more questions?
Certificate of consent

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Print Name of Participant: ____________________

Signature of Participant: ____________________

Date: ____________________

Day/month/year

Statement by the researcher/person taking consent

I have accurately read out the information sheet to the potential participant, and to the best of my ability made sure that the participant understands the purpose of the research and the interview process.

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

A copy of this informed consent form has been provided to the participant.

Print Name of Researcher/person taking the consent: ____________________

Signature of Researcher/person taking the consent: ____________________

Date: ____________________

Day/month/year