EXPLORING CAREGIVER EXPERIENCES IN PROVIDING CONTINENCE CARE FOR OLDER ADULTS AT AIC KIJABE HOSPITAL’S AMBULATORY CARE: A QUALITATIVE STUDY

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A Thesis Submitted to the Institute of Postgraduate Studies of Kabarak University in Partial Fulfillment of the Requirements for the Award of Master of Medicine in Family Medicine and Community Health Degree

KABARAK UNIVERSITY

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DEDICATION

This thesis is dedicated to all the caregivers of older persons willing to share their deeply personal experiences with a stranger in the hope of change. I am honoured and grateful and hope to portray the stories honestly to the people who need to hear them.

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ABSTRACT

With increasing life expectancies, the burden of incontinence among older adults is rising. Incontinence in this population is often accompanied by comorbidity, requiring assistance with basic activities of daily living. Owing to the lack of affordable long-term care facilities, enabling environments and assistive technology in low-middle-income countries, the most significant burden is shouldered by family caregivers. Not much research in continence care for older adults has been done in low-resource settings, less so among caregivers in the community. Available evidence shows that incontinence is greatly stigmatized and invisible, presenting barriers to help-seeking in caregivers. Furthermore, there is insufficient support from primary care teams, who often overlook the problem. This research aimed to gain insight into caregivers' experiences in continence care and explore help-seeking behaviour in caring for home-based, care-dependent older adults with incontinence. This qualitative research was conducted among caregivers of older adults with either stool, faecal or mixed incontinence, with participants obtained using purposive sampling guided by the Australian-Modified Karnofsky Performance Scale. Ethical approval was sought from ethical review committees at Kabarak University, African Inland Church (AIC) Kijabe Hospital and National Commission for Science, Technology and Innovation (NACOSTI). Focus group discussions and in-depth informant interviews using semistructured questionnaires were done. After data collection, a thematic analysis of emerging themes was done, and conclusions were drawn. Caregivers of older adults with incontinence suffer significant physical and psychological strain, financial burden, social isolation and impacts on personal relationships. The healthcare challenges encountered are stigma, limited support from healthcare providers, and lack of information. Support from religious communities, stronger bonds with the care recipient, reciprocity and a sense of purpose and fulfillment were perceived benefits of caregiving. Recommendations include establishing community-based programs, enhanced caregiver education, economic empowerment, and increased access to resources to better support caregivers and improve the quality of care for older adults with incontinence. Caregivers should alsoleverage religious communities as auxiliary support.Findings will help spread awareness of the problem and influence policy to promote continence care for older adults living with incontinence.

Keywords: *Incontinence, Caregiver Burden, Older Adults, Caregiver Experiences, Care-Dependent Older Adult, Caregiver Challenges, Caregiver Quality of Care, Help-Seeking Intention*

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS AND ACRONYMS

AIC -African Inland Church

BPH - Benign Prostatic Hyperplasia

COVID-19 – Corona Virus Disease 2019

DM - Diabetes Mellitus

HIV/AIDS - Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome

ISERC - Institutional Scientific and Ethical Review Committe

KDHS - Kenya Health Demographic Survey

NACOSTI - National Commission for Science, Technology and Innovation

T2DM - Type 2 Diabetes Mellitus

WHO - World Health Organization

CONCEPTUAL OPERATIONAL DEFINITION OF TERMS

Continence Care - all areas of support required to meet the needs of the person experiencing incontinence, conservative management and pharmaceutical treatment together with specialised interventions (Goranson *et al.*, 2023, O’Regan*et al.*, 2023)

Decubitus Ulcer - skin and soft tissue injuries that form as a result of constant or prolonged pressure exerted on the skin; pressure sores (Gefen *et al.*, 2022)

Family Caregivers- unpaid persons belonging to the same family as the older adults with incontinence for home they are providing care (Wagg *et al.*, 2019)

Incontinence – the loss of voluntary bladder or bowel control (Abrams, *et al.,* 2002, Norton, & Cody, 2012)

Older Adult - persons aged 60 years and older (World Health Organization)

Unpaid Caregivers- a family member or a natural person who aids and supervises the daily cares of a disabled person (US legal, 2024)

Primary Caregivers- individuals who are responsible for providing care to someone who cannot take care of himself or herself. (Yan, 2021)

CHAPTER ONE

INTRODUCTION

1.1 Introduction

This chapter includes the background to the problem, statement of the problem, justification for the study, significance of the problem and the study objectives.

1.2 Background of the Study

This section discusses the prevalence and impact of incontinence as well as the importance of understanding caregiver experiences.

Overview

If incontinence were a country, it would be the third most populated nation after China and India (Taylor, 2019). Incontinence is the loss of voluntary control of bladder or bowel function. The types of incontinence can be urinary, fecal or mixed. The risk factors for incontinence are advancing age, white race, obesity and being female (Devore *et al*., 2013). Underlying conditions associated with incontinence can be neurological, cardiovascular, endocrine or musculoskeletal, impacting mobility and cognitive function. These illnesses include dementia, diabetes, hypertension, heart disease, severe arthritis and cancer, whose prevalence increases with age.

Some causes of incontinence are iatrogenic, resulting from therapeutic or diagnostic interventions. To treat certain geriatric conditions, medications such as diuretics, calcium channel blockers and antidepressants are used. These medications however,have a negative impact on continence, causing new onset incontinence or worsening pre-existing incontinence. Incontinence may occur as a complication of certain surgical procedures and treatments. Among women, pelvic floor complications from instrumentation during obstructed labour and procedures such as hysterectomy for uterine disorderscontribute to an increased risk of future incontinence (Brown *et al*., 2000). Some men have urine incontinence as a complication of prostate surgery for cancer or benign urological conditions. (Sandu *et al*., 2019)

Epidemiology

Incontinence of all types affects more women than men with no sex predilection beyond 80 years (Dziekaniak *et al*., 2019). Urinary incontinence on the other hand, affects women of childbearing age due to changes in the pelvic floor during pregnancy and childbirth. However, the prevalence is still highest among older adults.Older adults with incontinence form 29% of the care dependent demographic worldwide (WHO,2017). Due to underreporting, estimates for the prevalence of incontinence are inconsistent and vary widely, with global faecal incontinence prevalence at 15% in Western populations (Sharma & Rao, 2020) and urinary incontinence among adult women in the developing world ranging from 2.8% in Nigeria to 57.7% in Iran (Mostafaei *et al*., 2020). A systematic review by Ackah *et al.*,2022 found the estimated pooled prevalence of urine incontinence among women aged 15-100 years to be 21%. There is paucity of data on local prevalence studies for all types of incontinence in Kenya.

Caregivers and Incontinence

Incontinence is generally viewed as a social rather than a medical problem, unless complications of poor continence care arise. As a result, when it comes to continence care of older persons, primary caregivers, who are often unpaid family members, form the majority of caregivers (Zachariou & Filiponi,2016). It is therefore crucial to understand the different factors that impact caregiving in continence care of alder adults.

Care Deficit and Older Caregivers

An erosion over the years of the traditional customs in pre-independence Kenya that ensured social protection of older persons occurred due to globalization. Similar to other

East and southern African nations, the HIV/AIDS crisis changed family support structures, forcing older adults to care for HIV/AIDS orphans despite their own decreasing intrinsic capacity for self-care (Ademak *et al*., 2020; Schatz & Seeley., 2015). The result was the loss of support for the older adult population and a rise in age-related inequality (Lusambili *et al*., 2023).

The age dependency ratio in Kenya is steadily declining owing to a decline in fertility and a shift in age structure evidenced by more adults joining and staying on the workforce (Global Economy, 2023). According to the 2019 Kenya Population and Housing Census, more than 80% of adults over 60 were working, and 4% were seeking employment.This demographic dividend has yet to be tapped into for the benefit of the care of older adults in Kenya (Aboderin & Gelfand, 2019). Informal caregivers, often drawn from the family, are not included in the paid labor workforce.

Amplification in gerontological literature of older persons as recipients rather than providers of social support and care, according to Mbuthia *et al*., 2018, has led to an underestimation of the role of older persons as caregivers. Older adults with incontinence and comorbidity are often bedridden. For the caregivers, this implies assisting with daily medications and hospital visits, emotional support, comfort, and basic activities of daily living such as feeding, grooming, and even toileting, a fundamental human activity.

Older spouses, siblings, and adult children may themselves assume the responsibility of co-resident caregivers for older persons living with incontinence. This poses a tremendous challenge as they have to balance the self-care of their ageing bodies and the care of their care recipient. Sadly, as they grow older, their intrinsic capacity and capability to care for fellow dependent older adults with incontinence declines. Thus, despite the best efforts, communities will likely see an upward trend in caregiver burden and deficit (Schatz & Seeley, 2015).

Respite Care

Only when the household cannot provide care for their loved ones does the family opt for respite care to provide relief for primary caregivers. Respite care comes from caregivers delivering health and social care during home visits as needed. Alternatively, families can admit their loved ones needing assistance to long-term care facilities. Where long-term facilities are not an option, as is the case in resource-limited settings, the only respite obtained occurs during hospitalization for complications of incontinence such as decubitus ulcers and urinary tract infections (Wagg *et al*., 2019; Tseng, 2015). Informal caregiving done in developed countries is done to prolong ageing in place and as a cost-saving measure as it is more affordable than institutionalization. A shift towards promoting ageing in place has been influenced by the just-ended COVID-19 pandemic, where aged care facilities lost the trust of families due to high morbidity and mortality. Similarly, government policies in developed nations started leaning towards the World Health Organization's measures to foster healthy ageing using ageing in place as a more economical means of caring for older adults (UN Decade of Healthy Ageing [2021-2030], Dominguez-Castillo, Bonilla-Campos and Izquierdo, 2022). This underscores the importance of community caregivers as the mainstay of care for care-dependent older adults, such as those needing assistance with toileting.

Financial Implications

Incontinence exerts a substantial financial toll on those affected. For many families, the one burden that puts the most strain on the household, resulting in seeking long-term care, is incontinence in their ill-loved ones. In low-resource settings, where health is financed out-of-pocket, competing needs and limited resources mean that long-term care facilities are out of reach for many families. In addition, even though only a quarter of Kenyans have some form of health insurance (Kenya Demographic and Health Survey,

[KDHS] 2022), this coverage does not cater for continence care services and products, rather than age in long-term care facilities, most older adults in Kenya age in place, mostly in rural areas, where family members take up the caregiving role. In rural areas, inequitable allocation of funding to primary care for non-communicable conditions that plague older adults leads to poor outcomes (Hooley *et al*., 2022).

Sometimes, caregivers must give up formal employment to become full-time caregivers for their affected loved ones. Other family members must take up additional jobs (Musyimi *et al.,* 2022) to afford continence care services and products for their loved ones. For those in employment, there is a risk of losing their jobs; for the unemployed, the risk of being left out of the labour market continues. Unlike in more developed and wealthier nations, caregivers in Kenya are not reimbursed for their services, and neither are they provided with financial support or material support for containment products or respite care.

Quality of Life

Incontinence is a condition that has a tremendous impact on the quality of life of both the care recipient and the caregiver (6th International Consultation on Incontinence, [ICS] 2017). It causes both physical and mental health problems for those affected. Caregivers live in poor psychological health and silently suffer from conditions such as anxiety and depression (Gratao *et al.,* 2019; Yan *et al.,* 2022). Bedside caregiving is a physically demanding job, predisposing to back pain from transfers, disturbed sleep from night care and abuse when dealing with behavioural issues of the care-recipient with cognitive impairment or depression (Suzuki *et al*., 2016; Ostaszkiewicz *et al*.,2020). Abuse of the caregiver may also come from other family members (Ostaszkiewicz *et al*., 2018), especially where there is family dysfunction.

Purchasing continence products such as adult diapers puts a financial toll on the family resources, sometimes calling for measures to cope with unaffordable products. These include reducing intake of fluids and food, strict adherence to toileting routine, and creative use of readily available alternatives of absorbent continence products and regular washing with soap to maintain hygiene (Ansari &White, 2022). This may affect the psychological health of the caregiver, who may be unable to cope with these measures (Cole *et al.*, 2022., Murphy *et al.*, 2021; Taylor & Cahill., 2018). Stigma and isolation surround incontinence and force those affected to keep it hidden, resulting in social withdrawal and isolation. All these factors negatively affect quality of life.

Help-seeking Intention

Caregiving is hard work, yet caregivers do not receive sufficient or appropriate support from primary care teams who often overlook the problem (Drennan *et al.*, 2011; Cole *et al.*, 2022). Among caregivers, a lack of information on how to handle sanitation and choice of containment products causes hypervigilance out of fear of complications like skin breakdown, yet these are not addressed by primary care teams (Tseng *et al.*, 2015). Likewise, caregivers do not seek help from their healthcare provider regarding the incontinence of their care recipient. This may be due to the belief that incontinence is a normal physiological change associated with ageing. Due to ignorance, caregivers may be unaware that some forms of incontinence are reversible. In sub-Saharan Africa, lack of aged care specialists with competence to provide continence care patient engagement is another problem (Adamek *et al.*, 2020). These factors contribute to incontinence remaining an invisible problem.

Research shows that the stigma and taboo associated with incontinence hinder seeking help for the problem. Surprisingly, older adults with incontinence are likely to confide in their primary care physicians about their incontinence well before discussing it with family members (Cowan *et al.*, 2020). According to Devendorf *et al.* (2021), on average, this discussion between doctor and patient takes place more than one year after the onset of symptoms. This denotes the vital role of primary care in supporting patients and their caregivers with incontinence. It has been found that the most desired form of support required from primary care is information regarding containment products, how to deal with skincare and emotional support (Grimsland et al., 2019; Carsughi *et al.*, 2019; Zachariou & Filiponi, 2016).

Gender Inequity

Studying caregiver experiences in continence care while disregarding the role of gender is being shortsighted. Caregivers play an essential role in public health, yet caregiving for older adults with incontinence is a social stigma, often gendered, invisible, with low status (Boddington & Featherton, 2018). Social and cultural norms are gender-biased towards women due to perceptions of warmth despite no real differences in competence (Halper *et al.*, 2019). The labour workforce does not include informal caregivers of older persons with incontinence. These may be wives, daughters or sisters of the affected persons who do not get compensated for their services. In a systematic review by Ibanez *et al.*, (2021) looking at dementia care in Latin American countries, female caregivers are likely to be underpaid and not receive caregiver training compared to their male counterparts. Additionally, they bear the greater share of caregiver burden, predisposing them to poor physical and mental health (Ibanez *et al.*, 2021).

Only recently has gender earned recognition as a social determinant of health (Miani *et al.*, 2021). Gender inequity leaves women at a socioeconomic disadvantage due to loss of productivity from taking up unpaid caregiving roles (Ibanez *et al.*, 2021) and affects their decision-making ability. This makes them vulnerable to abuse as caregivers while at the same time altering their help-seeking intention, as evidenced by higher levels of perceived stress . A systematic review by Xiong *et al*., (2020) found that female caregivers of older adults with dementia have higher physical and mental health burdens and stress compared to male caregivers. Having a lower socioeconomic status associated with caregiving makes women assume greater caregiving responsibility despite less access to formal support (Abajo *et al*., 2016) for the challenges of continence care. Recent studies show that among spousal caregivers, husbands were better at seeking help early and recognized the importance of self-care more than wives to care-dependent husbands (Xiong *et al*., 2020). Additionally, being female with the sole responsibility of caregiving predisposes one to reduced space and time for oneself in attempts to fulfil the conventional caring, feminine role (Dominguez-Castillo *et al*., 2022).

Support for Continence Care

Despite the substantial social, psychological and physical effects on older adults (Schlögl *et al*., 2022) and their caregivers, little has been done to promote and support continence care. Little is known about the presence of continence care specialists such as nurses to complement the work of caregivers. Few public health initiatives focusing on continence care in primary care settings exist. Much of the research done focuses on urinary incontinence, with faecal incontinence remaining primarily ignored. Over time, however, the research has evolved from studies attempting to prevent and treat incontinence to a focus on containment measures and quality of life living with incontinence (ICS, 2017). This shift has occurred perhaps due to a new realization that regardless of advancements in therapeutic options for incontinence, complete bladder or bowel control is not an attainable goal for everyone, as the multitude still needs support with containment (Fader *et al*., 2014).

In low- and middle-income countries such as Kenya, caregivers' experiences and strategies for continence care of their older adults with incontinence are not well understood; thus, research in this area is necessary (ICS, 2017). The African Inland Church (AIC) Kijabe Hospital is a 360-bed tertiary teaching and referral hospital situated in a semi-urban part of central Kenya, whose services reach a primarily rural population. Its ambulatory service has a general out-patient clinic and specialty clinics. Approximately 4% of the general population attending these clinics are aged 60 years and older, many of whom require assistance with activities of daily living, and have various types of incontinence. This research, therefore, aims to gain insight into the experiences of caregivers of older adults living with incontinence as well as the help-seeking behaviour for continence care.

The findings of this research will be helpful in spreading awareness of the problem of caregivers in the continence care of older adults with incontinence. It will help increase priority in education, capacity building, reducing stigma and reallocation of resources towards continence care of this population.

1.3 Statement of the Problem

With ageing populations across the world, an estimated larger burden of health and social care for older adults will increasingly lie within low-and middle-income countries. Incontinence is often viewed as a social problem by healthcare providers (Hunter & Wagg, 2018), leaving the burden to families who provide both financial and physical care. In the past, societies in Africa were tight-knit, and social and cultural conventions had avenues that ensured care for the aged in communities (Lusambili *et al*., 2023). However, due to rural to to-urban migration of youth in search of jobs, in contrast with urban to rural migration of seniors upon retirement, there is a resultant deficit in caregiving for care-dependent older adults. Gradually, there has been a shift in research on pelvic floor disorders towards focusing more on containment and quality of life in incontinence rather than therapeutic measures. (Molina *et al.,* 2024).

Little is understood about the experiences, practices and help-seeking behaviour of caregivers in low-and middle-income nations such as Kenya. This research will explore the caregiver experiences, strategies and help-seeking behaviour in providing continence care of communitydwelling, care-dependent older adults. It will provide Kenyan insights into a body of research mostly focused on European and American studies, contributing to the discussion on continence care of older adults.

1.4 Study Justification

Many studies on incontinence have been done in developed countries, with the majority focusing on urinary incontinence. The studies involving care-dependent older adults look at the burden of caregivers of older adults with incontinence and comorbidity, with dementia being the most studied. The setting for these studies has been long-term care facilities where trained nurses provide continence care for their older residents with incontinence. There is a limited number of researchers who have studied informal caregivers' experiences for care-dependent community-dwelling older adults. In developing nations, especially in East and Southern Africa, research in continence care of community-dwelling older adults in Africa is underdeveloped, with stagnation even in developed nations (Burholt *et al*., 2020). With an ageing population in a country forging towards universal health coverage, work must be done to ensure quality health services for older adults with incontinence. Research in help-seeking behaviour will boost public health campaigns on continence care.

A qualitative design will allow for the phenomenon to be studied in its natural setting, and a rapport is built with the participants, thus directing focus on the study material (Akinyode & Khan, 2018). Focus group discussions with open-ended questions in which the participants relate their experiences without restriction of their opinion (Akinyode &

Khan, 2018) will yield detailed information and a potentially deeper understanding of the topic.

In Africa, most older adults live in rural areas. Long-term care facilities are few and costly for the average Kenyan, so older people in Kenya generally age in place. Ageing in place means ‘remaining living in the community, with some level of independence, rather than in residential care’ (Wiles *et al*., 2012).Cultural norms and religious norms in Kenya dictate that the younger generations provide care for their elders.

Due to an increasingly ageing population, the burden of care for older persons lies with families. Kenya is one of the few countries in sub-Saharan Africa that have adopted national policies in support of the health and social care of older persons. For instance, the Inua Jamii 70+ Cash Transfer for Older Persons Program, a universal cash transfer program for older persons over 70 years of age, illustrates the government's commitment to healthy ageing by addressing poverty in this population (Gelb *et al.*, 2023). This initiative, however, is just the tip of the iceberg for care in ageing, a season of life accompanied by intrinsic losses and comorbidity requiring increasing health and social support. As it works towards universal health coverage, a lot needs to be done to improve healthcare for this population.

This research will focus on the experiences of caregivers of care-dependent older adults living with incontinence in the community. It will shed light on the care practices and challenges of caregivers in providing care. The findings will be useful to primary care physicians and their teams, caregivers, and policymakers in the care of older persons. By adding knowledge to the body of research in the field of continence care, it will also be beneficial for building capacity in primary care teams in support of families in the community. The voices of caregivers will inform gaps and opportunities in primary care practice, stimulate ideas and shape policy in support of continence care of older adults in Kenya and the region.

1.5 Research Purpose and Objectives

i. To gain insight into the experiences in continence care by caregivers of home-based care-dependent older patients with incontinence attending AIC Kijabe's ambulatory care
ii. To understand the factors that affect caregivers' help-seeking intention for continence care of their care recipients in managing incontinence at AIC Kijabe hospital's ambulatory care.

1.6 Research Questions

i. What are the caregiver experiences and management practices in continence care of community-dwelling older adults presenting to AIC Kijabe Hospital's ambulatory care?
ii. What are the factors that affect caregivers' help-seeking intention from primary care practitioners in managing incontinence?

1.7 Significance of the Study

This study's findings will benefit public health practitioners, primary care teams, and caregivers in making decisions for appropriate continence care measures and support. The voices of community caregivers will raise awareness of the problem of incontinence and contribute to research and policy that may help to structure continence care service implementation and financing in Kenya and beyond.

1.8 Study Limitations

In focus group discussions, one assumption made was that the group would give honest and unbiased responses about their individual experiences. To reduce responder bias, clustering the participants into homogeneous focus groups was done. This grouping was based on similar characteristics such as age, gender, experience, relationship with the care recipient, care recipient comorbidity and whether the caregiver is paid or unpaid. A small sample size in focus group discussions may produce findings not generalizable to the general population. To mitigate this, key informant interviews were conducted to attain more representative findings. The interview guide used in this research was a semi-structured interview guide rather than an existing validated tool. To mitigate the risk of poor-quality data from using a non-validated tool, adequate time was allocated for the data collection and use of open-ended questions was done.

CHPATER TWO

LITERATURE REVIEW

2.1Introduction

This section contains an overview of the literature on continence care and the conceptual framework for the study.

2.2 Literature Review

Incontinence is defined as loss of control of bowel or bladder(Abrams, *et al.,* 2002, Norton, C., & Cody, J. D. 2012). Different types of incontinence exist: urine, stool, mixed, and functional. Urine incontinence is further subdivided into urge, stress, overflow, and mixed (Holroyd-Leduc *et al*.,2008). Types of faecal incontinence are passive, urge, and functional (Jaekel *et al*., 2023, Sharma *et al*., 2016).

Functional incontinence occurs due to the inability to make it to the toilet in time due to physical limitations to mobility, such as those seen in severe arthritis, cognitive impairment or amputation (Cole*et al*., 2022, Wagg *et al*., 2019). Incontinence is caused by pelvic floor muscle dysfunction due to trauma, surgery, radiation, pregnancy and birth, and neurological disorders (Göransson*et al*., 2023). People at increased risk of incontinence are those who have had surgery or trauma to the brain, spinal cord or pelvic floor, multiparous older women (Bliwise *et al*., 2019,) and those with cognitive impairment. Immobility among care-dependent persons is also a risk factor for functional incontinence. For most older adults, the underlying causes cannot be reversed, so containment measures are the only option available for coping with the condition Göransson *et al*., 2023).

Incontinence has detrimental effects on the physical, emotional and social well-being of those affected (Schatz & Seeley, 2015). Skin breakdown from dermatitis and pressure ulcers, anxiety and depression, loneliness, social isolation, abuse and stigma are all complications of incontinence (Ostaszkiewicz*et al*., 2020). Depleting financial resources from the constant requirement of continuous care products and services can cause poverty (Taylor & Cahill, 2018). These effects harm the quality of life (Przydacz *et a*l., 2023).

Caring for older adults with incontinence is associated with stigma both on the caregiver and the care recipient. This is due to the view that the loss of independence and the need for assistance with toileting is a regression from the norm into childlike behaviour (Peroni *et al*., 2022). Older adults who were once parents to their now adult children must deal with loss of dignity in needing assistance with toileting. According to Sandberg *et al*. (2019), relying on family members for continence care was one of the two leading reasons for moving from home to long-term care facilities. In Africa, where nations have the highest total dependency ratio in the world, older adults constitute the second largest social support burden after children (He, Aboderin, & Adjaye-Gbewonyo, 2020). Due to globalization and the resultant migration of populations and culture change, a shift in social support structures from the once integrated and tight-knit societies to the current collapse in the previously assured support for older adults requiring care. This trend is already apparent in the developing world, where there is an increasing shortage and rising demand for aged care workers (Manchha *et al*., 2021) with the backdrop of an aged population. In Africa, poverty, HIV/AIDS and urbanization complicate elder care, especially among elders without family support, emphasizing the need for government support and international funding for families in caring for the older adults (Adamek *et al*., 2020).

According to Manchha *et al*., 2021, continence care for older adults is associated with low status, and low value is attached to old age care, often gendered, invisible, and with low status (Boddington & Featherton, 2018). Incontinence is often overlooked by healthcare providers, leaving the caregivers unsupported and feeling invisible (Cole *et al*., 2022). According to Ansari and White (2022), who studied caregivers of older persons with incontinence in India, despite its association with stigma, providing care for older adults is a social responsibility as dictated by social and religious customs. The same applies to Kenya, where the burden of care for patients with chronic illness in the community is shouldered by unpaid family members (Johnstone, 2017). When asked about tasks in providing care to patients with chronic illness and disability requiring assistance, toileting appears to be the one task caregivers would want to resolve (Burholt *et al*., 2021) due to its limitation in social interaction.

Goffman (1963) defines stigma as behaviour directed at people perceived to have an undesirable attribute that sets them apart from others by others in society. The diagnosis of incontinence is associated with stigma on both the patient and the caregiver and can be external or directed at oneself. Self-directed stigma results in negative feelings about oneself. Murphy *et al*. (2022) found that different factors that influence the perception of incontinence stigma vary from the sex of the person, the underlying cause of incontinence, and cultural differences to the type and severity of incontinence. This stigma often has negative consequences for the caregiver as it leads to social isolation (Murphy *et al*., 2021) as well as withdrawal from society (Ansari & White., 2022). Some of the reasons for this withdrawal from society are due to perceived feelings of inadequate provision of care, as evident by complications of continence care, such as skin breakdown.

External stigma comes from the public and healthcare professionals. In healthcare settings, in the milieu of other illnesses, incontinence often gets underrecognized (Schlögl & Gordon, 2021), and even when identified, it is largely ignored. Competing attention and resources such as care and medications have to be shared between incontinence and comorbidity such as diabetes, cancers and cardiovascular disease. Because it is not immediately life-threatening, continence care does not get the respect it deserves until complications occur (Taylor & Cahill, 2018).

2.2.1 Caregiving Burden

Negative Health Consequences

Caring for an older adult with incontinence is a physical, psychological and financial burden that families bear daily. Continence care is a physically demanding job, and many caregivers experience a toll on their health as a result (Tseng *et al.,* 2015; Murphy *et al.*, 2021; Mello *et al.*, 2017). Frequent night changing and resistance to care from care recipients with behavioural challenges or mental illness can result in backache, physical abuse and sleepless nights. This also has consequences for the caregiver's emotional well-being (Gratão *et al.,* 2019; Murphy *et al.,* 2022; Beach *et al.*, 2021; Ainamani *et al.,* 2020), manifesting as hypervigilance, burnout, stress, anxiety and even depression while providing care for their ill family members with incontinence.

Not enough support exists to support the caregiver neither for their physical or emotional problems arising from their job (WHO, 2020; Donnelly *et al.,* 2018; Hunter & Wagg, 2018).

Stigma

Social isolation from the time-consuming task of providing round-the-clock bedside care limits one's social interaction, resulting in loneliness. This is also worsened by the stigma of a low-status job of providing care in bodily fluids.

Despite the rising demand, working in aged care is a risk factor for job discrimination as caregivers encounter negative emotions from low value attached to their character and their job (Manchha *et al.,* 2021). Caregivers must quickly cope with their new identity emanating from the new role as caregivers of an older adult with incontinence. This is done so as to reduce conflict with other family members who may be more empowered financially, socially and educationally. Managing human excrement leaves caregivers feeling dirty (Taylor & Cahill, 2018), so caregivers heavily rely on soap and water to maintain cleanliness and purity as a requirement in social and religious circles, especially in the developing world (Ansari & White, 2022). Some caregivers experience discrimination by being perceived as unclean for taking part in bodywork (Ansari & White, 2022).

Financial Implications

Caregiving is often gendered, with women being the majority, partly due to higher unemployment rates among women (Zachariou & Filiponi, 2016). This further worsens their employment prospects as caregiving is a time-demanding occupation that locks them out of the labour market. In Kenya, there is currently no policy to support family or unpaid caregivers in the community, as found by one study of caregivers of older adults living with dementia (Musyimi *et al.,* 2022). Family members have to get additional jobs to be able to afford continence care, while others experience reduced income by having to take time out of regular occupations to provide care for their loved ones living at home with incontinence.

Owing to the physical, psychological and financial effects on the well-being of the caregiver, the quality of life with prolonged durations of providing care declines. Studies have shown that the health-related quality of life of caregivers of older adults can be improved by decreasing caregiver burden (Du *et al*., 2017). Data obtained from research exploring caregiver burden incontinence care in the Kenyan context will provide information needed to tackle the problem.

2.2.2 Management Practices

Containment Measures

Management practices for incontinence have shifted over time from medical and surgical therapeutic interventions to conservative measures aimed at containment. In order to optimize continence care, research and development teams around the world are working on advancing continence products to be recyclable, hypoallergenic, antimicrobial and even smart, with sensors to detect volumes while alerting users. Lack of information regarding continence products has been cited by many researchers as one of the problems experienced by caregivers (McDaniel *et al*., 2020; Grimsland *et al*., 2019; Carsughi *et al*., 2019; Zachariou & Filiponi, 2016; Murphy *et al*., 2022; Gove *et al*., 2017; Wagg *et al*., 2019).

In developed countries, containment is achieved by the use of absorbent materials such as diapers, ostomies and urinary catheters (Ostaszkiewicz *et al*., 2020). The cost of containment products may be covered by health insurance while in long-term care facilities. In the community, most individuals still have to pay out-of-pocket for the containment products as well as contribute to social protection funds for older persons.

Hygiene Products

In the developing world, not much data exists on containment strategies. One study from India found that access to soap and clean water was essential in maintaining hygiene during the provision of continence care (Ansari & White, 2022). This heavy reliance on soap and water was essential in reducing unpleasant smells as a coping mechanism.

Dietary Restriction

Reducing dietary intake has been found in studies as another coping strategy for minimizing frequent bowel and bladder movements (Roe *et al*., 2011; Ansari & White, 2022). Although this may be beneficial in reducing fatigue in caregivers required to provide round-the-clock bedside care, it may have detrimental effects on the care recipient's physical and psychological well-being, especially where medications have to be administered for existing illnesses. The caregiver may also have to cope with feelings of guilt for denying necessities to the care recipient.

In sub-Saharan Africa, most countries lack structures for social support of older adults, a concerning problem (Adamek *et al*., 2020) which leads to catastrophic spending and increased vulnerability. There is scarcity of data looking at specific management practices employed by caregivers inmanaging incontinence in Africa. In Kenya, healthcare is mostly paid out-of-pocket, with less than a quarter of the population affording health insurance (KDHS, 2022). For many community-dwelling caregivers, options such as respite care and financing for incontinence are unavailable, inaccessible and unaffordable. Furthermore, existing health insurance schemes in Kenya generally do not cover continence care products or services.

2.2.3 Factors Affecting Help-Seeking Intention

Despite incontinence being a debilitating condition, those affected will take long durations to report to their primary care provider. This reluctance to inform physicians about incontinence stems from stigma and a lack of information on treatment options (Przydacz *et al*., 2023). For many patients and their caregivers, incontinence is a normal part of ageing, and therefore, they do not believe that any medical remedy exists to correct or support the condition. Regardless, for non-care dependent older adults with incontinence, the primary care provider is the first person to whom the problem will be disclosed, not close family members. A qualitative study in long-term care facilities in Ethiopia found that lack of information and training against a backdrop of low resources resulted in significant burden negatively affecting caregivers, recommending training of primary care practitioners in geriatric training (Dawood *et al.*, 2021).

Incontinence is typically linked with a greater comorbidity burden (Gomes *et al.*, 2020). To that effect, incontinence in the presence of more worrisome diagnoses is seen as a minor bother not worthy of mention or attention. Just as primary care providers are not keen on asking about incontinence, caregivers and even patients themselves also do not volunteer information about their incontinence. In other contexts, discussion of incontinence is considered taboo and shameful and thus must be kept hidden (Peroni *et al.*,2022; Grimsland *et al.*, 2019; Schlogl *et al.*, 2022; Gove *et al.*, 2017). Talks touching on incontinence are seen as obscene and improper, and thus, due to the negative emotions elicited, they are avoided altogether.

The longer a caregiver has been providing care for an older adult with incontinence, the more likely he is to be living in poorer health or experiencing a worsening of his own health.

Caregivers only seek help in the form of respite care when they are unable to cope or when they themselves fall ill during care provision. Some of the coping mechanisms are dissimulation, that is, pretending everything is okay, focusing on the task at hand and reorienting oneself to a new identity as a caregiver (Taylor & Cahill, 2018; Tseng *et al.*, 2015) in order to reduce conflict within the family.

Caregivers struggle to find a balance between their own needs and the needs of the care-dependent person. Family members who have to leave their full-time occupations to care for their loved ones may find it hard to accord time to seek help for continence care of their loved ones. Even though the relationship between the caregiver and the care recipient may grow due to a bond being developed, conflict with other family members is not uncommon (Schatz & Seeley, 2015; Cole *et al.*, 2022). For these families, conflict occurs due to disintegrated and insufficient support from health and social care for continence care (Cole *et al.*, 2022). In some cases, other family members also do not provide the emotional and logistical support needed to seek care for incontinence.

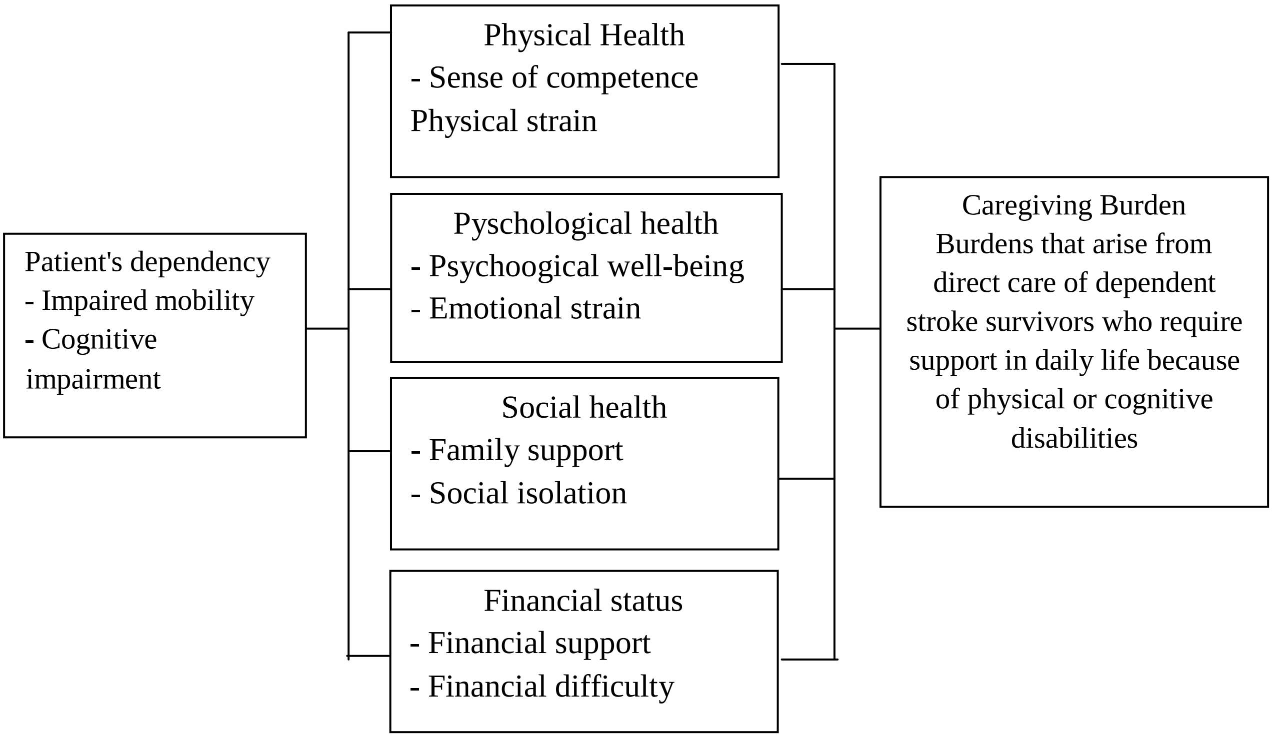
Lack of government funding and financial constraints to support continence care also negatively affects the help-seeking behaviour of caregivers of older adults living with incontinence. Resources are most likely to be directed at other more pressing health needs such as medications for co-existing illness.

2.3 Conceptual Framework

This section contains the conceptual frameworks with an integrated view of the problem that will guide a systematic approach to the research.

Figure 1

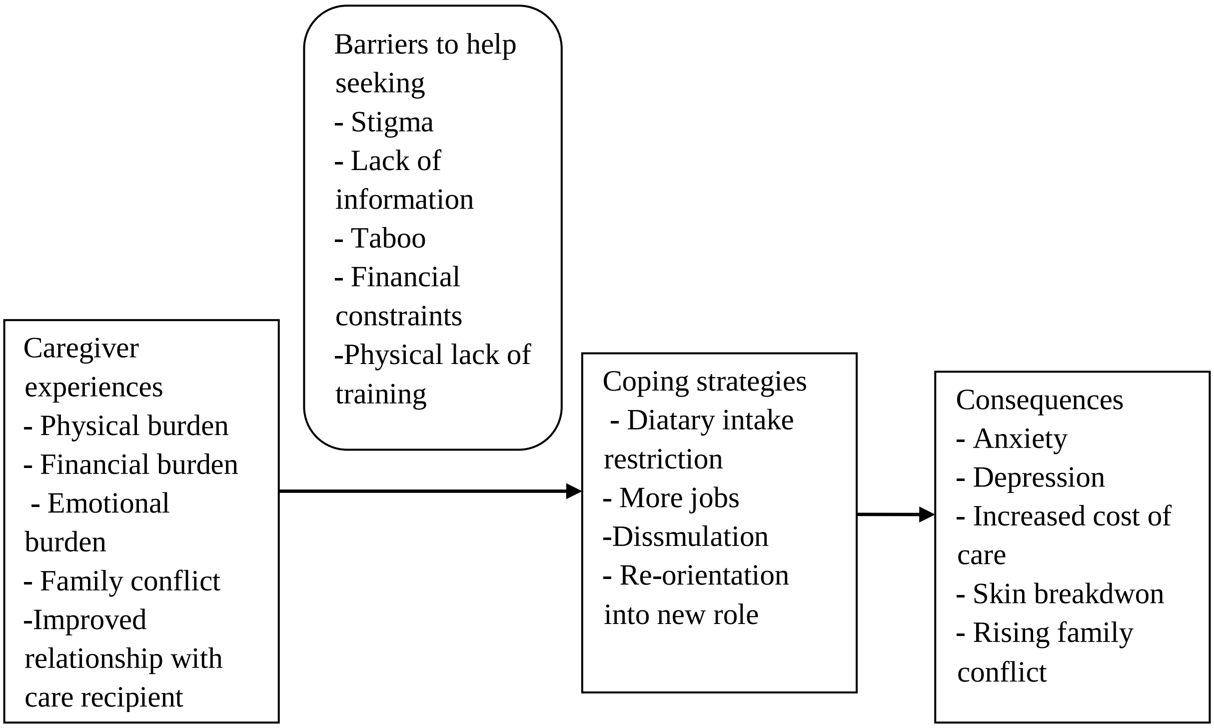
Caregiving in Stroke Conceptual Framework



Source: Kim & Roh (2021)

Figure 2

Conceptual Framework on Caregiver Experiences in Continence Care of Older Adults



This conceptual framework outlines how the different aspects of providing continence care are connected. It consists of the experiences, barriers, coping strategies, and consequences among caregivers of care recipients with incontinence. The burdens that caregivers face span accross physical, financial, and emotional domains, as well as strained family relationships, although some caregivers report that their role fosters improved relationships with their care recipients. Known barriers to help-seeking among caregivers include stigma, lack of information, cultural taboos, financial constraints, and insufficient training of healthcare workers. In order to cope with these challenges, caregivers adopt strategies such as dietary intake restriction, taking on additional jobs, dissimulation which is an emotional removal of oneself form the task at hand, and re-orienting themselves into their caregiving role.These experiences, barriers, and coping mechanisms contribute to negative outcomes, including anxiety, depression, increased care costs, worsening health of their ill loved ones such as skin breakdow, and escalating family conflicts.

2.4 Study Gap

The experiences of caregivers of older adults with incontinence span their bio-psychosocial burden, lack of support and help-seeking behaviour. Due to stigma, competing needs and lack of information, caregivers do not seek help for incontinence. The stigma associated with incontinence emanates from embarrassment due to a breach of autonomy, privacy and loss of independence, resulting in fear of being ridiculed or humiliated. Culture may also act as a barrier in continence care. Differences in age, sex, religion, attitudes and values between the caregiver and the primary care provider hinder discussions surrounding the incontinence of older adults, both the caregiver and the healthcare provider, as many cultures consider incontinence a taboo.

For patients with comorbidity, as is the case with older age and illnesses associated with incontinence, attention is often diverted towards these other illnesses. Resources such as money are spent on more concerning medications and doctor visits for these conditions, but little is allocated towards continence care. The remaining resources are focused mostly on containment and sanitation products.

Caregivers themselves do not receive any psychosocial or technical support towards handling incontinence in their care recipients. Caregivers suffer physical ailments such as chronic low back pain, anxiety, depression, physical abuse and social isolation while providing care. In developed countries, respite care, educational initiatives for continence care, and technology for enabling environments reduce the burden of continence care in families. In order to cope with the burden of care, caregivers' strategies such as dissimulation, reducing dietary intake of their care recipients and self-reorientation into their new role as full-time caregivers.

Primary care providers do not accord sufficient attention to support family caregivers of patients living in the community with incontinence. This is due to a general ignorance of the impact of incontinence on families as well as a lack of training to gain competencies in the holistic care of patients with incontinence. Additionally, incontinence is largely ignored, with attention focused on immediate life-threatening illnesses for which most patients present in the clinic.

Although family caregivers play an essential role in public health, they do not receive adequate social and technical support for the care of their loved ones with incontinence. Lack of information on products and approaches for containment leave caregivers ill-equipped for the task.

The financial impact that incontinence has on families caring for patients is concerning yet not well understood. Family members have to leave their occupations to become full-time caregivers, while others have to take up extra jobs to be able to raise funds for care. This loss of income and resources causes strain on families and impacts relationships among family members. Since caregiving is often gendered, with women being the majority, they end up being locked out of the labour market as informal caregiving is not a paid job. This worsens gender inequality as women are left out of decision-making and continue to lose access to social and economic resources and opportunities by working as caregivers. When female caregivers fall ill, they are expected to resume their responsibilities soon after recovery, in contrast to men, who will likely be nurtured to health by women carers long after their recovery. Last but not least, social determinants of health that affect women in low-income nations, such as income, social protection, social inclusion, poverty and lack of education, influence the help-seeking behaviour of caregivers.

In conclusion, caregivers providing care for incontinence in older adults play an essential role that is, to a large extent, ignored by primary care providers, public health practitioners, as well as researchers and policymakers. Qualitative research to explore the experiences of caregivers, as well as their help-seeking behaviour, is needed to better understand and inform public health policies and continuous care service delivery in primary care in support of families.

CHAPTER THREE

METHODOLOGY

3.1 Introduction

In this chapter, the research design, location of the study, the population of the study, sampling, sample size and recruitment, inclusion and exclusion criteria, data collection tools, data collection procedures, data management and analysis, as well as ethical and budgetary considerations, will be discussed.

3.2 Research Design

This wasa phenomenological explorative qualitative research that attained its objectives using key informant interviews and focus group discussions to gain insight into caregivers' experience in continence care as well as the factors that affect help-seeking from primary care providers.

3.3 Location of the Study

This research was done in a tertiary teaching hospital located in Lari sub-county, one of 11 subcounties in Kiambu County found in Kenya’s central province. Lari has a mainly agricultural semi-urban population that practices subsistence farming, and a life expectancy of 60.8 years in males compared to 72.8 years in females (WHO, 2019) . The hospital is a 360-bed tertiary teaching and referral hospital situated in a semi-urban part of central Kenya, whose services reached a mostly rural population. Its ambulatory service has general out-patient clinics and specialty clinics that cater to patients with varied health needs, including care-dependent older adults with incontinence.

In the hospital, the research was conducted in two locations: in the community and at the hospital. At the community level, the target was focus group discussions among participants who attended AIC Kijabe Hospital's ambulatory care, while the discussions in the hospital focused on healthcare providers. Focus group discussions were held in the community at a convenient central location within a public facility such as a church or school. Key informant interviews were conducted within the hospital.

3.4 Population of the Study

This qualitative research was conducted among caregivers of care-dependent older adults with either stool, faecal, or mixed incontinence. Participants were caregivers of home-based older adults with incontinence who attended AIC Kijabe Hospital's ambulatory care. Participants were adults of all genders and were not discriminated against based on socioeconomic status. Care recipients' level of dependence was evaluated by the Australia-modified Karnofsky Performance Scale (AKPS) to include participants caring for older adults with scores of less than 50.

3.5 Sampling, Sample Size and Recruitment

3.5.1 Recruitment

Purposive sampling was used to identify and draw relevant and willing respondents from members of the community attending AIC Kijabe Hospital's out-patient department. The out-patient department included the general clinic as well as specialty clinics. After notifying the clinical teams in these clinics about the research, contacts of the principal researcher were placed in strategic places within the clinical spaces for ease of recruitment. The clinicians acted as the gatekeepers who identified and obtained initial verbal consent during clinic visits. The willing prospective participants among family caregivers were approached by the clinical teams during the clinic visits, and initial contact was established by the researcher to explain some details of the research and obtain consent from both the caregivers and the care recipients. For care recipients who lacked mental capacity, a family proxy or the appointed individual with power of attorney was approached to give consent on behalf of the care recipient.

This was helpful in building rapport with the participants prior to consent and data collection. The contacts of the willing participants were obtained for further communication. Subsequently, verbal consent was obtained after explaining via phone, in a clear and simple manner, the purpose of the study and the planned logistics. Participants' characteristics such as age, sex, relationship with the care recipient, duration of caregiving, and prior experience providing continence care were obtained to allocate the caregivers into appropriate focus groups for discussion. However, given the possibility of substantial distances between the participants, geographical location was given priority over the participants' characteristics when allocating the focus groups.

This was informed by the fact that the hospital was a tertiary facility whose patients came from regions beyond its catchment area. Participants were informed of the freedom to opt out of the research at any point without affecting the services they received from AIC Kijabe Hospital. They were also informed of the possibility of obtaining initial psychological support and ongoing assessment for psychological needs arising from the discussion of sensitive caregiver issues. Signed consent was then obtained prior to administering the interview and focus group discussion, with copies kept by both the researcher and the study participants. Contact information of the principal investigator was provided to the participants to allow questions and concerns to be raised easily.

3.5.2 Sample Size

Data saturation is a concept used to gauge sample size in qualitative research (Guest, Namey & Chen, 2020) as well as substantiate the themes. When the research objectives are narrow and the study population homogeneous, qualitative research achieved data saturation with relatively small sample sizes, that is, between 4 to 8 focus groups (Hennink & Kaiser, 2022). A low prevalence of codes means that saturation can be reached with 2 to 8 focus group discussions (Hennink *et al.*, 2019). Thus, for this research, a total of 3 key informant interviews and 3 focus group discussions with 5 participants each were undertaken. Thematic saturation was arrived at when the majority of the responses pointed to the same theme, and no further themes emerged from the data (Akinyode & Khan, 2018). For instance, Guest, Namey, and Chen (2020) acknowledge that assessing data saturation is a difficult task that relies on the judgment and experience of the researchers. Therefore, method triangulation, keeping a low threshold for new information, having multiple coders with experience, and the use of a coding script for consensus were done to ensure saturation was achieved. If new information was found, more data collection and analysis were done until data saturation was achieved.

The duration of data collection influenced data saturation in qualitative research. The study adopted a recommendation by a systematic review of 24 articles by Mwita (2022), which proposes 59 minutes as adequate time for each focus group discussion or interview. Thus, for this research, 59 minutes was used as a guide together with data saturation to determine the end of the discussions. Additionally, field notes and a coding script were also used to ensure no valuable themes were left out. This convergence of data sets from the interviews, focus group discussion notes, and transcripts enabled a well-rounded understanding of continence care (Carter, 2014).

3.6 Inclusion and Exclusion Criteria

3.6.1 Inclusion Criteria

Caregivers of care recipients with incontinence at Australia-modified Karnofsky Performance Scale (AKPS) scoring less than 50 points.The AKPS is an assessment tool used to gauge the performance status geriatric patients. Participants scoring less than 50 points spend a considerable amount of time in bed and require assistance with activities of daily living, posing a significant challenge to the caregivers.

Caregivers of home-based care-dependent older adults with incontinence.

3.6.2 Exclusion Criteria

Participants who opted out of the research due to psychological distress

a. Paid Caregivers of patients in elder care homes

b. Caregivers of patients scheduled for surgical correction of causes of incontinence

c. Caregivers of participants receiving ostomy care

d. Caregivers of care-dependent older adults with incontinence who are unable to communicate in English or Kiswahili

3.7 Data Collection Tools

A semi-structured questionnaire was used to guide key informant interviews and focus group discussions. The discussions were semi-structured and were in two parts: the first was a sign-in sheet for details on the participants' socio-demographic data such as age, gender, income and education level. This sign-in sheet was filled upon arrival by the participants, without revealing their personal information. The second part consisted of broad, open-ended questions to guide conversations on strategies, challenges, and understanding of incontinence as well as containment practices, for example: '*Tell me about how you care for your loved one when it comes to incontinence matters*'.

This helped in exploring help-seeking behaviour, knowledge and perception of incontinence as well as challenges in continence care. Two different investigators led the discussions to enable a richer, more diverse and less biased observation of the phenomenon (Carter, 2014). The principal investigator led two discussions, while the assistant researcher led one discussion. All 3 key informant interviews were led by the principal investigator. The interviews focused on the strategies and challenges of family caregivers from the key informants' perspectives.

Audio recordings were done using a single rechargeable wireless digital audio recorder (Dictaphone) with a built-in microphone with 8GB storage. The recordings were backed up in a computer under an encrypted folder only accessible to the researchers. The audio recordings of the sessions were transcribed in either English or Kiswahili. The languages used were Kiswahili and English, with translation of the Kiswahili transcripts into English before data analysis. To mitigate threats to rigour from inaccurate reporting, there were independent checks on translation to achieve consensus for the transcripts, as proposed by Squire, Sadarangani and Jones (2020).

The focus group discussions were held in the community at a quiet space in a health center for ease of access for the caregivers, some of whomhad time limits. Provision of transport to support logistics, use of positive language and a call to action were used to facilitate recruitment. For instance, prospective participants were told about anonymity and the usefulness of their voices as caregivers in shaping policy and structuring support from primary care.

Initial socio-demographic data of the participants, including information on their relation with the care recipient, duration of care, prior experience, and whether they are paid or not, were obtained through sign-in forms. Care-recipient characteristics such as gender, age, comorbidity, presence of indwelling catheter and duration of incontinence were elicited. A moderator facilitated the discussions in the presence of an observer whose work was to take discussion notes. Verbal consent was obtained before each of the audio recordings begins.

3.8 Data Collection Procedures

Focus groups stimulate dynamic and interactive dialogue, thus enabling a diverse group of individuals to give multiple perspectives on the same problem (Carter, 2014). Five participants dropped out of the participation on the set date due to inability to find respite care so as to attend the discussions. The majority of those who did not consent during recruiting had the same challenge of unavailable respite care. Data collection was done over one month and occurred simultaneously with data analysis. 3 focus group discussions were conducted in a discussion room within Marira Health Center, for ease of access for the participants. The focus group discussions were led by investigators skilled in collecting sensitive data and each discussion took an hour. Open ended questions were asked and the participants related their experiences, with each contributing to the discussions.

Three key informant interviews were done in the hospital's out-patient department and took an average of 50 minutes each. The key informants were healthcare workers in the hospital, in nursing and clinical medicine departments, who provide home visits to older adults in the community, apart from attending to palliative patients in the out-patient service. One of the key informants had experience in paid primary caregiving in the community. The key informants were selected due to the large numbers of older adults that their department serves, and also their understanding of the community they serve thanks to home visits. The key informant interviews were led by the principal investigator and were conducted in English. Data collection involved audio recording, followed by transcribing and translating the responses obtained during the interviews and focus group discussions. To increase rigor and transparency of the translation process, an independent translator was included to review the audio recordings, proof-read the translated script before a final discussion, and editing for consensus of the information.

3.9 Data Management and Analysis

In order to increase trust and rapport, all data was de-identified, and in the place of names, unique participant codes were used so as to maintain confidentiality, anonymity and dignity of the participants. The audio data was anonymized and later archived in encrypted folders. Meanings were generated through the interpretation of data, and using these, themes, which are broader subjects of the ideas, were derived (Braun & Clarke, 2006).

Braun and Clarke's 6-step framework of thematic analysis involves processes of transcription, coding, analysis and writing a report. The first step was familiarizing with the data set. This involved transcribing the data obtained from the audio recordings and translating the scripts that were in Kiswahili to English. After that, the scripts were read multiple times while noting down patterns or codes that occur. Thiswas followed by the generation of initial codes from the transcript, which was achieved by reducing the data into organized clusters and collating the data into relevant codes that answered the research question. This process was thorough and comprehensive to ensure all relevant extracts were accorded the necessary attention.

The third step was listing the emerging themes and assigning the data to the various themes, with a description of what each of the overarching themes meant. Reviewing the themes was the fourth step of Braun and Clarke's thematic analysis model applied in this study. In this step, the themes were studied to find coherence and consistency between the themes themselves and against the entire data set gathered. This resulted in the generation of a thematic map which showed the process of understanding the themes to tell an accurate story of the data. Care was taken to ensure that the themes were not just paraphrased but critically looked at. After this, the analysis entered the fifth step, which was defining and naming themes. In this step, the data within each existing theme was reviewed to be included in the final presentation, with caution to prevent overfragmentation but obtain deeper meaning beyond the superficial ones in each story. The names of each theme that contributed to the best understanding of the stories were selected and finalized. The sixth and final step of the thematic analysis model was producing the report. Here, a detailed, concise and logical narrative of the story with the themes was written down.

Qualitative research is subjective in nature, with personal experiences described verbally (Akinyode & Khan, 2018), so verbatim extracts were included to ensure honesty and integrity by illustrating the analytical claims in the justification of the research findings.

This thematic analysis ran simultaneously with data collection until no new codes were yielded. Having multiple coders and the use of a coding agreement for consensus was done to ensure reliability.

Dissemination of the findings was done to spread awareness of the challenges of providing continence care for older adults. Findings will be shared among all participants of the research, primary care teams including community-based initiatives for older adults, older adults themselves as well as researchers and policymakers in older adult care.

3.10 Ethical Consideration

The research complied with ethical principles that govern research involving identifiable human subjects and sensitive topics. Ethical approval was obtained from research ethics committees of Kabarak University (KUREC), AIC Kijabe Research Ethics Committee and NACOSTI. NACOSTI License No : NACOSTI/P/24/37376 and Kijabe Hospital ISERC Approval No: KH/ISERC/02719/0020/2024.

Participants received clear explanation of what the research entails, including methods of data collection, anticipated risks and plans for mitigation. They were informed of the right to withdraw at any point of the research without risk of affecting the services they receive from AIC Kijabe hospital. Additional consent was obtained from the care recipients who had mental capacity to consent. Each participant retained a copy of their signed consent after providing both written and verbal consent. Participants was assured about the confidentiality, including anonymity, ensuring privacy during data collection and analysis. They were also informed of the plans to share the findings after data analysis, including its implications.

Data was de-identified, and in the place of names, codes were used to maintain confidentiality and anonymity. Data was stored in encrypted files only accessible to the principal investigator and research assistants. This raw data will be destroyed two years after the research is concluded.

All interviewees will be followed up to assess any ongoing psychological needs after the discussions. This will be done during and after dissemination of findings via phone call and physical meetings where feedback will be obtained and the emotional well-being of the participants adressed.

CHAPTER FOUR

RESULTS, DATA ANALYSIS AND PRESENTATION

This chapter contains the results and the discussion.

4.1 Introduction

4.1.1 General Information

After conducting 3 focus group discussions and 3 key informant interviews, data saturation was reached. The focus group discussions involved 16 participants all from the community around the hospital, each lasting 1 hour 15 minuteswhile the key informant interviews involved 3 participants, done in the hospital's out-patient department and took an average of 50 minutes each, resulting in a total of 18 participants for the entire study.

4.1.2 Demographic Data

A total of 18 participants took part in the study. There were 9 males and 6 females, whose ages ranged from 23 to 79, with an average age of 44.5 years and an average level of education attained being secondary school.

Table 1

Demographic Data

Participants	Charateristics	N=15
Age	48-35	3
	26-30	10
	>60	2
Sex	Male	6
	Female	9
Education	Primary	1
	Secondary	6
	College	8
Relationship to care recipients	Spouse	2
	Child	9
	Grandchild	4
Emplyment status	Self employment	7
	Emplyment	4
	Unemployment	4
Duration of caregiving	2-5yrs	8
	6-20yrs	3
	>20yrs	4
Caregiving tasks	Unpaid	0
	Paid	15
Age of care recipients	60-70yrs	1
	70-80yrs	2
	90-106yrs	13

The majority of the caregivers were adult offspring caring for their par**en**ts with incontinence, with most of them providing care for an average of 8 years. 3 key informant interviews were done with the healthcare workers in the hospital from the palliative department. The healthcare workers had a background in nursing and clinical medicine. The most common comorbidities were stroke, type II diabetes mellitus and hypertension.

Table 2

Participant and Care Recipient Characteristics

Caregiver	Care Recipient	Diagnosis & Comorbidities	Relationship	Duration of Caregiving	Paid/ Unpaid
27,M	76, F	Urine incontinence, hypertension, DM	Grandmother	5 years	unpaid
36, F	98, F, 104, M	Urine incontinence, hypertension, heart failure, DM	Parents	8 years	Unpaid
23, F	97, M	Urine incontinence, hypertension, dementia	Grandfather	5 years	Unpaid
27, M	97, M	Urine incontinence, dementia, Type 2 diabetes mellitus (T2DM)	Grandfather	7 years	Unpaid
57, M	100, F	Arthritis, dementia, mixed incontinence	Mother	>20 years	Unpaid
40, F	96, F	Hypertension, urine incontinence, DM	Mother-in-law	4 years	unpaid
F, 43	89, M	Arthritis, urine incontinence, hypertension, heart failure, stroke	Father	8 years	unpaid
44, M	96, M	Stroke, urine incontinence, Benign Prostatic Hyperplasia (BPH), dementia	Father	4 years	Unpaid
48, F	86, F	Stroke, hypertension, DM, mixed incontinence	Mother-in-law	>20 years	Unpaid
50, M	82, F	Mixed	Mother	2 years	Unpaid

		incontinence, stroke, hypertension, arthritis			
46, M	83, M	Stroke, urine incontinence	Father	3 years	Unpaid
79,M	73,F	Stroke, DM, Hypertension	Spouse	5 years	Unpaid
35,F	78, M	Dementia, mixed incontinence, hypertension	Father	5 years	Unpaid
53, M	89, F	Arthritis, stroke, urine incontinence	Mother	>20 years	Unpaid
60, M	89, F, 94, M	Stroke, hyptension, arthritis, dementia, DM, heart failure	Parents	11 years	Unpaid

4.2 Themes and Sub-Themes

A total of 7 themes each with 4-6 sub-themes were elicited from the data. These 7 themes were: family dynamics, the effects of caregiving on the caregiver,financial burden, practical measures and strategies, healthcare system dynamics, cultural perspectives and respite care challenges.

Table 3

Themes and Sub-Themes

No	Themes	Sub-Themes
1	Family Dynamics	(i) Role dynamics (ii) Family conflict: blame, inequitable burden, inheritance, favoritism (iii) Family organization, unity (iv) Perceived Benefits of caregiving: stronger bond with care recipient
2	Effects on Caregivers	(i) Physical effects: poor sleep, fatigue strain), neglect of own health (ii) Emotional strain: stress, anxiety, hypervigilance, depression, grief, abuse (iii) Stigma: self-stigma, community, hospital) (iv) Isolation:full-time caregiving, stigma, loneliness
3	Financial Burden	(i) Financial peril from debts (ii) Expensive medicines and interventions (iii) Containmentand hygiene products (iv) Transportation to hospital (v) Loss of income
4	Practical Solutions and Strategies	(i) Innovation (flushing system, frequent checks) (ii) Frequent waking (iii) Soap and water, bed liners, diapers (iv) Frequent stopping during commutes (v) Home catheter changing (vi) Respite care: paid caregivers
5	Healthcare System Challenges	(i) Stigma (ii) Invisibility of incontinence (iii) Ignoring incontinence (iv) Financial burden (v) Inappropriate medical response (vi) Cultural Persepective and Perceived Positive Benefits
6	Cultural Perspective	(i) Gender roles (ii) Stigma (iii) Perceived benefits
7	Respite Care Challenges	(i) Inconsistency of caregivers (ii) Cost of respite care (iii) Abuse (iv) Lack of integrity of paid caregivers

4.2.1 Family Dynamics in Caregiving

Appointment into the Caregiving Role

Handling incontinence is a challenge that many families have to cope with, usually without prior planning. Caregivers are usually not selected, they will often be family members in the nearest geographical proximity to the older adult with incontinence. This may be the spouse or adult children of the ailing older adult, assisted by the rest of the family members.

- ✓ *Caregiving roles are often assumed by the nearest family member, which may impact the trust and emotional attachment necessary for effective care. [K1]*
- ✓ *"My mother was able to wrap him in those diapers but because of her weakness she was still not able to carry him to the toilet and out of the house."*
- ✓ *"I was the main caregiver for my wife, doing all the work and also had a daughter that would come from Nairobi to assist me together with the other children." [G2R4]*

Mostly, the familial expectation is that the adult sibling living within familial land, usually male, will automatically become the primary caregiver. If married, the spouse also takes up some roles to support him.

- ✓ *"I am among siblings of seven and I'm the last one but when our parents are suffering I have to take responsibility."* (G2R4)
- ✓ *"My wife had to take time out and become her caregiver and the eventual challenges also fell on me." [G2R1]*

In some instances, the ailing older adult with incontinence is the one who will select an appropriate family member to take up the role of the primary caregiver. This presents a significant burden to the primary caregiver, who has to ensure that all the basic needs are met, including health concerns.

- ✓ *"On the last day of my father being alive, I took him to the hospital and his last words were 'I am leaving your mother to you, where her legs will be unable to reach, make sure you reach that place for her.'"* (G2R1)
- ✓ *"If an old person chooses you, you are the one that will become his or her caregiver... it affects relationships within the family." [K1]*

Refusing or neglecting caregiving responsibilities could attract curses while accepting them brings spiritual blessings. This, together with the guilt and fear of regret also appear influence the choice carry out caregiving obligations.

- ✓ *"It's the blessing, you know your parent can curse you but it's very difficult to get the curses because it would mean you have been very evil and have pushed them to the brink as their child…, parents will just take you as their child and will bear with you."* (G2R4)

Where finances allow, family members may opt to pay a caregiver to take up the job of caregiving, or consider respite care in the form of a long-term care facility for older adults. However, these cease to be options to families when competing resources become scarce and families are unable to pay for care.

- ✓ *"…when it came to a point where we had no money to pay the caregivers and when the caregivers himself would also get tired of the caregiving job, they would walk away."* (G2R1)
- ✓ *"I had to fire the caregiver because I could not pay her…my wife then took up the role of a caregiver to my parents."[G1R1]*

- ✓ "*Sometimes it gets to a point where the community suggests that this person be taken to an elder care home to be cared for there. But even when you go there you find that the challenges in the care home are even worse than what the person would have gone through at home.”* (R1)

Due to the financial demands of paid caregivers and the unavailability of appropriate long-term care facilities, the majority of the caregiving role is shouldered by family members who often come together to assist each other in making decisions on caregiving.

- ✓ *"We sat down and discussed and decided that given her condition we should build her a toilet..." [G1R1]*

Family Conflict

However, in some families, there appears to be a preference for certain family members to become primary caregivers, as primary caregivers have the final say when it comes to decision-making, including role distribution among family members. This can lead to tensions within families, particularly when it is perceived that some siblings are disfavored over others in caregiving responsibilities. Caregivers assigned bedside caregiving roles are usually those who are available to give up their time and have fewer sacrifices to make to provide care. In such cases, economic disparities are evident, as the roles are unequitable.

- ✓ *"The one with the lower social class is the one that is given the task of being the bedside caregiver ...assisting with activities of daily living."[K1]*
- ✓ *"The ones who have the money will support the family financially, and are also the ones who will come and blame the person at home for not doing a very good job." [K2]*

- ✓ “*For others, when they come to visit they do not want to deal with the smell or the burden of the manual bedside care and this results in withdrawal from the patient themselves.” [K1]*

This unequitable distribution of roles among family members can breed conflict and resentment, which affects how family members relate to each other and their care recipient.

- ✓ *“My wife would see that I was not going to work and that my brothers were going to work and had a lot of money and would come with big cars and money, she would start to ask herself, ‘Why is it that my husband doesn’t go to work and why is he the one that has to stay at home taking care of her parents?’”* (G2R1)

Care recipients undergoing mental health challenges pose a risk of abuse to the caregivers. Aggressive behavior, anger and bitterness in the care recipient may contribute to a socially charged environment fraught with fear of potential conflict. Primary caregivers often found themselves playing the role of peacemaker within the family, mediating conflicts that arise due to caregiving responsibilities as well as communication challenges, including differing opinions on how to care for their elderly relatives.

- ✓ *"They usually called me to the side and advise me on what they want with him regarding his help or in anything that they have difficulties talking to him." [G1R5]*
- ✓ "*But when I go to confront him about it, I met with a very serious anger because he is short-tempered, and the result is verbal violence." [G3R3]*
- ✓ *"There is some sort of a competition and blame game which results in guilt in the one doing the bodily work at home." [K1]*

- ✓ *"Yes, there's a time he hits things, for example, if something is on the table he will hit it."[G3R5]*

Caregiving for recipients with behavioral challenges encompassed physical and emotional support, requiring mediation skills to manage strained interpersonal dynamics, taking an emotional toll on caregivers.

4.2.2 Effects of Caregiving

Sacrifices on Personal Freedom, Career, Finances and Health

In ensuring the patient's comfort, caregivers struggle with physical and emotional effects on their physical and emotional well-being. Physically, providing care for an older adult with incontinence is a task that causes overwhelming physical and mental exhaustion.

- ✓ *"It affected my health, from getting fatigued to feeling like my brain was at a standstill." [G2R1]*

Primary caregivers often put the health of their ill loved one with incontinence ahead of their own, ending up living in poor health.

- ✓ *"They will usually put the needs of the patient before their own. They self-sacrifice and family will also sacrifice them to take care of the one who is more critically ill" [K1]*
- ✓ *"Even when we take our father to the hospital, she would not want to be cared for, and would say no just take care of that." [G2R2]*
- ✓ *"They rarely prioritize themselves or even take an opportunity to have a health check for themselves."[K2]*

Emotionally, it causes stress and anxiety. Due to the repetitive nature of the full-time task of caring for an incontinent person, caregivers strain to ensure that the care recipient’s toileting needs are attended to in a timely fashion. This results in constant vigilance, adding to emotional strain.

- ✓ *"I have to wake her up three to four times every night to avoid her messing on the bed." [G2R4]*
- ✓ ‘*I slept on the sofa every night for two good years, without lying in a bed, because... I would be called anytime any minute, to attend to my mother’[G2R1]*
- ✓ *"The alarm is in the brain it’s a sort of self-programming it has to be, if it's about medication or going to the toilet you just automatically remember."[G2R3]*

Caregiving was found to be a full-time job that resulted in the loss of personal freedom and limitation of social interaction. Participants perceived confinement into the unending caregiving responsibilities and this was linked to feelings of loneliness and isolation. Dependence from the care recipient exerts a psychological weight on the caregiver, resulting in a sense of physical and emotional constraint.

- ✓ “*I slept on the sofa every night for two good years, without lying in a bed, because... I would be called anytime any minute, to attend to my mother”*[G2R1]
- ✓ *“The days are long. You find that you are unable to leave the house and able to leave the compound because you have to stay at home with your sick parent and if they fall asleep you have to stay there and watch them because you do not want them to wake up and not find you. After all, they then become anxious’*[G2R1]
- ✓ “*So, we too would fail to sleep, and during the day because you were always there would have to stay with him. So constantly someone had to be with him throughout*." [G1R3]
- ✓ *“As for me if I have to leave to go to town I have to make sure that I come back quickly because I have to stay with my mom and keep her company even if it's*

> *just the two of us. It is something that seems to have no end because we know that she's not going to recover and she will never return to her normal self" [G2R2]*

The perpetual focus on the care recipient's needs denied the caregiver freedom to participate in personal and social engagement, including pursuing personal development, evidenced by forfeiting career opportunities and professional engagement towards future prospects. This would impact the ability to sustain regular employment or even maintain self-employment.

- ✓ *"Some jobs are far away from home that you cannot take... and on clinic days you have to stop going to work." [G3R2]*
- ✓ *"I was going to work and I had to stop working." [G3R4]*
- ✓ "*And also, if you get a job you cannot take a job which is going to make you come home late because if you come home late it becomes an issue to grandpa because he cannot sleep and until he sees that you have arrived home. So, you have to have an employer who is understanding.*"[G1R5]
- ✓ *"...if it's work one has to leave early, if you are at home you have to stay inside the house, and we are still young, you see we are still at the age of 20s, trying to make a living" [G3R3]*
- ✓ *"Even when I get a job and someone calls me to come where are you there's a job here, I will receive that phone call in secret so that he does not hear it because I fear his anger." [GIR5]*
- ✓ *"Because of how he can talk to you on the phone which makes you feel very hurt." [G3R1]*

Some participants chose to prioritize caregiving, resulting in disruptions that would impact the household and affect relationships among family members. For instance, relocation from their own home to live with the care recipient or, accommodating the care recipients into their homes.

- ✓ *"I completely moved... I had to close my business and come and start afresh at my mother's."[G3R1]*
- ✓ *"My wife would start to ask herself, 'Why is it that my husband doesn't go to work and why is he alone, among all the siblings the one that has to stay at home taking care of the parents?'" [G2R1]*
- ✓ *"I had to move from a small house to a much bigger house that would be large enough for my parents and my family."*

Some caregivers had to restrict their participation in social activities to fulfil their care roles. Caregivers of their spouses who have incontinence often forfeited intimacy with their ill loved one due to the physical incapability from the illness but also due to psychological barriers.

- ✓ *"I was a church elder before my wife fell ill, but I had to resign, eventually only attending church and not all the other meetings outside of the church services." [G2R3]*
- ✓ *"Even when there's a party near home and she has been invited she's unable to completely go"[G1R1]*
- ✓ *"The days are long. You find that you are unable to leave the house...I just encourage myself and I also encourage my mother because what must be has to be." [G3R5]*

- ✓ *"When I have a problem, it is my children who come to help me...the neighbors are used to my absence and they have no problem with it." [G2R3]*
- ✓ *"It also affects sexuality where some feel like they're no longer man enough to be providing conjugal rights to their wife and then they usually will have thoughts of fear, that is paranoia of infidelity"[K2]*

Social withdrawal, isolation, dependence on other family members was found to alter the social, emotional, and personal lives of caregivers, often leading to a diminished sense of identity.

Emotional and Psychological Impact

Caring for loved ones with chronic illness including incontinence was found to cause significant psychological effects on caregivers. Stress, anxiety, guilt, hypervigilance and poor sleep impacted on caregivers.

They would have to responsibly deal with the mental health challenges of their loved ones who would struggle with feelings of despair and exhaustion, and express anger from a perceived sense of neglect.

- ✓ "*He doesn't live far from me... he gets angry... I felt that if I continued with him I would get angry too." [G2R5]*
- ✓ *"He would become as though he was in depression... he was always in a negative state of mind." [G3R2]*
- ✓ *"The older adult gets tired of life and feels as though they are not worthy of the care they receive from their children." [G3R1]*
- ✓ *"So, it's like he has sold fear to them, because if anybody wants something they are afraid of telling him directly." [G1R4]*

- ✓ *"I have to take care of the words that I use with him because it's easy to make him angry and become enemies." [G3R3]*

Sleep was also disturbed, not just by having to wake up to maintain hygiene but also being kept up by care recipients with sundowning from dementia, leading to measures to induce sleep such as sleep medicine.

- ✓ *"I have to wake her up three to four times every night to avoid her messing on the bed." [G2R3]*
- ✓ *"There are nights he would talk the whole night, and we had to start giving him sleeping pills." [G3R1]*

In other instances, they would resist care due to the perceived sense of being a burden to the caregiver.

- ✓ *"The smell of the fecal matter or the urine, makes the patient start withdrawing from receiving that care."[K3]*

Caregivers would do this by self-control, suppressing their own emotions to focus on the caregiving routines, but at times this took a toll on them, resulting in physical ailments and substance use disorder to cope with the stress and overwhelm.

- ✓ *"My mother... had so much stress that she suffered a stroke too.When she suffered a stroke she too lost her speech, lost her ability to walk, and also required diapers." [G2R1]*
- ✓ *"I felt like I was going to lose my mind, I would stand in the middle of the shopping center and pray very loudly and let out a scream." [G3R2]*
- ✓ *"I would get tired, my brain felt like it was on a standstill, and I would drink all kinds of alcohol, to be honest, I have taken all kinds of alcohol from Chang'aa to Busaa, to... all of them, and that is just to survive."* (G2R1)

Stress would also emanate from other family members who would blame the caregiver for failing to fulfill the family's expectations on caregiving, further affecting the emotional well-being of the caregiver by breeding anger and resentment. In other instances, when the care recipient would pass away, guilt would persist in the caregiver who would feel responsible for their loved one's death.

- ✓ *"The guilt can go on even beyond the death of the patient, so we need to clarify to the patients and the family that this is the disease progression that has caused the death of your parents." [K1]*

Hopelessness, grief and resignation from perpetual caregiving was found to affect the participants. This resulted from the realization that the condition of their loved one was unchanging and would therefore require continuous care reinforcing feelings of hopelessness. Resignation would come from accepting that the caregiving role meant endless responsibility and a never-ending cycle of sacrifice to care for an ill loved one with no hope of improvement. There was also profound sadness from the anticipated death of their loved ones.

- ✓ *"It is something that seems to have no end because we know that she's not going to recover and she will never return to her normal self." [G2R2]*
- ✓ *"...you have to take care of them throughout the life that God has given them, up until the time of their God-appointed death." [G1R1]*

Embracing the task of caregiving was found to be an emotional journey towards resilience that caregivers had to contend with to adapt to the multifaceted challenges that come with it. When asked whether they felt like giving up, caregivers expressed that despite the burden, their support for their ill loved one was resolute, as the illness of the older adults with incontinence was not by choice. Coming to terms with their role appeared to be inspired by a deep sense of obligation towards their care recipients, undeterred by the challenges of devoting their entire existence to caregiving. A religious responsibility also influenced the determination to provide lifelong care until natural death.

- *"...since our wedding in 1973, the church wedding, there was a covenant that we had with each other and I remember that covenant and I will not break it. So, I have no problem or any difficulty because I made a promise to her." [G2R4]*

A moral obligation to care for older adults is also a tradition rooted in the caregivers' culture.

- *"...it's also like a tradition because you see how you have to be responsible because this person once was your parent and now that they're in need... "[G3R1]*

Stigma

Despite measures of maintaining hygiene, family members would still encounter stigma from the community. Due to stigma, caregivers do not disclose their care recipients' health issues touching on incontinence so as to maintain their dignity. In the discussions, it emerged that fear of negative comments and lack of helpful responses from the community influenced the choice to keep the issue of incontinence private.

- ✓ *"You see it becomes a shame and truly it's shameful but you can see that she's not intending it." [G1R1]*
- ✓ *"When they ask what condition she is in... you only tell them she's fine, you will not expose her issues to them."[G2R2]*
- ✓ *"Once the issue is exposed to the rest, it has already been told out to everyone. Especially the issue of incontinence, it's a shameful thing."*

Families may go to the extent of restricting visitations to family members only and duration of visits to maintain the dignity of their loved one. This results in social isolation in some cases.

- ✓ *"When they come to visit they only allow us into the sitting room... it's because of the shame that they would hide what was going on with her."[G3R1]*
- ✓ *"The first thing when you enter the compound or the homestead is that you are met with a very bad smell." [G1R7]*
- ✓ *"People will still talk but you try your best not to give them a reason to talk... you will welcome them well to your home, but there are also those who will come and say that house stinks." [G3R2]*

Despite the proximity to the ill older adult with incontinence, some family members opt to distance themselves from the care recipient with incontinence and opt for paid caregivers or abandon the task to other family members due to their discomfort with the task of caring for an incontinent person. This may breed sentiments of unfairness among family members, particularly siblings.

- ✓ *"It takes a lot of courage... it takes a lot of courage because not everyone has the heart or the willingness to take the excrement and discard it."[G3R2]*
- ✓ *"You have to be secretive... you will not expose her and her issues to them (neighbors) because they have no help... It's better to have discussions with the doctor."[G1R1]*

Because of stigma, caregivers and their care recipients shy away from social gatherings for fear of shame. This affects the caregiver's well-being due to isolation and lack of interaction with others.

✓ *"She fears being found out by others because she only stays a short while before having to leave the celebration and if she doesn't leave she will have incontinence and that will be shameful for her."[G3R1]*

✓ *"For example, today there's a dowry payment celebration, and she had been invited but will not be able to go. She has said no .. because of her condition of urinating, for fear that if not managed well, it will be shameful."[G1R1]*

However, some community members may be understanding and even supportive despite the isolation. In those instances, families will be welcoming to the community members, which was found to promote social engagement in an otherwise homebound lifestyle. During the visits, church was found to be a form of social support

✓ *"If somebody comes to visit him, we do not restrict, we just allow them to come but we have to sit there and see him then they go."[G3R5]*

✓ *"She doesn't even go to church anymore; her prayers and fellowship are brought home by her fellow churchmates."[G1R2]*

✓ "*People understand me, despite my absence from community activities, and they appreciate me, they do not despise me and when they come to see my wife I welcome them*." [G2R4]

From these findings, it was evident that religious affiliations and a supportive community we source of auxiliary support, particularly emotionally.

4.2.3 Financial Burden

In order to afford maintenance of hygiene standards, financial sacrifices would be made. This would go into the purchase of soaps, containment products, medicines and assisted living equipment.

- ✓ *"Her main problem is the diapers because she uses three packs of diapers… you know each pack costs 1,000 shillings." [G2R3]*
- ✓ *"Her medicine is also a challenge because she needs medicine for the heart and for blood clots." [G3R5]*
- ✓ *"When my mom recovered she was then able to wrap him in those diapers but because of her weakness she was still not able to carry him to the toilet and out of the house, so we needed a wheelchair."[G2R4]*

The cost of caregiving spanned beyond the financial burden of maintaining hygiene into transport costs incurred during hospital visits.

- ✓ *"Initially, she would go by matatu by herself... now she needs a taxi to take her to the hospital, and even after treatment she would take one just outside the hospital to bring her back home." [G1R1]*
- ✓ *"The family members feel so burdened that they prefer to have the patient die so they will not continue to suffer because of so many needs." [K3]*
- ✓ *"If there is no money, and basic needs such as food are a problem, this care is affected." [K1]*

Caregivers often found themselves having to make financial sacrifices such as selling family assets to be able to afford the costs of caregiving. Others would have to encounter challenges on personal safety to make ends meet for the cost of caregiving. For some families, adapting to the new financial demands meant changing their income-generating strategies to shorter-term earnings. Others would have to take up temporary jobs or work many hours and sacrifice their time for rest and family time.

- ✓ *"Earlier I used to own a car and had many cows all of which I sold because of my wife, she needed medicine she also needed hospital admissions she needed diapers, and so on."*[G2R3]
- ✓ *"I sold my car overnight at a throwaway price because I had got to the end of the road, I had many debts I had a family to take care of rent, and the patients.I would have to walk home at 2am with the lamp from the shopping center to my house and a distance of two kilometers while trading the light on the road."* (*"*[G2R1]
- ✓ *"Every week we needed money so we had to change from businesses that were paying monthly to those businesses that pay weekly for instance we would be taking milk to a cooperative circle where payment would come at the end of the month but we stop that and had to so it's smaller shops where we would get money daily or weekly."* (R2)
- ✓ *"Aside from that we had to find daily jobs from where we would get wages to go to clinics."* (G2R2)
- ✓ *"I am a carpenter… I had to find a way to survive other times working 72 hours without sleep and continuously going from work to work." [G3R1]*

Based on the financial strain and resultant economic adaptation, the resilience of families was evident from the profound economic, physical, and emotional sacrifices they would have to make.

4.2.4 Practical Measures and Solutions

In this research, participants were caregivers of older adults with incontinence whose functional status was at the Karnofsky Performance Scale of 50 and below, requiring considerable assistance and medical care. The older adults with incontinence had other comorbidities that resulted in dependence on activities of daily living such as eating, grooming and administration of medications to enhance adherence.

- ✓ "*Every day we would dispense her meds for her... If I didn't do that she would make mistakes in taking them." [G2R4]*

To handle incontinence, participants reported using hygiene measures such as frequent washing and airing of bedding, using adult diapers, polythene liners on beddings, frequent emptying of the urine bag in those using catheters, and emptying excrement from bedside basins.

- ✓ *"...due to poverty, the houses lack a toilet within the room and there's a problem of urgency and frequency, so they will usually use a bucket or a basin for bedside needs."[K1]*
- ✓ *"Using a basin or a bucket is a shameful thing. By building a system for flushing for her we have eliminated shame, because with that flushing system the smell has been eliminated and hygiene has been maintained."[G1R1]*
- ✓ *"So, hygiene is very important... after using a bucket, there has to be someone who is responsible who will take the bucket and pour the excrement and discard it."[G3R1]*
- ✓ *"Some families will use the blankets plus a polythene bag that is lined on the bed in order to prevent the mattress from getting wet." [K3]*
- ✓ *"The family that has a financial muscle is willing to buy the hospital bed, a ripple mattress, potted water in the rooms."[K1]*
- ✓ *"When he was unable to walk, he had incontinence, so we had to wrap him in diapers."*[G2R2]

- ✓ *"He had a prostate problem... He stayed with [the catheter] for 12 years." [G3R2]*

In some instances, home modifications were made to facilitate the toileting needs of the care recipient. For those without tap water, potted water was used to maintain hygiene while others used innovative built-in flushing systems in the rooms. Some families use air fresheners and ventilation to deal with unpleasant odors for the comfort of the household. These strategies were done to protectthe dignity of their ailing loved ones, but this hands-on work was harder when the care recipients with cognitive impairment were unable to express their care needs.

- ✓ *"My wife is unable to talk about her needs because she lacks mental capacity but up to now I am in charge of her everyday activities from eating to bathing going to the toilet her medications and even our leisure activities."* (G2R4)
- ✓ *"Because he's unable to express or remember when he needs to go, you find urine has leaked already." [G3R4]*

For those with immobility, coping strategies such as use of a hospital bed, wheelchairs and walking aids were used. Other than managing medications, caregivers would also take part in the rehabilitation of their care dependents, especially those who suffered immobility following stroke.

- ✓ *"I built for myself at home a similar thing like a trough by which someone will support themselves as they rise up to walk."[G2R3]*
- ✓ *"She was always in bed and would need to be wheeled out on a wheelchair." [G3R1]*
- ✓ *"I asked my children to get a wheelchair so that I could take her out of the room and even out into the sun."[G2R4]*

To cope with the challenge of incontinence, these practical strategies were self-learned by caregivers who suddenly found themselves in the role of caregiving.

- *"When my mother got a stroke, our lives changed all at once because of how things were going." [G2R2]*
- *"It's only while in her hospital that I was taught how to take care of her."[G2R4]*
- ‘*No, we just had to learn by ourselves and we had to get used to it because when something like this hits you, would you have the time to run to Kijabe?’.[G3R2]*
- *"Her condition was getting worse she was weak on her legs possibly because of bleeding*." [G3R5]
- *"He had a catheter placed in two times... Other times when he would say his catheter was leaking, we would bring him to the hospital."[G1R5]*

Further adjustments in caregiving routines would be made to support the changing needs of their care recipients with deteriorating health, such as unforeseen catheter dislodgement necessitating a hospital visit.

4.2.5 Healthcare System Challenges

4.2.6 Healthcare and Communication

Caregiving for older adults with incontinence is accompanied by health challenges including complications of incontinence, resulting in frequent hospital visits. Notwithstanding, caregivers do not discuss their challenges with healthcare providers. The study found that reluctance to disclose their struggles with incontinence arises from a perception of shame and fear that they may not be well understood and their problems not managed with effective practical solutions for their problems at home. Caregivers expressed that healthcare workers ignored the problem, only asking about incontinence if it touched on a problem that could be resolved with urgent medical intervention, for instance, catheter leakage. Additionally, time constraints at the doctor’s consultation room often compelled caregivers to only focus on apparently urgent matters rather than chronic conditions such as incontinence. Fear of judgment and embarrassment from healthcare workers as well as other patients influenced non-disclosure. This was compounded by a lack of access to timely care, resulting in adaptations to manage complications as they arise.

- *‘No, we just had to learn by ourselves (catheterization) and we had to get used to it because when something like this hits you, would you have the time to run to Kijabe?’[G2R2]*

The hospital environment appeared to be intimidating to caregivers and their care recipients due to stigma and fear of public embarrassment from healthcare workers and other patients. Several caregivers would accompany the care recipient to ensure a comfortable and expedited clinic visit and would share tasks such as queuing for services, and maintaining hygiene for incontinence as well as mobility support.

- *"You feel that even if you're coming back for a refill of medications, you do not have to come with the patient to the hospital because it can become overwhelming." [G3R2]*

In hospital, patients with incontinence may receive expedited care for the comfort and dignity for others in the hospital, often with assumptions and insensitivity of financial resources of caregivers.For some families, caregivers would opt forhospitals near home which permit quick attendance to the patient's needs while avoiding frequent toilet visits.

- *"The biggest rush comes in because we do not want to create a scene... there will be a bad smell which even the healthcare providers will tell you." [G3R2]*

- *“Sometimes nurses will ask the caregiver, ‘have you come with the diaper? Have you changed him?’… if they say no they are directed to the shop and asked to buy a diaper and change the patient immediately.” [K1]*

An aversion to addressing the full extent of the challenges of incontinence also arose from internalized stigma and financial concerns. Caregivers were apprehensive of financial burdens from unnecessary investigations and prescriptions which made no difference to the patient’s condition of incontinence. Fear of high pill burden in complex drug regiments was also raised as a concern for not wanting to express their struggles with incontinence. Consequently, attention would be diverted from futile continence care management to other more pressing health concerns such as control of hypertension and diabetes, leading to fragmented care in patients with complex health needs.

- "*First of all, it's shameful, then one has to ask themselves, ‘In as much as I will talk to this doctor about this issue will it change?’" [G2R1]*
- *“For us, anything to do with the private parts… it’s just a shameful topic. Incontinence is a private topic…[K2]*
- *"Well, you feel it's a bother just that it will not be taken care of. Another thing... it will not help [to go into the doctor’s room] financially if I have not gotten that catheter for free." [G1R3]*
- *"... one has to ask themselves, ‘In as much as I will talk to this doctor about this issue will it change?’…" [G1R1]*

Healthcare workers admitted to discomfort in asking about incontinence due to lack of adequate training.

- *“Most of us do not know how to cope or provide care for some issues such as incontinence ...our training has taught us to only ask about the things that we can fix.”[K2]*
- *“We fear asking because we are triggering pain and trauma but not really providing solutions to that issue.” [K1]*

Caregivers develop coping mechanisms to accept their difficult reality. Suppression of the discussions during hospital visits may fail to conceal their challenges when healthcare workers perceive them to be affected by their role. In general the struggles faced by caregivers are often overlooked by healthcare workers, who focus mainly on the patient.

- ✓ *“Caregivers coming to the clinic looking really tired but they put on a brave face because they do not want to show the struggles they go through at home…but during the consultation (in the doctor’s room), they may become irritable.”[K2]*

The majority of primary caregivers providing bedside care of their ill relatives with incontinence were found to be women. However,due to cultural expectations of tolerance, they were found to be less likely to voice their challenges to gain support compared to male caregivers who more openly expressed their challenges. Women were less likely than men to express their needs openly and were more innovative in coping with care for incontinence. Despite their better understanding of the patient’s condition, female caregivers were often left at home, or outside of the consultation room during hospital visits.

- ✓ *"Our mother… was taking care of him with assistance from our wives."[G2R2]*

- ✓ *"Generally, most men do not take good care of their parents whether it's a father or mother because they are not tolerant and lack the heart to care for the sick patient." [K1]*
- ✓ *"Most of the female caregivers will struggle to talk about their difficulties especially when the patient is present." [K2]*

From the discussions, it was evident that women bore a greater burden of caregiving compared to men as they were likely to be assigned the role of primary caregiver, performing the bedside care tasks.

Health Financing

Health insurance did not cater for continence products, forcing caregivers to pay out-of-pocket for the products and services. Despite financial challenges, caregivers highlighted the support provided by NHIF (National Health Insurance Fund) for elder care, which helps cover medical expenses related to their elderly relatives' conditions, alleviating some financial burdens associated with hospital visits.

4.2.7 Cultural Perspective on Caregiving

Gender

Caregiving has traditionally been taken to be a feminine duty due to the nurturing nature of women. Discussions with the participants revealed that women are most likely to be given the primary caregiving role owing to their ability to be more emotionally resilient and therefore tolerant of the constant needs of their care recipients with incontinence. Additionally, the position of women as meek, lowly, unemployed and thus amenable and available for the caregiving role makes them preferred as caregivers. In some communities, males caring for their female parents with incontinence was considered taboo and could attract curses due to the perceived exposure of the parent’s dignity in providing continence care.

- ✓ *"Generally, most men do not take good care of their parents whether it's a father or mother because they are not tolerant and lack the heart to care for the sick patient." [K1]*
- ✓ *"Our mother… was taking care of him with assistance from our wives." [G2R2]*
- ✓ *"The friends of my father usually come when I am around...They have often told me if your mother is one day unable to take care of your father, do not be afraid of his nakedness." [G2R3]*
- ✓ *"For me, people said you cannot you must not take your mother to the toilet because you will see her nakedness how will you see her nakedness? You will be cursed" [G3R1]*

However, when it came to finances, the men were more likely to take up the financial responsibilities in providing care for their older relatives with incontinence.

- ✓ *"We go to a point where when due to the debt, were nearly losing the family land and this gives so much pressure to appearance that my mother ended up suffering a stroke." [G2R1]*
- ✓ *"My sister was abusive to my parents… I had to take up the debt on behalf of my sister and my parents in order to save the family land. [G1R3]*

Stigma

Incontinence can make patients feel weak and shameful, leading to emotional detachment and worsening mental health. In the discussions, participants said that stigma about incontinence stems from the belief that incontinence is a complication sexually transmitted infections acquired from sexual promiscuity.

- ✓ *“Others also tend to be violent and become harsh with their family members because they feel their sense of manhood is lost.”[K2]*
- ✓ *“Men do not want to appear weak and therefore will not want to be helped especially when it comes to matters of incontinence.”[K3]*
- ✓ *“Patients feel like they did something wrong to result in this incontinence, for instance, the men may believe that incontinence is caused by sexually transmitted diseases.” [K1]*

For older adult males with incontinence, feeling weak, shamefulness, and fear of societal judgment led to an additional burden of incontinence that in turn affected the caregivers.

Perceived Benefits and Positive Effects of Caregiving

Caregivers found that caring for their older relatives with incontinence strengthened their bond through increased trust between the primary caregiver and the care recipient. For participants who inadvertently became caregivers due to geographical proximity to the ill relatives, gaining trust took time and effort.

- ✓ *“She trusts me so much that even right now I have her ID card and also I know where she keeps her title deeds and her land documents” [GIR1]*
- ✓ *"When they come in, there is no emotional attachment and they have to work to get the trust back." [K1]*

Additionally, caregivers found that the community appreciates their work of fulfilling familial duties caring for their loved ones. Participants believed that caring for their ill loved ones with incontinence was a path to spiritual blessing, manifested in various ways such as prosperity, success and inherent rewards such as good health. They also believed that if they failed in their duty, they would suffer the same fate when they needed help later in life. Participants also reported that in fulfilling their responsibilities of caregiving, they were setting an example for the younger generation.

- ✓ *"When visitors come they always have to call me and when they are home and find that my father is well taken care of they appreciate our work." [G3R3]*
- ✓ *"Karma rule states that anything you do to someone whether good or bad will come back to you."[G3R4]*
- ✓ *"I pray to God that on my last day, I will be strong enough not to need a caregiver and that if I must need a caregiver I pray that they will treat me to their level best." [G3R5]*

Paid caregivers also appreciated the benefits of income and the lessons learned from spending time with older adults who would inspire them with their life experiences.

- ✓ "*I have grown by interacting with older adults because of their age difference, I've gained wisdom and that contributes to me getting inspired" [K3]*

However, community members provided moral support by encouraging the caregivers to continue with caregiving. Caregivers found the church helpful in providing emotional support through visitation and adapting church practices, to meet the care recipient's needs through fellowship with them in their homes.

- ✓ *"Even when she was admitted, it's only the church who were concerned... when they came they saw her there in hospital and even upon discharge from hospitals, they made sure that they came home to see her."[G3R1]*
- ✓ *"The friends of my father usually come when I am around...They have often told me if your mother is one day unable to take care of your father, do not be afraid of his nakedness." [G2R3]*
- ✓ *"...when children see that their grandfather is being cared for and washed by his children then they should follow that example." [G2R2]*

- ✓ *“The church people who come to visit are the ones who understand why my mom is not coming out of the house.”[G3R1]*

Religion was found to offer a source of hope and a way to connect with their ill care recipients.

- ✓ *"I sing for her the hymns and even though she does not remember any of the words I can see from her actions that she's able to follow." [G2R4]*

4.2.8 Respite Care Challenges: Difficulties With Caregivers

When families lack the capacity to provide care for their loved ones, they opt for paid caregivers as a form of respite. This however would come with challenges of lack of consistency, caregiver integrity, and conflict with caregiving companies. Some caregivers would quit work due to pay conflict, or abuse from the care recipient and other family members as well as an unstable home environment. In other instances, it was found that caregivers would in return abuse the care recipient emotionally, by neglect and even physically.

Due to financial burden, lack of consistent provision of supplies to maintain hygiene of the care recipient was found to cause psychological strain among the paid caregivers.Discrepancies between family expectations, actual supply and usage of containment products would lead to disputes. Additionally, lack of equipment to facilitate transfers or even rest during the night contributed to physical exhaustion. Paid caregivers also struggled to communicate the need for rest.

- ✓ “*Sometimes…the family wants the patient to have that diaper and they want to control the amount that can be used.”[K1]*

- ✓ *“Sometimes the family members will start complaining of financial constraints and this becomes a big issue and this usually will result in restriction of care supplies.” [K3]*
- ✓ “*They expect you to stay awake at all times and they will not even provide you a place to rest for the night. All that you have will just be a single-seat couch, no bed to lie on for the night*.” [K3]
- ✓ *“Getting an off becomes an issue and you are forced to therefore quit work because you cannot take it anymore, you need to rest.”[G3R1]*

When complications such as infection and pressure ulcers arose in the care recipient as a result of poor quality care from unhygienic conditions, family members would blame the caregivers for the deteriorating health of their ill relatives.

- ✓ *“The patients begin to see that they are being neglected yet the family are the ones who are not providing the supplies needed.” [K1]*

Caregivers faced a lack of respect for their role and devaluation, through verbal abuse from the care recipient, often bitter about their poor health. In turn, paid caregivers would project their frustration to the care recipient, resulting in a vicious cycle of harm within the home: abuse of the care recipient, high turnover of caregivers, poor coordination of care, and overall dissatisfaction.

- ✓ *“Some of these patients ... tend to be very abusive to the caregiver. ... they release this bitterness to the caregiver. They will usually be upset or angry about the change in their health condition… feeling that they are important people in society who have all the resources yet are now suffering.”[K2]*
- ✓ *“They (care recipient) will even tell you outright ‘You only here for money, for my children’s money’ and some will even refuse to receive care from you.” [K3]*

- ✓ *“They always wonder ‘What is this person coming to do, the equivalent of my grandchild coming to wash and feed me?’”[K3]*

Despite the presence of a work contract particularly from caregivers sourced from caregiving companies, families would often breach the agreement by increasing the workload and responsibilities of the caregiving to include household chores. This too provokes the departure of the caregivers. Sometimes, families that would prefer direct payments to caregivers, would compromise agreements with the caregiving company, whose core role is to provide alternatives for respite care.

- ✓ *“Sometimes it's not even about the money because you may want to employ someone but that person eventually regrets taking up the job and starts abandoning your patient and even abusing them.”*[R1]
- ✓ *“When they (caregivers) are called, they would go quiet and sometimes refuse to work and other times they would even hit the patient.”*[R1]
- ✓ *“I too have the same challenge because when our father would get visitors coming to the home after chatting with him they would leave some money let’s say 2,000 or 3,000 for medicine. But the caregiver that would be there at home would steal the money and not talk about it.”*[R4]
- ✓ *“The caregivers themselves would cook for themselves when they felt hungry at night and would eat without even remembering our mother.”*[R1]

However, paid caregivers complained of misunderstanding due to false accusations from manipulative care recipients which caused mistrust and strife among them and the rest of the family members.

- ✓ *“Pain is inevitable, although we try as much as possible to minimize the pain and make them as comfortable as possible… when you touch them and they have pain some patients will blame you and report it to their family members.”[K3]*

In conclusion, the interconnectedness of these themes underscores the vicious cyclical nature of caregivers’ challenges: family dynamics, financial strain, and systemic shortcomings, which intensify the negative effects, while inadequate practical solutions and healthcare responses as well as stigma perpetuate isolation and emotional burden.

CHAPTER FIVE

DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 Discussion

This section shall discuss the interpretation and implications of findings.

5.2 Family Dynamics

5.2.1 Assumption to the Caregiving Role

Assuming the caregiving role is informed by either normative commitments from societal expectations or affectual commitments based on existent relationships among family members. (Awuviry-Newton *et al.*, 2022, Vangen & Herlofson, 2023). In this study, the authors found that a good relationship with one's parents rather than expectations from society were the key driver to taking up the role of caregiving. Also in this study, geographical proximity, filial piety driving a strong sense of respect to their older adults were found to influence the motivation to becoming a caregiver. This was evidenced by the obligation to honor an appointment by an older adult to become a caregiver. It was also found that those living in close proximity to the care-recipient were the ones that participated in the research.

Additionally, a sense of reciprocity motivates caregivers to continue providing care for their ill loved ones. Family caregivers provided care for the older loved ones in return for their care when they were young and also for the assurance of future care provided to them by the young generation (Awuviry-Newton *et al*., 2022). Similarly, in our study, caregivers admitted providing care as gratitude to their parents and also as an example for their own children to emulate.

However, when it comes to gender, social norms have been found to have an influence on which gender becomes the primary caregiver. Male caregivers only take up the primary caregiver role, providing bedside care when there is a shortage of female family members to do it (Vangen & Herlofson, 2023). Similarly, a Ugandan study of caregivers of women with incontinence also found that society more often provided sympathy and social support to male caregivers (Ayadi *et al.*, 2023). Society often views women as more nurturing.

Social norms also make family members fear judgement (Awuviry-Newton *et al*, 2022). In our study, relatives talked of not wanting curses for failing to fulfil their caregiving duties to their ill loved ones.

Religious conviction also informs the choice to take care of older adults with incontinence. Some caregivers struggle to adjust to their new role of caregiving due to feelings of inadequacy and uncertainty about the condition of their care recipient (Ninnoni & Owoo, 2023).

5.2.2 Effect on Relationships

A desire to maintain independence among ill care recipients often leads to resistance against caregiving (Tan *et al.*, 2023). This resistance can create conflict when their declining health results in refusal of assistance with basic daily activities. Such resistance is exacerbated in older adults with cognitive impairment, where the perception of an infringement on personal dignity and privacy is heightened (Ostaszkiewicz *et al.*, 2020). This strain can lead to frustration and sub-optimal care from primary caregivers, sometimes resulting in neglect and abuse. For instance, paid caregivers, who may already be despised by both the care recipient and their employers, were observed neglecting care recipients by bathing them in cold water, refusing to assist with feeding, or not turning them regularly in bed (Mohamed *et al.*, 2023).

Additionally, spousal relationships often suffer from strained intimacy and sexual deprivation as the caregiving demands prevent the fulfillment of conjugal duties

(Ninnoni & Owoo, 2023; Ayadi *et al*., 2023). In this study, spousal caregivers had to give up sexual intimacy due to the prolonged and permanent incapacitation of their ill care recipients. Caregivers who had to move to live with their parents or those who took turns to stay with their ailing parents had a physical separation from their spouses, which strained their marital relationship. For others, having to host their ill parents meant that there was a lack of personal freedom and space for intimacy with their spouse.

5.3 The Effects of Caregiving on the Caregiver

5.3.1 Physical Effects

Being an older adults with incontinence is associated with severe functional disability, signifying either severe or terminal illness (Chen & Yu,2024). This implies requiring assistance with bathing, dressing, transferring, feeding and continence. The well-being of the primary caregiver is largely ignored by the caregivers themselves and also by the rest of the family members as the task of caregiving is primarily targeted for the care recipient, according to a study on caregiving for patients with prostate cancer by Ninnoni and Owoo, 2023. As a result, primary caregivers conceal their challenges and continue to live in poor health. Among the physical effects of caregiving for incontinence are persistent fatigue, muscle aches and poor concentration (Gratão*et al*., 2019). The levels of strain are higher in the unending physical demands of caregiving found in those cohabiting with the care recipient (Mello *et al*., 2017). The participants in this study also complained of physical strain, especially during transfers in those with immobility and being too fatigued to continue with caregiving responsibilities. The implication of this is that primary care practitioners should be vigilant for signs of burnout among caregivers cohabiting with and providing intensive care to their care recipients, as the level of physical strain in them is greater.

5.3.2 Disturbed Sleep

Poor sleep is a common factor among caregivers of older adults with incontinence. A study of such caregivers in Uganda reported that caregivers suffered physical symptoms of poor and interrupted sleep due to changed sleeping conditions, often having to sleep on hard surfaces to be in close proximity for the round-the-clock continence care (Ayadi *et al*., 2023). Likewise, the participants in this study also complained of aching bodies, poor concentration and constant fatigue due to uncomfortable sleeping arrangements. Sleep problems are intensified when the care recipient also has sleep problems, a common feature in older adults (Mohamed *et al*., 2023).

5.3.3.Psychological Effects

Caregiver burden encompasses various psychological challenges associated with the caregiving role. Caregivers often experience stress from constant anxiety and hypervigilance regarding complications from comorbidities (Tseng *et al*., 2015), as well as the demands of daily care, poor sleep, uncertainty about the care recipient’s health, and lack of support (Mohamed *et al*., 2023). The absence of integrated services to support continence care for older adults has been shown to cause persistent sadness and exhaustion in caregivers (Carsughi *et al*., 2019).

In our study, caregivers who brought their care recipients to the hospital exhibited feelings of helplessness and irritability. Additionally, significant life changes, such as those resulting from sudden impairments like stroke and vascular dementia, disrupt caregivers’ routines and force them to make sacrifices in many aspects of their lives (Mohamed *et al*., 2023).

Owing to the significant psychological caregiver burden, better communication between caregivers and healthcare providers is needed. Integrated services for patients with incontinence, to support the mental health of caregivers will not only benefit the caregivers but also the care recipients.

5.3.4 Reduced Social interactions

Caregivers often reduce their social interactions and participation in leisure activities (Ninnoni & Owoo, 2023), which leads to isolation and estrangement even from extended family members (Ayadi *et al*., 2023,Mohamed *et al*., 2023). In this study, a strain in spousal relationships was evident in caregivers had to spend time away from their nuclear families to care for their ill parents. Isolation of caregivers causes loneliness.

5.4 Financial Burden

Financial strain can significantly impact families who dedicate time to caregiving. Caregivers often face a loss of livelihood and income interruptions as they may forfeit job and career opportunities by either terminating their employment or accepting less-demanding jobs (Ninnoni & Owoo, 2023; Tan *et al*., 2023). In Uganda, for instance, younger caregivers frequently have to suspend their career development to manage caregiving responsibilities (Ayadi *et al*., 2023). This study found that the average age of participants was 44, and many had to put their personal aspirations on hold, affecting their future prospects. In addition to managing daily needs, medications and frequent hospital visits, the financial burden is exacerbated by the additional costs associated with providing continence care (Ayadi *et al*., 2023). Many caregivers have to sell their property and other valuables to be able to support continence care (Ansari & White, 2022). In this study, caregivers described selling their cattle and cars, and changing their income strategy in order to afford care for their loved ones.

Economic empowerment through perhaps community-based investment or savings programs will provide financial assistance to caregivers. Sensitization and partnership with employers to be more lenient and flexible to such caregivers may save families from financial catastrophe. For policy-makers, advocacy for local and central governments initiatives to provide tax deductions and subsidies on continence care services and products should be pursued.

5.5 Practical Measures And Solutions

In order to handle incontinence in low resource settings, caregivers adopt innovative ways to maintain the hygiene and dignity of their care recipients. Heavy reliance on soap and water, significant amounts of cleaning, limiting food and drink, and sticking to routine are some of the strategies employed (Ansar & White, 2022, Tseng *et al.*, 2015). In our study, participants described methods such as designing a flushing system within the house, using polythene to line the bed, frequent waking and checking especially at night, frequent stopping during the commute to hospital, and using diapers. Urinary catheters were only used if prescribed by doctors. For unpleasant odor, caregivers would use soap, frequent airing of bedding change of clothes, but deodorizers were deemed costly.

5.5.1 Coping Strategies

A phenomenological study in Ghana of caregivers of stroke survivors, many of whom had incontinence found that support from the religious community helps caregivers cope better by compensating for loneliness and isolation from limitations on social interactions such as participation in religious activities (Hyde, 2020). In our study, family members appreciated the visitation and encouragement from visiting church members. This implies that religious communities are a resource that can be harnessed to provide auxiliary appropriate support for caregivers of incontinent older adults.

5.6 Healthcare System Challenges

A lower socio-economic status is linked to limited access to information and higher levels of fear and anxiety in caregiving, largely due to uncertainty about the care recipient's health challenges (Tan *et al*., 2023). Participants in this study, who were from a low-resource setting with poor financial status, lacked a full understanding of their ill relatives' health changes. This resulted in diminished confidence in their caregiving tasks, a situation that was especially pronounced among caregivers of patients with dementia, who face particularly challenging behavioral symptoms.

Incontinence is often considered unpleasant and somewhat taboo (Gove *et al.,* 2017), which contributes to a fear of stigma and acts as a barrier to help-seeking (Ayadi *et al*., 2023; Murphy *et al*., 2021). This stigma leads caregivers to conceal the challenges they face while providing continence care. Moreover, caregivers are frequently devalued because of their lowly status as continence care providers (Ayadi *et al*., 2023). As a result, hospital staff often dismiss both caregivers and their care recipients when it comes to continence care (Ayadi *et al*., 2023). Additionally, caregivers may shy away from asking healthcare workers for help due to fears of criticism and concerns about receiving insufficient assistance (Cole *et al.*, 2022). One unanticipated finding in this study was the discovery that caregivers opted not to discuss incontinence with their care providers due to fears of added costs for futile investigations and therapies that would not change the condition of their care recipients.

This fear informed the choice to avoid going to tertiary hospitals and also to avoid presenting with their patients to hospital when in need of refills of supplies and medications. Consequently, the hospital environment remains a challenging space for both caregivers and their carerecipients (Ayadi *et al*., 2023).These challenges present missed opportunities for improvement in points of care such as training and integration of continence care onto healthsystems.

5.7 Cultural Persepective and Perceived Positive Benefits

A phenomenological study in Accra, Ghana found a positive effect of caregiving for older adults namely, a stronger bond between the caregiver and the care recipient as well as fulfillment from spiritual blessings (Kyei-Arthur *et al*., 2022). Caregivers felt a sense of purpose in the role of caregiving (Schatz & Seeley, 2015). Although many of the benefits of care work are intangible, some caregivers benefited from the inheritance of property once their caregivers died. Tan *et al*., 2023 found that spousal caregivers were more content, and suffered less strain compared to non-spousal caregivers, usually children of the ill relatives. Spouses prefer to provide care to their spouses themselves rather than delegate to others (Tan *et al.*, 2023). Similarly, in this research, spousal caregivers were often the first to take up caregiving, until their health also failed them. Many family members also opted to care for their ailing parents themselves, only leaving the task to paid caregivers when they could no longer cope.

Spiritual fulfilment and a focus on tangible benefits of caregiving are uncommon themes that this study found. Additionaly, this research also brings to the table a theme of a higher sense of duty and satisfaction with caregiving among spousal caregivers compared to adult offspring of the care recipients who tended to be more stressed by the role.

5.8 Respite Care: Paid Caregiver

Lack of respite care was found to be a major challenge for caregivers. In our research, many of prospective participants could not turn up due to a lack of respite care to stand in for them. Lack of caregiver integrity was also a challenge that came up for families that chose to employ paid caregivers either as part-time relievers or full-time caregivers. On the other hand, paid caregivers struggled with challenging caregiving environments due to family conflict, inadequate resting space and inconsistent supply of hygiene products.

5.9 Summary of Findings and Discussion

This qualitative study of continence care in an aging society explored caregivers' experiences and challenges at a tertiary hospital’s ambulatory care. It focused on how family dynamics, including societal expectations and personal relationships, influence caregiving roles. Furthermore, gender norms and religious beliefswere found to impact on caregiving. Care recipients' resistance to careresulted in conflicts among family membersand strain in spousal intimacy. Physical and psychological effects on caregivers included fatigue, disrupted sleep, and increased stress, exacerbated by financial burdens and reduced social interactions. Practical solutions applied by caregivers included innovative care strategies and support from religious communities.Healthcare system challenges discouraged caregivers from seeking help due toincontinence, compounded by financial concerns from families. The study also highlighted perceived benefits of caregiving, such as spiritual fulfillment and strengthened familial bonds, despite significant issues like the lack of respite care and the devaluation of caregivers.

5.10 Recommendations

Salient recommendations from the key informants to enhance the care of older adults focused on building caregiver resilience. In particular, self-help groups and readily available practical informationon continence care would be helpful to caregivers. Additionally, economic empowerment for caregivers was recommended to improve both the caregiving environment and the care recipient’s hygiene. Training of healthcare providers to integrate continence care into their existing healthcare systems would also benefit caregivers.

Policymakers should develop community-based programs aimed at reducing caregiver burnout. These programs could include support groups that recognize and build on the rewards of caregiving, including the intangible benefits. It is also important to leverage the support of religious communities to assist caregivers.

Increasing access to healthcare resources, such as continence products, medications, mental health support, and respite care, is also crucial. Finally, prioritizing research on caregiver resilience and primary care strategies for managing continence care will help refine support systems.This will be in line with the United Nation's recommendations on Decade of Healthy Ageing 2021-2030to provide resources, training, and financial support to family members or unpaid caregivers (WHO). Research should also examine the impact of different types of incontinence on caregivers to better inform strategies for supporting families.

New insights arising from this research affecting respite care for incontinence are lack of integrity of paid caregivers and challenging working environments, themes previously not commonly discussed in existing research. This suggests the need for more comprehensive, culturally sensitive measures in support of both paid and unpaid caregivers.

Data dissemination Plan

Initial dissemination will begin with the research participants who will be called to share the findings. Findings will be shared via phone call and further discussion can be done through organizing a physical meeting for those available and interested. The next level of dissemination will be at the university level during a scientific conference where a presentation will be made. Other forms of dissemination will follow these and will include abstracts shared in other conferences, the article shared among official digital groups of primary care providers, presentations during support groups of older adults as well as hard copies of the article shared with health authorities at the county and ministry of health offices.

5.11 Conclusion

In conclusion, the findings from this study underscore the multifaceted challenges associated with continence care in an ageing society, highlighting the significant burden placed on caregivers. The insights gained reveal the intricate interplay between societal expectations, personal relationships, and the physical, psychological, and financial strains experienced by those in caregiving roles. To address these issues effectively, it is essential to implement community-based programs that offer both practical and emotional support, leveraging the resources of religious communities and focusing on caregiver resilience through targeted education and economic empowerment. Improving access to healthcare resources, including continence products and mental health support, is crucial in alleviating the burden on caregivers. Additionally, prioritizing research on caregiver resilience and the impact of incontinence types will help tailor support strategies, ultimately enhancing the well-being of both caregivers and their care recipients.

REFERENCES

Abajo, M., Rodríguez & Sanz, M., Malmusi, D., Salvador, M., & Borrell, C. (2017). Gender and socioeconomic inequalities in health and living conditions among co- resident informal caregivers: A nationwide survey in Spain. *Journal of Advanced Nursing*, *73*(3), 700-715.https://doi.org/10.1111/jan.13172

Abrams, P., Cardozo, L., Fall, M., Griffiths, D., Rosier, P., Ulmsten, U., ... & Wein, A. (2003). The standardisation of terminology in lower urinary tract function: report from the standardisation sub-committee of the International Continence Society. Urology, 61(1), 37-49.https://doi.org/10.1016/S0090-4295(02)02243-4

Ackah, M., Ameyaw, L., Salifu, M. G., OseiYeboah, C., Serwaa Ampomaa Agyemang, A., Acquaah, K., ... & Opare-Appiah, A. (2022). Estimated burden, and associated factors of Urinary Incontinence among Sub-Saharan African women aged 15–100 years: A systematic review and meta-analysis. PLOS Global Public Health, 2(6), e0000562. https://doi.org/10.1371/journal.pgph.0000562

Adamek, M. E., Chane, S., & Kotecho, M. G. (2020). Family and kin care of elders in sub-Saharan Africa. In Health and care in old age in Africa (pp. 61-77). Routledge. https://www.taylorfrancis.com/books/mono/10.4324/9780429020759/health-care-old-age-africa?refId=6ce031cf-76f3-408a-9cb5-1ba231fa8c8d&context=ubx

Akinyode, B. F., & Khan, T. H. (2018). Step-by-step approach for qualitative data analysis. International Journal of built environment and sustainability, 5(3).https://doi.org/10.11113/ijbes.v5.n3.267

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

Awuviry-Newton, K., Tavener, M., Wales, K., & Byles, J. (2022). Using ethics of care as the theoretical lens to understand lived experiences of caregivers of older adults experiencing functional difficulties. Plos one, 17(5), e0267658.https://doi.org/10.1371/journal.pone.0267658

Ayadi, A. M., Mitchell, A., Nalubwama, H., Miller, S., Semere, W., Barageine, J. K., ... & Byamugisha, J. (2023). The social, economic, emotional, and physical experiences of caregivers for women with female genital fistula in Uganda: A qualitative study. Global public health, 18(1), 2242458.https:// doi.org/ 10.1080/17441692.2023.2242458

Boddington, P., & Featherstone, K. (2018). The canary in the coal mine: Continence care for people with dementia in acute hospital wards as a crisis of dehumanization. Bioethics, 32(4), 251–260.https://doi.org/10.1111/bioe.12446

Bliwise, D. L., Wagg, A., & Sand, P. K. (2019). Nocturia: a highly prevalent disorder with multifaceted consequences. *Urology*, *133*, 3-13. https://doi.org/ 10.1016 /j.urology.2019.07.005

Burholt, V., Davies, J., Boyd, M., Mullins, J. M., Shoemark, E. Z., & Centre for Ageing, Dementia Research, Expert Review Group on Continence, Dementia. (2022). A research agenda for promoting continence for people living with dementia in the community:

Recommendations based on a critical review and expert- by- experience opinion. Journal of Clinical Nursing, 31(13-14), 1933-1946.https://doi. org/10.1111 /jocn.15537

Carsughi, A., Santini, S., & Lamura, G. (2019). Impact of the lack of integrated care for older people with urinary incontinence and their family caregivers: results from a qualitative pilot study in two large areas of the Marche Region. Annali dell'Istituto Superiore di Sanità, 55(1), 26-33.DOI: 10.4415/ANN_19_01_06

Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. J. (2014, September).

The use of triangulation in qualitative research. In *Oncology Nursing Forum* (Vol. 41, No. 5, pp. 545–547). https://doi.org/10.1188/14.onf.545-547

Chen, C., Yu, L. Chinese older adults' prior-to-death disability profiles and their correlates. BMC Geriatr 24, 479 (2024). https://doi.org/10.1186/s12877-024-05105-y

Cole, L., Drennan, V. M., Manthorpe, J., Hatzidimitriadou, E., & Iliffe, S. (2022). Experiences of intimate continence care and the impact on the family dyad relationship for people living at home with dementia and their co-resident family members. *Dementia*, 14713012221076667 .https://doi.org /10.1177 /147130 1222 1076667

Cowan, L., Bradley, S., Devendorf, A. R., Barks, L., Orozco, T., Klanchar, A., & Hale-Gallardo,

J. (2020). Understanding the impact of incontinence on Veterans' self-management strategies, quality of life and treatment experiences. medRxiv, 2020-11. doi:https://doi.org/10.1101/2020.11.25.20231506

Damba, F. U., Mtshali, N. G., & Chimbari, M. J. (2022). Barriers and facilitators of translating health research findings into policy in sub-Saharan Africa: A Scoping Review. *Humanities and Social Sciences Communications*, *9*(1), 1-15.https://doi.org/10.1057/s41599-022-01070-2

Dawud, M., Kotecho, M. G., & Adamek, M. E. (2022). "It is all About Giving Priority to Older Adults' Needs:" Challenges of Formal Caregivers in Two Old Age Homes in Ethiopia. Ageing International, 47(4), 847-865.https://doi.org/10.1007/s12126-021-09436-8

Dziekaniak, A. C., Meucci, R. D., & Cesar, J. A. (2019). Urinary incontinence among older adults living in the rural area of a municipality in southern Brazil. Geriatrics, Gerontology and Aging, 13(1), 4-10. https://doi.org/10.5327/Z2447-211520191900021

Devendorf, A. R., Bradley, S. E., Barks, L., Klanchar, A., Orozco, T., & Cowan, L. (2021). Stigma among veterans with urinary and faecal incontinence. Stigma and Health, 6(3), 335.https://psycnet.apa.org/doi/10.1037/sah0000260

Devore, E. E., Minassian, V. A., & Grodstein, F. (2013). Factors associated with persistent urinary incontinence. American journal of obstetrics and gynaecology, 209(2), 145-e1. https://doi.org/10.1016/j.ajog.2013.05.002

Drennan, V. M., Cole, L., & Iliffe, S. (2011). A taboo within a stigma? A qualitative study of managing incontinence with people with dementia living at home. *BMC geriatrics*, *11*(1), 1-7. doi:10.1186/1471-2318-11-75

Dominguez-Castillo, P., Bonilla-Campos, A., & Izquierdo, M. (2022). 'Why should I feel guilty? I always give my best. Guilt in Spanish women caring for dependent relatives from a gender perspective. Aging & Mental Health, 1-9.https://doi.org/ 10.1080/13607863.2022.2135681

Du, J., Shao, S., Jin, G. H., Qian, C. G., Xu, W., & Lu, X. Q. (2017). Factors associated with health-related quality of life among family caregivers of disabled older adults: a crosssectional study from Beijing. *Medicine*, *96*(44).https://doi.or g/10.1097%2FMD.0000000000008489

Dumont, S., Jacobs, P., Turcotte, V., Anderson, D., & Harel, F. (2010). Measurement challenges of informal caregiving: a novel measurement method applied to a cohort of palliative care patients. *Social Science & Medicine*, *71*(10), 1890-1895.https://doi.org/10.1016/j.socscimed.2010.08.003

Fader, M. J., Cottenden, A. M., Gage, H. M., Williams, P., Getliffe, K., Clarke- O'Neill, S., ... & Green, N. J. (2014). Individual budgets for people with incontinence: results from a 'shopping' experiment within the British National Health Service. Health Expectations, 17(2), 186–196.https://doi.org/10.1111/j.1369-7625. 2011 .00750.x

Gefen, A., Brienza, D. M., Cuddigan, J., Haesler, E., & Kottner, J. (2022). Our contemporary understanding of the aetiology of pressure ulcers/pressure injuries. *International wound journal*, *19*(3), 692-704.https://doi. org/10.11 11/ iwj.13667

Gelb, A., Mukherjee, A., & Webster, B. (2023). Models of Social Payments through Inua Jamii. *Center for Global Development: Washington, DC. https://www. cgdev. org/sites/default/files/models-social-payments-through-inuajamii. pdf*.https://www.cgdev.org/publication/models-social-payments-through-inua-jamii

Gomes, C. M., Averbeck, M. A., Koyama, M., & Soler, R. (2020). Impact of OAB symptoms on work, quality of life and treatment-seeking behaviour in Brazil. Current Medical Research and Opinion, 36(8), 1403- 1415.https://doi. org/10.1080/03007995.2020.1760806

Göransson, C., Larsson, I., & Carlsson, I. M. (2023). Art of connectedness: Value- creating care for older persons provided with toileting assistance and containment strategies—A critical interpretive synthesis. Journal of Clinical Nursing, 32(9-10), 1806-1820.https://doi.org/10.1111/jocn.16216

Gratão, A. C. M., Brigola, A. G., Ottaviani, A. C., Luchesi, B. M., Souza, É. N., Rossetti, E. S., ... & Pavarini, S. C. I. (2019). Brief version of Zarit Burden Interview (ZBI) for burden assessment in older caregivers. *Dementia & neuropsychologia*, *13*, 122-129.https://doi.org/10.1590/1980-57642018dn13-010015

Grimsland, F., Seim, A., Borza, T., & Helvik, A. S. (2019). Toileting difficulties in older people with and without dementia receiving formal in- home care—A longitud inal study. Nursing Open, 6(3), 1055-1066.https://do i.org/10.1002/nop2.289

Guest, G., Namey, E., & Chen, M. (2020). A simple method to assess and report thematic saturation in qualitative research. PloS one, 15(5), e0232076. https://doi.org/10.1371/journal.pone.0232076

Halper, L. R., Cowgill, C. M., & Rios, K. (2019). Gender bias in caregiving professions: The role of perceived warmth. *Journal of Applied Social Psychology*, *49*(9), 549–562.https://doi.org/10.1111/jasp.12615

Hennink, M. M., Kaiser, B. N., & Weber, M. B. (2019). What influences saturation? Estimating sample sizes in focus group research. Qualitative health research, 29(10), 1483-1496.https://doi.org/10.1177%2F1049732318821692

Hennink, M., & Kaiser, B. N. (2022). Sample sizes for saturation in qualitative research: A systematic review of empirical tests. Social science & medicine, 292, 114523.https://doi.org/10.1016/j.socscimed.2021.114523

Hooley, B., Mtenga, S., & Tediosi, F. (2022). Informal Support Networks of Tanzanians With Chronic Diseases: Predictors of Support Provision and Treatment Adherence. *International journal of public health, 67,* 1605366. https://doi.org/10.3389/ijph.2022.1605366

Hunter, K. F., & Wagg, A. S. (2018). Improving nurse engagement in continence care. Nursing: Research and Reviews, 8, 1.http://dx.doi.org/10.2147/NRR.S144356

Holroyd-Leduc, J. M., Tannenbaum, C., Thorpe, K. E., & Straus, S. E. (2008). What type of urinary incontinence does this woman have?. Jama, 299(12), 1446-1456.JAMA. 2008;299(12):1446-1456. doi:10.1001/jama.299.12.1446

Hyde, P. (2020). Experiences of Informal Caregivers of Patients With Stroke in Cape Coast Metropolis, Ghana.Universty of Cape Cost, Ghana. https://ir. ucc.ed u. gh/xmlui

Ibáñez, A., Pina-Escudero, S. D., Possin, K. L., Quiroz, Y. T., Peres, F. A., Slachevsky, A., ... & Miller, B. L. (2021). Dementia caregiving across Latin America and the Caribbean and brain health diplomacy. The Lancet Healthy Longevity, 2(4), e222-e231. https://doi.org/10.1016/S2666-7568(21)00031-3

Jaekel, A. K., Rings, T. M., Schmitz, F., Knappe, F., Tschirhart, A., Winterhagen, F. I., ... &

Knüpfer, S. C. (2023). Urinary and Double Incontinence in Cognitively Impaired Patients: Impacts on Those Affected and Their Professional Caregivers. Journal of Clinical Medicine, 12(10), 3352. https://doi.org/10.3390/jcm12103352

Kim, S. S., & Roh, Y. S. (2021). A Validation Study of the Revised Caregiving Burden Instrument in Korean Family Caregivers of Stroke Survivors. International Journal of Environmental Research and Public Health, 18(6), 2960.https://doi.org/10.3390/ijerph18062960

Kyei-Arthur, F., Codjoe, S. N. A., & Badasu, D. M. (2022). Exploring positive experiences of primary and secondary caregivers of older persons in resource-limited urban settings in Accra, Ghana. PLoS One, 17(4), e0266269. https://doi.org/10.1371/journal.pone.0266269

Lusambili, A. M., Nyakundi, R., Ngaruiya, C., Muchanga, K. L., Ochieng, A. L., Vusolo, L. M., & Guni, N. J. (2023). Understanding influences on mental health among over 70-yearolds in Kenya using a life course theory. F1000Research, 12, 549.https://doi.org/10.12688/f1000research.132681.1

Mbuthia, K., Mwangi, S., & Owino, G. (2022). Implications of providing social support to close network members on the social well-being of older people in Kitui County, Kenya. Frontiers in Aging, 3, 897508.https://do i.org/10.3389 /fragi. 2022.897508

Miani, C., Wandschneider, L., Niemann, J., Batram-Zantvoort, S., & Razum, O. (2021). Measurement of gender as a social determinant of health in epidemiology—A scoping review. PLoS One, 16(11), e0259223. https://doi.org/ 10.1371%2 Fjournal.pone.0259223

Molina-Barea, R., Slim, M., & Calandre, E. P. (2024, March). Health-Related Quality of Life and Psychosocial Variables in Women with Colorectal Pelvic Floor Dysfunction: A Cross-Sectional Study. In *Healthcare* (Vol. 12, No. 6, p. 668). MDPI.https://doi.org/10.3390/healthcare12060668

Mohamed, E.R., Abou-Hashim, R.M. & Shaltoot, H. Assessment of stress in caregivers of acutely hospitalized elderly and its relation to hospital outcomes. Middle East Curr Psychiatry 30, 113 (2023). https://doi.org/10.1186/s43045-023-00385-3

Murphy, C., De Laine, C., Macaulay, M., Hislop Lennie, K., & Fader, M. (2021). Problems faced by people living at home with dementia and incontinence: causes, consequences and potential solutions. Age and Ageing, 50(3), 944-954.https://doi.org/10.1093/ageing/afaa262

Murphy, C., de Laine, C., Macaulay, M., Avery, M., & Fader, M. (2022). A qualitative study and preliminary model of living with dementia and incontinence at home: beyond containment. Age and ageing, 51(1), afab221.https://do i.org/10.10 93 /ageing/afab221

Musyimi, C., Weidner, W., Mutunga, E., Muyela, L., Comas-Herrera, A., Lorenz-Dant, K., &

Ndetei, D. (2022). Mapping dementia care in Kenya. Policy Summary. CPEC, London School of Economics and Political Science, London.https://stride-dementia .org/kenyasituation-report/

Mwita, K. (2022). Factors influencing data saturation in qualitative studies. *International Journal of Research in Business and Social Science (2147-4478), 11*(4), 414–420. https://doi.org/10.20525/ijrbs.v11i4.1776

Norton, C., Dibley, L. B., Hart, A., Duncan, J., Emmanuel, A., Knowles, C. H., ... & Hounsome, N. (2015). Faecal incontinence intervention study (FINS): self-management booklet information with or without nurse support to improve continence in people with inflammatory bowel disease: study protocol for a randomized controlled trial. Trials, 16, 1-9.https://doi.org/10.1186/s13063-015-0962-0

Ninnoni, J. P. K., & Owoo, B. (2023). Psychosocial experiences of caring by family caregivers of patients living with prostate cancer in a teaching hospital: A descriptive phenomenological study. Nursing Open, 10(9), 6268-6281.http s://doi.o rg/10.1002/nop2.1869

O'Regan, V. (2023). Continence Care in Health and Social Care. Retrieved 8th December 2024. https://www.highspeedtraining.co.uk/hub/continence-care-in-health-and-social-care/

Ostaszkiewicz, J. (2017). Reframing continence care in care-dependence. *Geriatric Nursing,38,* (6).https://doi.org/10.1016/j.gerinurse.2017.03.014

Ostaszkiewicz, J., Dickson-Swift, V., Hutchinson, A. & Wagg, A. (2020). A concept analysis of dignity-protective continence care for care-dependent older people in long-term care settings. *BMC Geriatr (20),* 266.https://doi.org/10.1186/s12877-020-01673-x

Peroni, L., Armaingaud, D., Yakoubi, T., & Rothan-Tondeur, M. (2022). Social Representations of Urinary Incontinence in Caregivers and General Population: A Focus Group Study. International Journal of Environmental Research and Public Health, 19(19), 12251.https://doi.org/10.3390/ijerph191912251

Roe, B., Flanagan, L., Jack, B., Barrett, J., Chung, A., Shaw, C., & Williams, K. (2011). Systematic review of the management of incontinence and promotion of continence in older people in care homes: descriptive studies with urinary incontinence as primary focus. *Journal of Advanced Nursing*, 67(2), 228-250.https://doi.org/10.1111/j.1365-2648.2010.05481.x

Sandhu, J. S., Breyer, B., Comiter, C., Eastham, J. A., Gomez, C., Kirages, D. J., ... & McCammon, K. (2019). Incontinence after prostate treatment: AUA/SUFU guideline. *The Journal of urology*, *202*(2), 369-378.https://doi.org/ 10.1097/ JU.0000000000000314

Schatz, E., & Seeley, J. (2015). Gender, ageing and carework in East and Southern Africa: A review. *Global public health*, *10*(10), 1185- 1200.https:// doi.org/ 10.1080/17441692.2015.1035664

Schlögl, M., & Gordon, A. (2021). HEARTS, minds and souls—it is time for geriatricians to bring more to continence management. *Age and Ageing*, 50(5), 1508-1511.https://doi.org/10.1093/ageing/afab088

Tan, K. P., Ang, J. K., Koh, E. B. Y., Pang, N. T. P., & Mat Saher, Z. (2023). Relationship of psychological flexibility and mindfulness to caregiver burden, and depressive and anxiety symptoms in caregivers of people with dementia. *International Journal of Environmental Research and Public Health*, 20(5), 4232.https://doi.org/10.3390/ijerph20054232

Taylor, D. W., & Cahill, J. J. (2018). Continence home care: a qualitative study of family carers and community-based continence care providers. J Health Sci, 8(2), 19-25. DOI: https://doi.org/10.5923/j.health.20180802.01. US Legal (n.d.). Informal Caregiver Law and Legal Defintion.https://definitions.uslegal.com/i/informal-caregiver/

Vangen, H., & Herlofson, K. (2023). Why care? How filial responsibility norms and relationship quality matter for subsequent provision of care to ageing parents. *Ageing & Society,* 1-25. https://doi.org/10.1017/S0144686X23000235

Wan He, Isabella Aboderin, and Dzifa Adjaye-Gbewonyo. US Census Bureau. Africa Aging: 2020 International Population Reports P95/20-1. *US Government Printing Office, Washington, DC,* 2020. https://bettercare network. org/sit es/ defa ult/files/2021-02/Africa%20Aging.pdf

Wagg, A., Gove, D., Leichsenring, K., & Ostaszkiewicz, J. (2019). Development of quality outcome indicators to improve the quality of urinary and faecal continence care.*International Urogynecology Journal*, 30, 23-32.https://doi.org /10.1007/s00192-018-3768-2

Wiles, J. L., Leibing, A., Guberman, N., Reeve, J., & Allen, R. E. (2012). The meaning of "aging in place" to older people. *The gerontologist*, *52*(3), 357-366.https://doi.org/10.1093/geront/gnr098

World Health Organization. (2002). Active ageing: A policy framework. Geneva: WHO. Retrieved from https://www.who.int/ageing/publications/active_ageing/en/

World Health Organization. (2021). WHO's work on the UN Decade of Healthy Ageing (2021–2030).Retrived from https://www.who.int/initiatives/decade-of-healthy-ageing

World Health Organization. (2024). Ageing and Health.Retrieved fromhttps:/ /www.who.int/ news-room/fact-sheets/detail/ageing-and-health

Xiong, C., Biscardi, M., Astell, A., Nalder, E., Cameron, J. I., Mihailidis, A., & Colantonio, A. (2020). Sex and gender differences in caregiving burden experienced by family caregivers of persons with dementia: A systematic review. *PloS one*, 15(4), e0231848.https://doi.org/10.1371/journal.pone.0231848

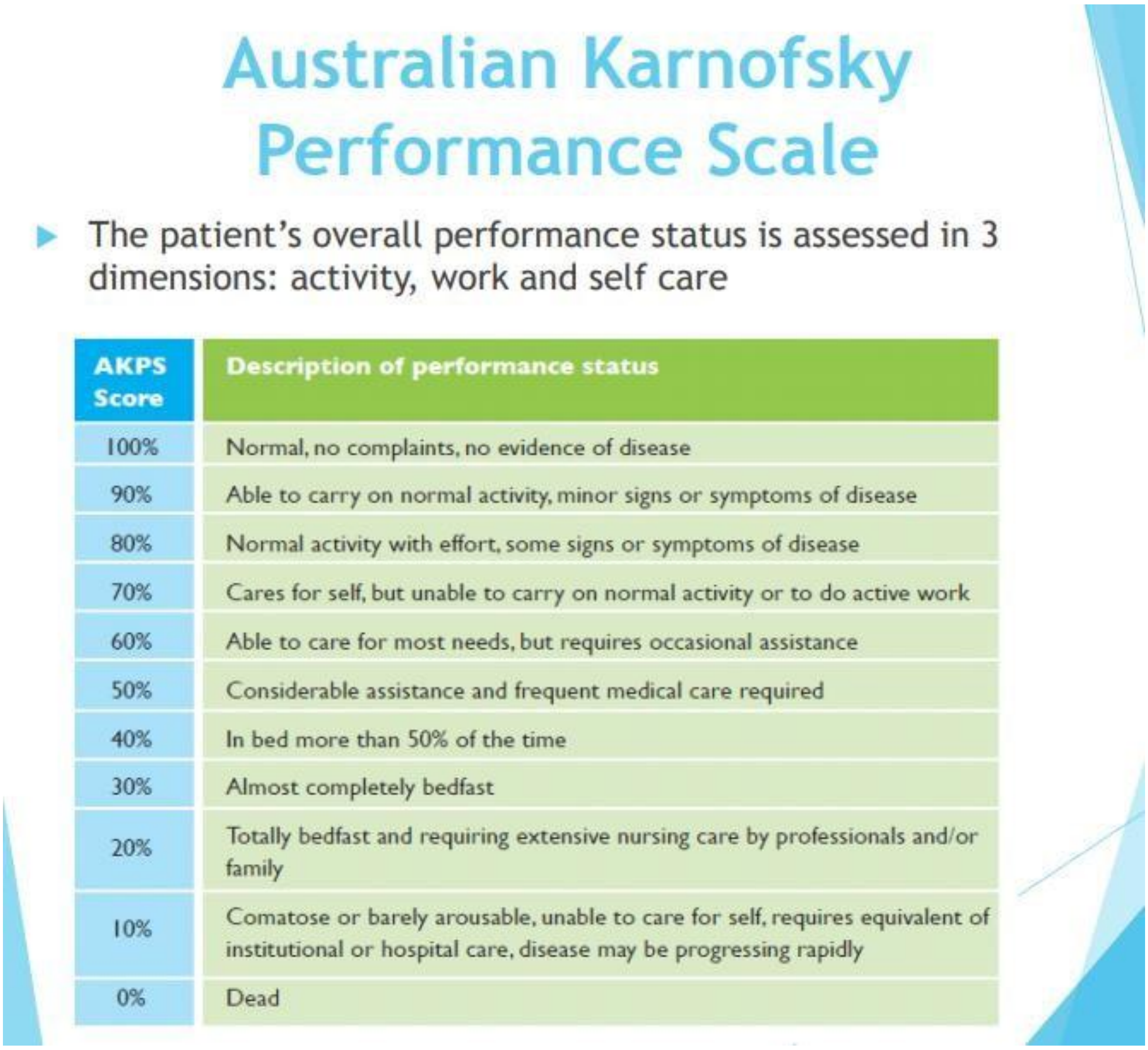
Yan, F., Xiao, L. D., Zhou, K., Li, Z., & Tang, S. (2022). Perceptions and help- seeking behaviours among community- dwelling older people with urinary incontinence: A systematic integrative review. *Journal of Advanced Nursing*.https: //doi.org/ 10.1111/jan.15183

Yan, E. (2022). Primary caregivers. In *Encyclopedia of Gerontology and Population Aging* (pp. 3958-3960). Cham: Springer International Publishing.https://doi.org /10.1007/978-3-030-22009-9_851

Zachariou, A., & Filiponi, M. (2016). Investigation of the factors affecting the burden on caregivers of elderly patients with urinary incontinence: a cross-sectional study in Greece. Hellenic Urology, 28(3 DOI:10.19264/HJ.V28I3.135

APPENDICES

Appendix I: Research Instruments



Australian Karnofsky Performance Scale

- The patient's overall performance status is assessed in 3 dimensions: activity, work and self care

AKPS Score	Description of performance status
100%	Normal, no complaints, no evidence of disease
90%	Able to carry on normal activity, minor signs or symptoms of disease
80%	Normal activity with effort, some signs or symptoms of disease
70%	Cares for self, but unable to carry on normal activity or to do active work
60%	Able to care for most needs, but requires occasional assistance
50%	Considerable assistance and frequent medical care required
40%	In bed more than 50% of the time
30%	Almost completely bedfast
20%	Totally bedfast and requiring extensive nursing care by professionals and/or family
10%	Comatose or barely arousable, unable to care for self, requires equivalent of institutional or hospital care, disease may be progressing rapidly
0%	Dead

FOCUS GROUP DISCUSSION INTERVIEW

CAREGIVER:

(I) AGE------------SEX------------ RELATIONSHIP TO CARE RECIPIENT-----------------

(II) LEVEL OF EDUCATION---- PRIMARY/ SECONDARY/ COLLEGE

(III) DURATION OF CAREGIVING----- (MONTHS)

(IV) EMPLOYMENT STATUS------ (EMPLOYED/ SELF-EMPLOYED/ UNEMPLOYED)

(V) CAREGIVING TASKS---------PAID/UNPAID

CARE RECIPIENT:

(I) AGE------------SEX------------

(II) COMORBIDITY—-------- MENTAL STATUS------ALTERED/NORMAL

(III) TYPE OF INCONTINENCE— URINE/ STOOL/ MIXED/ FUNCTIONAL

(IV) ABLE TO INDICATE NEED FOR TOILETING ASSISTANCE------YES/NO

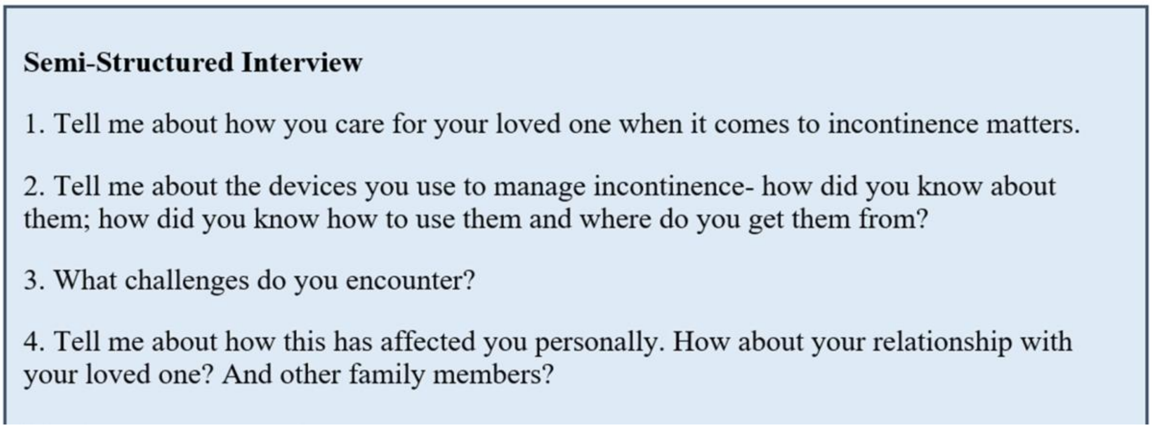
FOMU YA USAJILI

MLEZI

(I) UMRI ________________ JINSIA______________
(II) KIWANGO CHA ELIMU____MSINGI____SEKONDARI_______CHUO________
(III) MUDA WA MALEZI______________________ (MIEZI)
(IV) AJIRA ______________KUJIAJIRI___KUAJIRIWA_____BILA AJIRA
(V) MALIPO YA MALEZI _______KULIPWA___BILA KULIPWA

MPOKEAJI MALEZI

(I) UMRI_________ JINSIA__________
(II) MARADHI________________ HALI YA KIAKILI_SAWA/PUNGUFU
(III) AINA YA KUKOSA KUJUZUIA HAJA : HAJA NDOGO_____HAJA KUBWA____ ZOTE_____
(IV) UWEZO WA KUELEZA MAHITAJI_____ANAWEZA________HAWEZI________



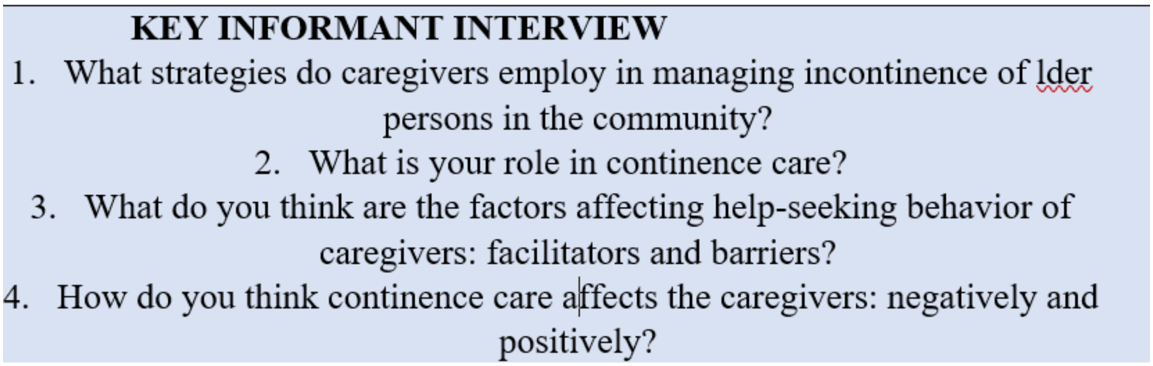
Semi-Structured Interview

1. Tell me about how you care for your loved one when it comes to incontinence matters.

2. Tell me about the devices you use to manage incontinence- how did you know about them; how did you know how to use them and where do you get them from?

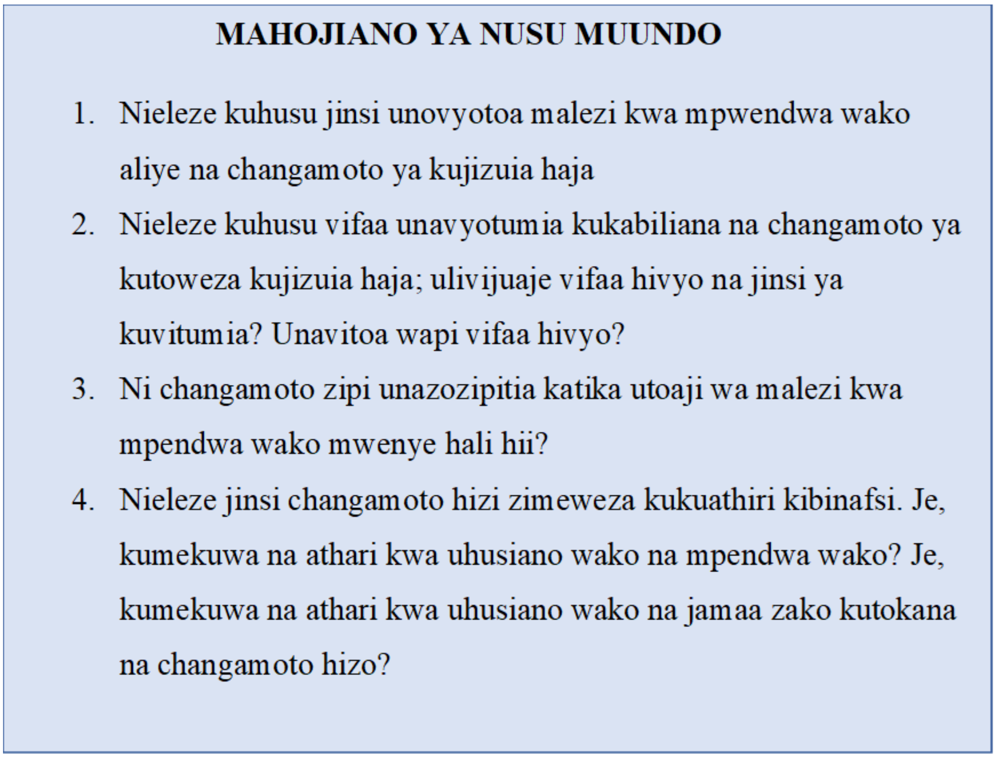
3. What challenges do you encounter?

4. Tell me about how this has affected you personally. How about your relationship with your loved one? And other family members?



KEY INFORMANT INTERVIEW

1. What strategies do caregivers employ in managing incontinence of lder persons in the community?
2. What is your role in continence care?
3. What do you think are the factors affecting help-seeking behavior of caregivers: facilitators and barriers?
4. How do you think continence care affects the caregivers: negatively and positively?



MAHOJIANO YA NUSU MUUNDO

1. Nieleze kuhusu jinsi unovyotoa malezi kwa mpwendwa wako aliye na changamoto ya kujizuia haja
2. Nieleze kuhusu vifaa unavyotumia kukabiliana na changamoto ya kutoweza kujizuia haja; ulivijuaje vifaa hivyo na jinsi ya kuvitumia? Unavitoa wapi vifaa hivyo?
3. Ni changamoto zipi unazozipitia katika utoaji wa malezi kwa mpendwa wako mwenye hali hii?
4. Nieleze jinsi changamoto hizi zimeweza kukuathiri kibinafsi. Je, kumekuwa na athari kwa uhusiano wako na mpendwa wako? Je, kumekuwa na athari kwa uhusiano wako na jamaa zako kutokana na changamoto hizo?

Appendix II: Information Sheet

EXPLORING CAREGIVER EXPERIENCES AND CHALLENGES IN PROVIDING CONTINENCE CARE FOR OLDER ADULTS AT AIC KIJABE HOSPITAL

I understand that even if I agree to participate now, I can withdraw at any time or refuse to answer any question without any consequences of any kind

I understand that I can witdraw my persimssion to use data from my interview within two weeks after the interview, in which case the material will be deleted

I have had the purpose and nature of the study explained to me in waiting and I have had the opportunity to ask questions about the study

I understand the participation involves a questionnaire and focus group discussion

I understand that I will not benefit directly from participating in this research

I agree to my interview being audio-recorded

I understand that all information I provide for this study will be treated confidentially

I understand that in any report on the results of this research, my identity will remain anonymous. This will be done by changing my name, my voice and any details of my interview which may reveal my identity or the identity of the people I speak about

I understand that de-personalized extractsfrom my interview, where all identifying information has been removed, may be quoted during scientific conferences and at the researcher's university thesis defense

I understand that signed consent forms, a transcript and original recordings will be retained in encrypted folders only accessible to the researchers and will be kept for a period of two years after the research

I understand that under freedom of information legalization I am entitled to access the information I have provided at any time of the duration of storage as specified above

I understand that I am free to contact any of the researchers to seek further clarification or information

FOMU YA IDHINI

Ninafahamu kuwa ingawa nimetoa idhini ya kuhusika katika utafiti huu, ninao uhuru wa kujiondoa wakati wowote ule, na pia uhuru wa kutojibu swali, bila kuathirika

Ninafahamu kuwa ninaweza kuondoa idhini ya kutumia nakala za rekodi zinazohusisha maoni yangu katika muda wa wiki mbili baada ya utafiti kulamilika. Idhini itakapoondolewa, nakala zitafutwa.

Nadhibitisha kwamba nimeelezewa lengo kuu la utafiti pamoja na jinsi utafiti utakavyoendeshwa, na nikapewa fursa ya kuuliza maswali kuhusu utafiti

Nafahamu kuwa utafiti utahusisha maswali na majadiliano

Nafahamu kuwa sitafaidika moja kwa moja na matokeo ya utafiti huu

Ninaidhinisha kurekodiwa kwa sauti yangu katika majadiliano

Ninafahamu kuwa nakala za maoni yangu zitahifadhiwa kwa usiri, na kwamba vitambulisho vyote vitaondolewa kwenye nakala hizo. Vitambulisho vitaondolewa kwa kuficha au kubadili majina yanayotambulisha wanaohusika

Nafahamu kuwa maoni yangu yatanukuliwa kwenye makala yatakayotolewa katika kongamano za kisayansi, zikiwemo kongamano za vyuo vikuu

Nafahamu kuwa nakala za utafiti zilizoidhinishwa zitahifadhiwa katika faili za siri zilizo wazi kwa mtafiti mkuu na wasaidizi wake pekee

Ninafahamu kuwa pindi nitakapomjulisha mtafiti mkuu kuhusu madhara ya kisaikolojia kutokana na kushirikishwa katika utafiti huu, mtafiti ana wajibu wa kuripoti madhara haya bila ya idhini yangu, licha ya kujadiliana nami

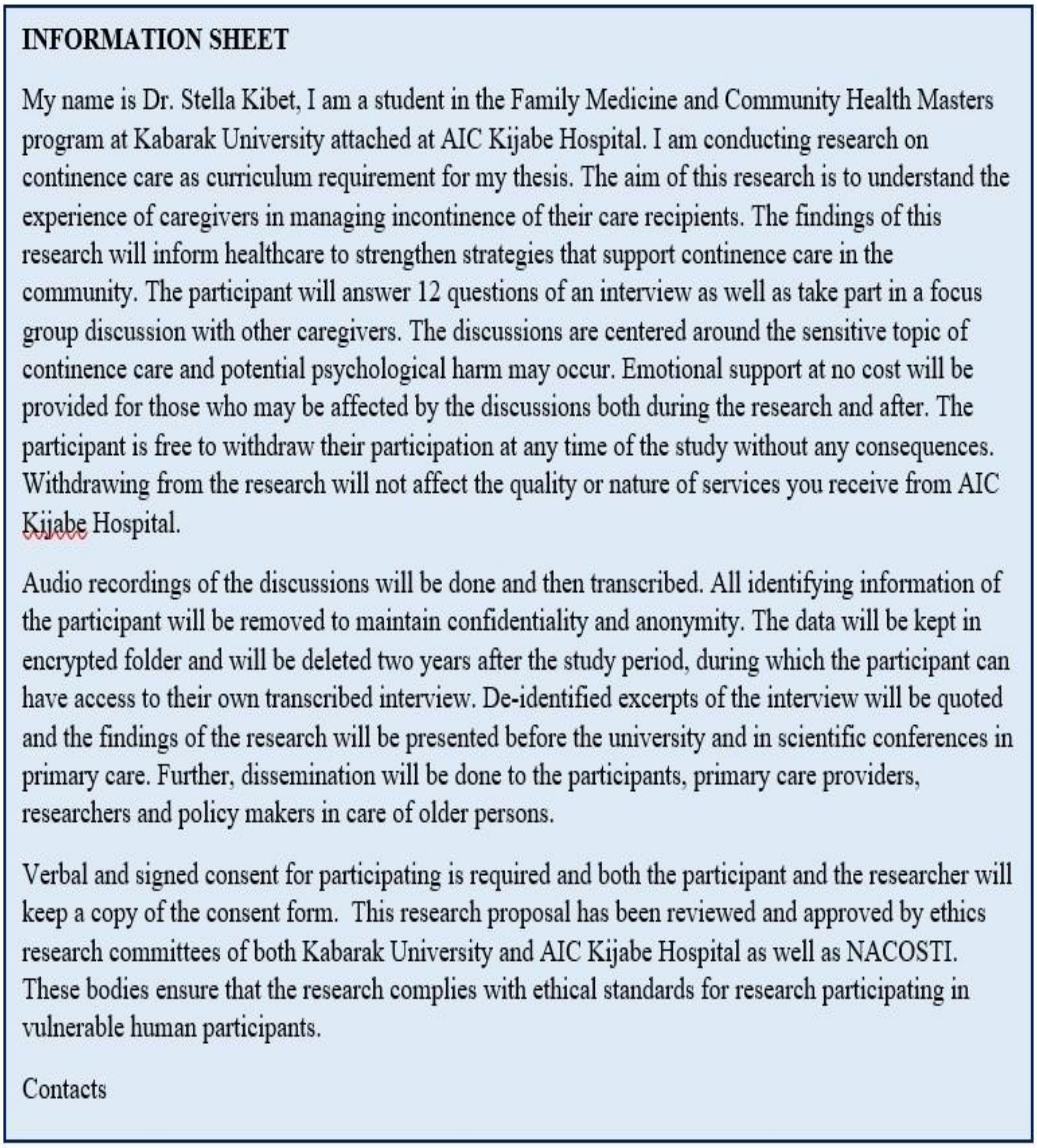
Nafahamu kuwa nakala za maoni ya wahusika zitaondolewa vitambulisho na kuhifadhiwa kwa usiri kwa muda wa miaka miwili baada ya kukamilika kwa utafiti

Ninafahamu kuwa nina haki ya kupokea nakala hizo wakati wowote katika mudo huo wa miaka miwili

Ninafahamu kuwa nina uhuru na uwezo wa kuwasiliana na mtafiti mkuu na wasaidizi wake nitakapohitaji kuwashauri kuhusu utafiti huu

Mimi____________________________ ninatoa idhini ya kuhusika na utafiti huu bila kushurutishwa

Jina__________________________________ Sahihi____________________ Tarehe______________



INFORMATION SHEET

My name is Dr. Stella Kibet, I am a student in the Family Medicine and Community Health Masters program at Kabarak University attached at AIC Kijabe Hospital. I am conducting research on continence care as curriculum requirement for my thesis. The aim of this research is to understand the experience of caregivers in managing incontinence of their care recipients. The findings of this research will inform healthcare to strengthen strategies that support continence care in the community. The participant will answer 12 questions of an interview as well as take part in a focus group discussion with other caregivers. The discussions are centered around the sensitive topic of continence care and potential psychological harm may occur. Emotional support at no cost will be provided for those who may be affected by the discussions both during the research and after. The participant is free to withdraw their participation at any time of the study without any consequences. Withdrawing from the research will not affect the quality or nature of services you receive from AIC Kijabe Hospital.

Audio recordings of the discussions will be done and then transcribed. All identifying information of the participant will be removed to maintain confidentiality and anonymity. The data will be kept in encrypted folder and will be deleted two years after the study period, during which the participant can have access to their own transcribed interview. De-identified excerpts of the interview will be quoted and the findings of the research will be presented before the university and in scientific conferences in primary care. Further, dissemination will be done to the participants, primary care providers, researchers and policy makers in care of older persons.

Verbal and signed consent for participating is required and both the participant and the researcher will keep a copy of the consent form. This research proposal has been reviewed and approved by ethics research committees of both Kabarak University and AIC Kijabe Hospital as well as NACOSTI. These bodies ensure that the research complies with ethical standards for research participating in vulnerable human participants.

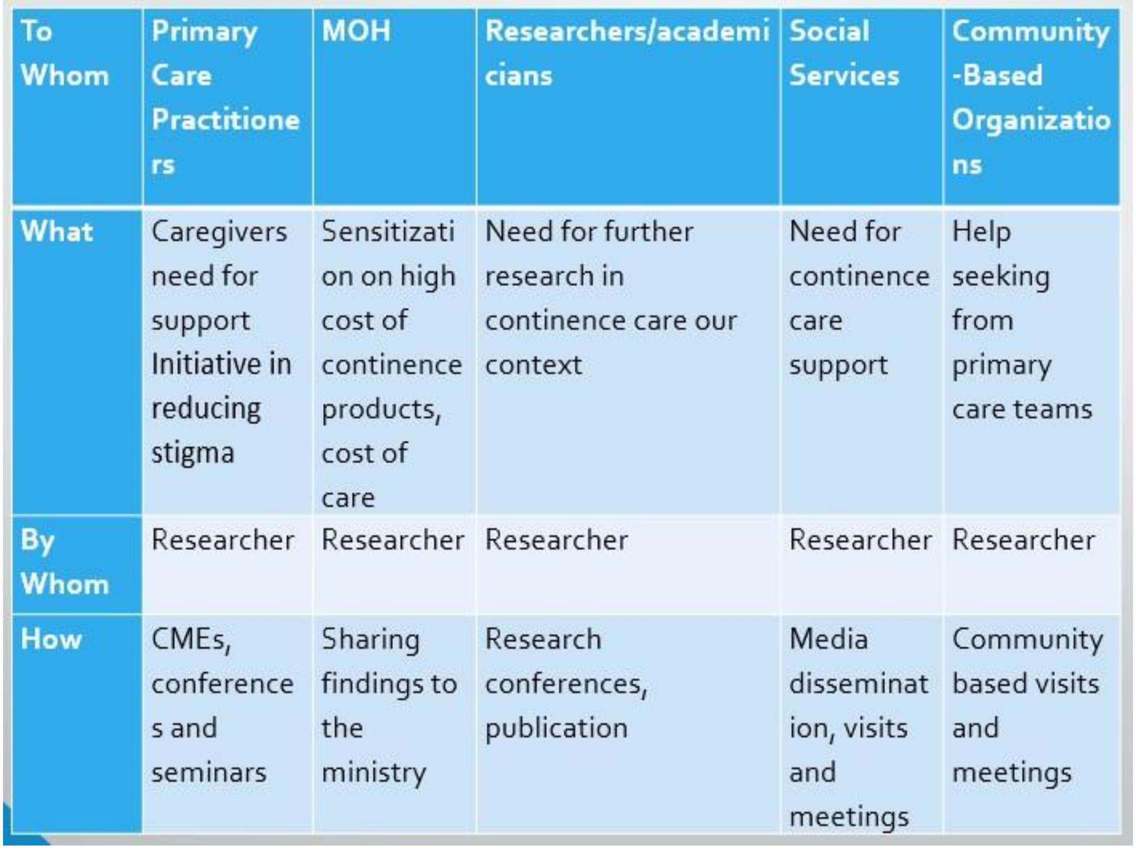
Contacts

MAELEZO KUHUSU UTAFITI

Jina langu ni Dkt. Stella Kibet, mimi ni mwanafunzi katika hospitali ya AIC Kijabe kutoka chuo kikuu cha Kabarak, katika idara ya Family Medicine, nikijitayarisha kupokea shahada ya uzamili. Kwa sasa ninafanya utafiti kuhusu matatizo ya kukosa kuijzuia kwa haja ndogo au kubwa miongoni mwa wangonjwa wenye umri mkubwa. Lengo kuu la utafiti huu ni kuelewa jinsi walezi wanakabiliana na mahitaji ya wapendwa wao wenye shida ya kujuzuia kwa haja ndogo au kubwa. Matokeo ya utafiti huu yatatumika na halmashauri ya afya, kuweza kuimarisha mahitaji ya wagonjwa wenye tatizo hili katika jamii. Watakaoshirikishwa kwenye utafiti huu watachangia majadiliano pamoja na walezi wenzao. Mada ya majadiliano ni mbinu zinazotumiwa kukabiliana na utoaji wa malezi kwa wanaougua matatizo ya kukosa kujizuia haja, na majadiliano hayo yana hatari ya madhara ya kisaikolojia. Msaada wa kisaokolojia utatolewa bure kwa watakaothirika wakati wa utafiti na baada ya utafiti kukamilika. Kila anayehusika ana uhuru wa kujiondoa kwenye utafiti wakati wowote atakapo, na kujiondoa huku hakutadhuru ubora wa huduma anazopokea kutoka hospitali ya AIC Kijabe.

Majadiliano yatarekodiwa kisha kutayarishwa kwenye nakala zilizoondolewa majina na vitambulisho vyote vya wahusika ili kuhakikisha kutojulikana na usiri kwenye utafiti huu. Nakala ambazo zitahifadhiwa kwa muda wa miaka miwili, katika faili zilizofungwa kwa ajili ya usalama zitapatikana kwa kila atakayehusika kwenye utafiti. Nukuu zisizokuwa na vitambulisho, zitatumiwa kwenye makala ya utafiti ambayo yatasambazwa katika chuo kikuu na pia kwenye makongomano ya kisayansi ya huduma ya afya ya kimsingi. Matokeo ya utafiti huu yatatolewa kwa walezi, wahudumu wa afya ya kimsingi, watafiti na watunga sera za wazee.

Appendix III: Knowledge Translation



To Whom	Primary Care Practitioners	MOH	Researchers/academicians	Social Services	Community-Based Organizations
What	Caregivers need for support Initiative in reducing stigma	Sensitization on high cost of continence products, cost of care	Need for further research in continence care our context	Need for continence care support	Help seeking from primary care teams
By Whom	Researcher	Researcher	Researcher	Researcher	Researcher
How	CMEs, conferences and seminars	Sharing findings to the ministry	Research conferences, publication	Media dissemination, visits and meetings	Community based visits and meetings

AIM: Spread awareness of incontinence, caregiving challenges and be a voice to the experiences of caregivers

Primary care teams: clinicians, nurses, family physicians- CMEs: scientific conferences

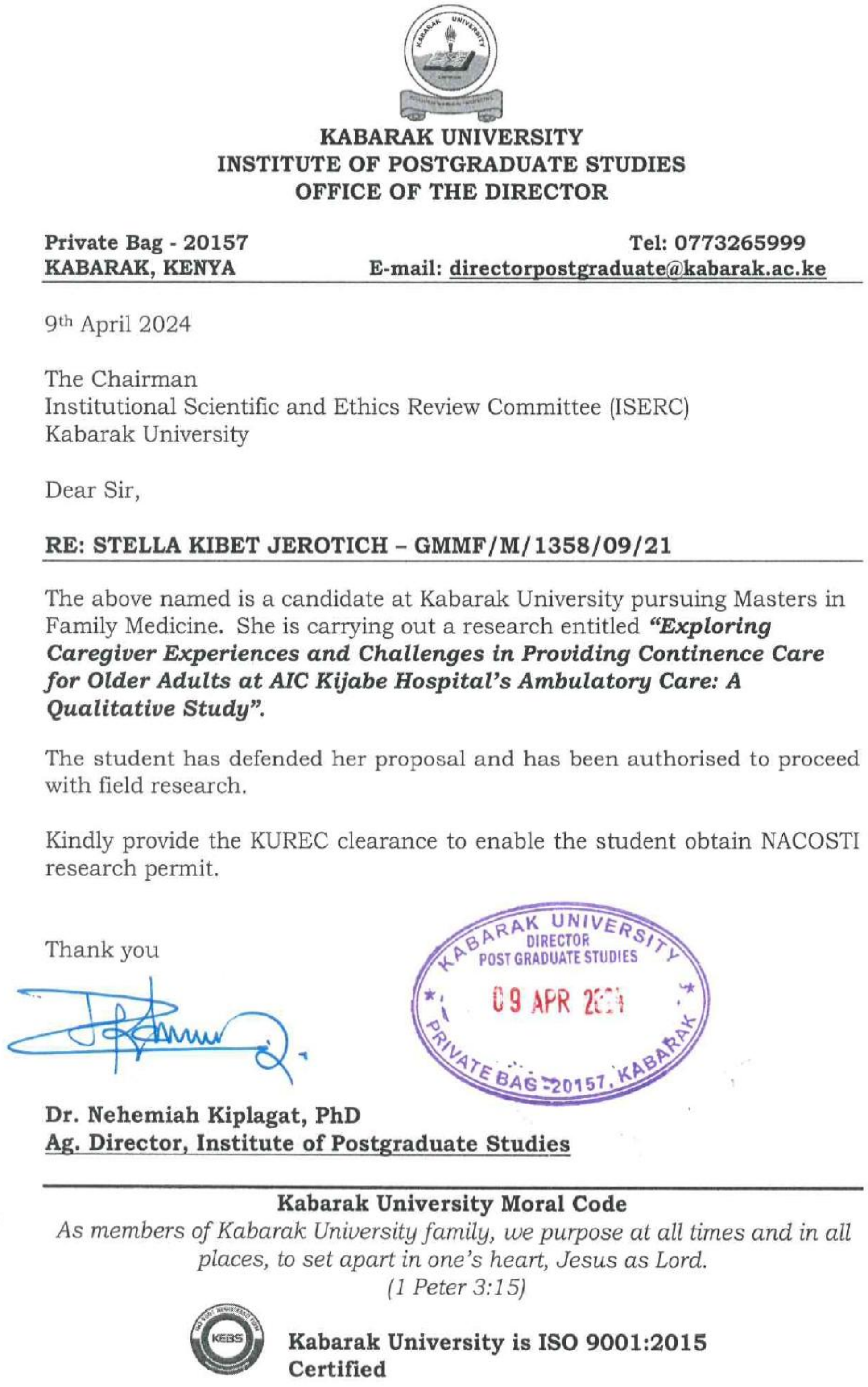
Caregivers of older adults, community health volunteers- meetings in the community, social and mainstream media channels

Community based initiatives for older: adults- social and mainstream media

Public health practitioners- publication in scientific journal, presenting at professional meetings

Ministry of health and policy makers- personal dissemination, presentation at professional policy meetings

Appendix IV: KUREC Introduction Letter



KABARAK UNIVERSITY
INSTITUTE OF POSTGRADUATE STUDIES
OFFICE OF THE DIRECTOR

Private Bag - 20157 **Tel: 0773265999**
KABARAK, KENYA **E-mail: directorpostgraduate@kabarak.ac.ke**

9th April 2024

The Chairman
Institutional Scientific and Ethics Review Committee (ISERC)
Kabarak University

Dear Sir,

RE: STELLA KIBET JEROTICH – GMMF/M/1358/09/21

The above named is a candidate at Kabarak University pursuing Masters in Family Medicine. She is carrying out a research entitled ***"Exploring Caregiver Experiences and Challenges in Providing Continence Care for Older Adults at AIC Kijabe Hospital's Ambulatory Care: A Qualitative Study".***

The student has defended her proposal and has been authorised to proceed with field research.

Kindly provide the KUREC clearance to enable the student obtain NACOSTI research permit.

Thank you

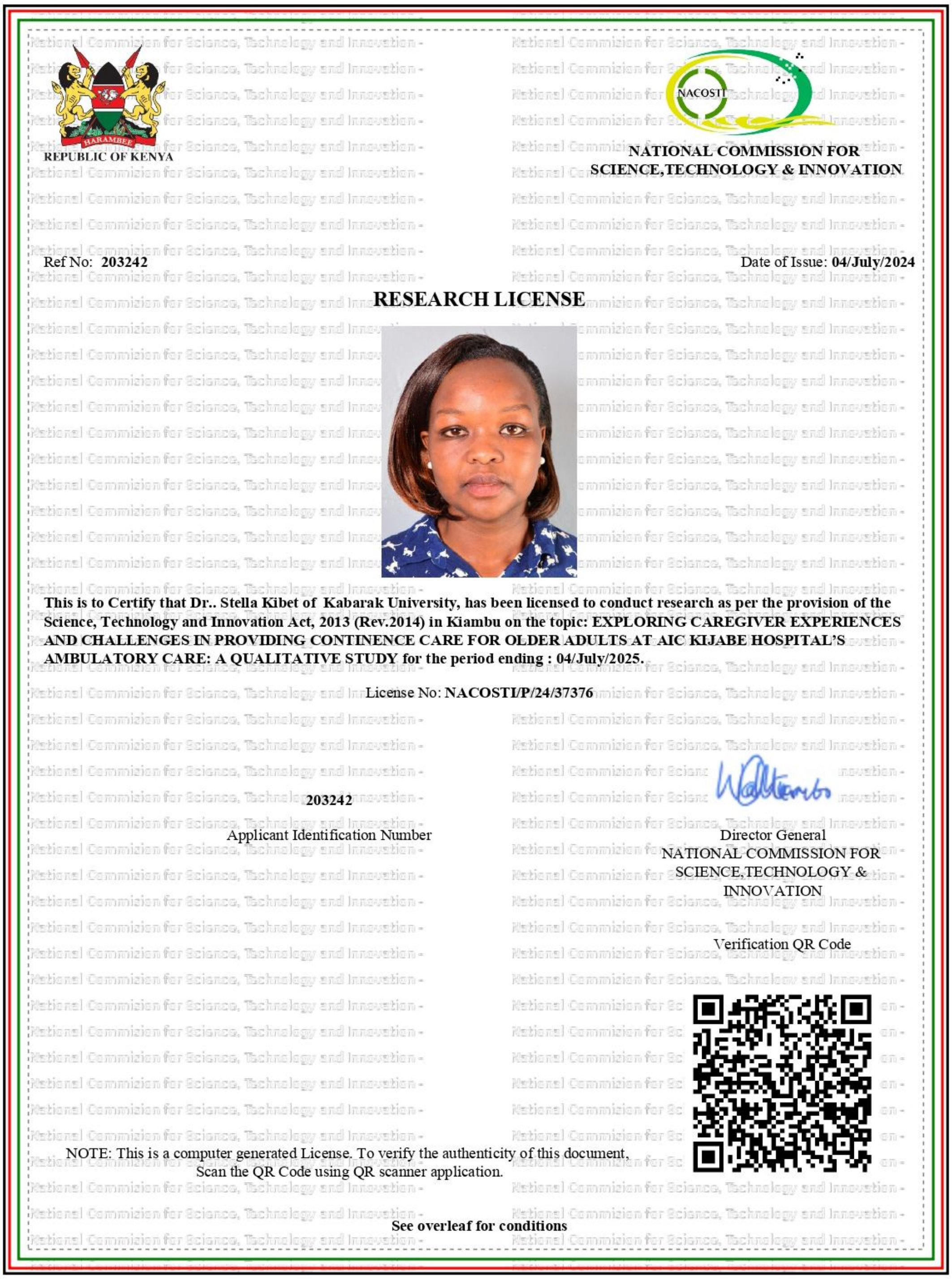
KABARAK UNIVERSITY
DIRECTOR
POST GRADUATE STUDIES
09 APR 2024
PRIVATE BAG -20157, KABARAK

Dr. Nehemiah Kiplagat, PhD
Ag. Director, Institute of Postgraduate Studies

Kabarak University Moral Code
As members of Kabarak University family, we purpose at all times and in all places, to set apart in one's heart, Jesus as Lord.
(1 Peter 3:15)

Kabarak University is ISO 9001:2015 Certified

Appendix V: NACOSTI Reserach Permit



REPUBLIC OF KENYA

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SCIENCE,TECHNOLOGY & INNOVATION

Ref No: **203242**

Date of Issue: **04/July/2024**

RESEARCH LICENSE

This is to Certify that Dr.. Stella Kibet of Kabarak University, has been licensed to conduct research as per the provision of the Science, Technology and Innovation Act, 2013 (Rev.2014) in Kiambu on the topic: EXPLORING CAREGIVER EXPERIENCES AND CHALLENGES IN PROVIDING CONTINENCE CARE FOR OLDER ADULTS AT AIC KIJABE HOSPITAL'S AMBULATORY CARE: A QUALITATIVE STUDY for the period ending : 04/July/2025.

License No: **NACOSTI/P/24/37376**

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See overleaf for conditions

Appendix VI: Evidence of Conference Participation

KAFP Kenya Association of Family Physicians

KAFP Kenya Association of Family Physicians

Conference

Theme

Building Resilient Healthcare Systems:
Leveraging Family Medicine for Sustained Impact
Date: 21st ~ 23rd May, 2025.
Venue: Pride Inn Paradise, Mombasa, Kenya.

Certificate of Merit

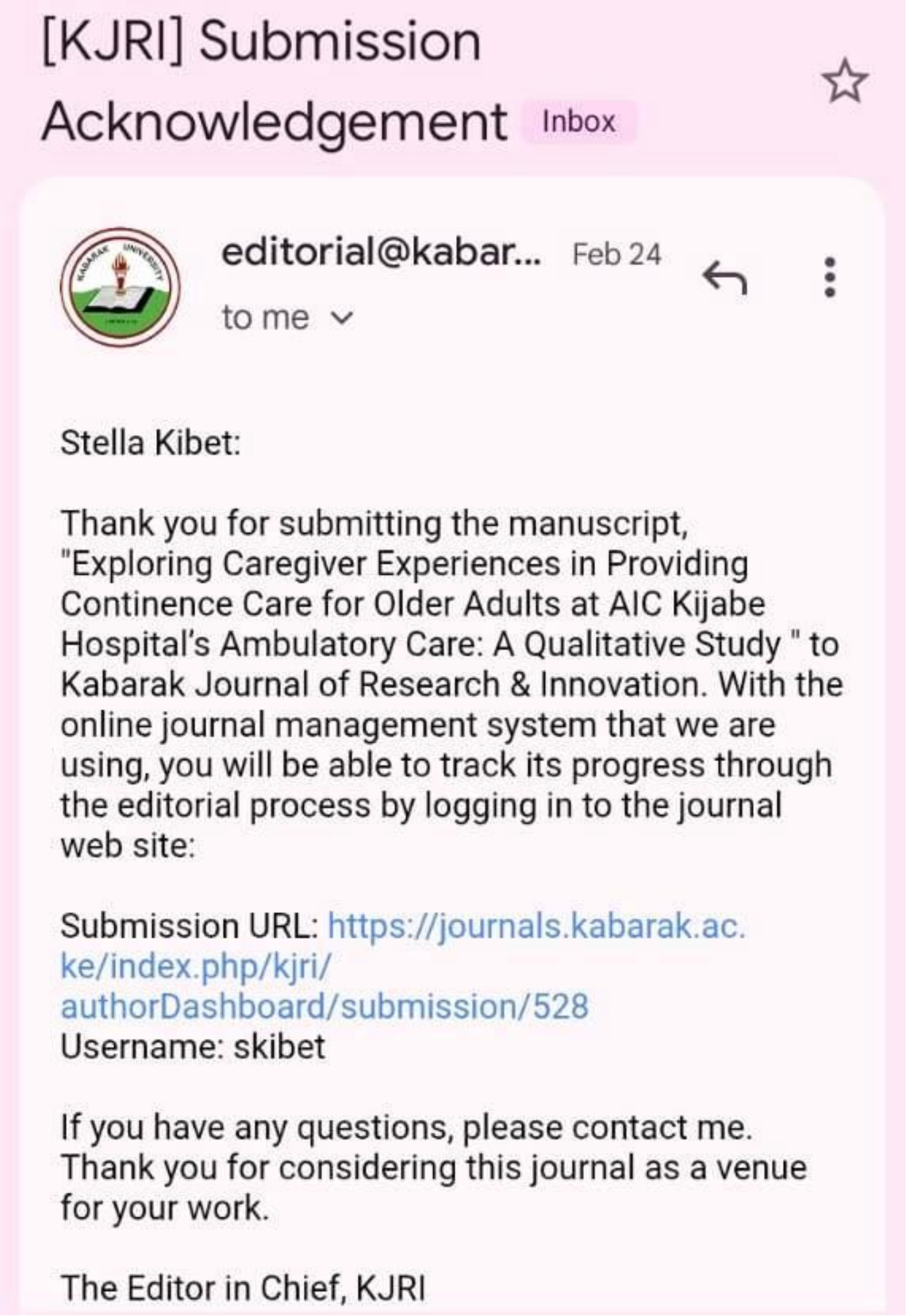
DR. STELLA KIBET

This certificate is awarded in recognition of outstanding achievement as the Best Abstract Presenter **(1st Position)** during the 2025 KAFP Annual Scientific Conference.

DR. JOY MUGAMBI
CHAIR KAFP NEC

DR. MERCY WANJALA
CHAIR KAFP 2025
CONFERENCE COMMITTEE

Appendix VII: List of Publications



[KJRI] Submission Acknowledgement

editorial@kabar... Feb 24

to me

Stella Kibet:

Thank you for submitting the manuscript, "Exploring Caregiver Experiences in Providing Continence Care for Older Adults at AIC Kijabe Hospital's Ambulatory Care: A Qualitative Study " to Kabarak Journal of Research & Innovation. With the online journal management system that we are using, you will be able to track its progress through the editorial process by logging in to the journal web site:

Submission URL: https://journals.kabarak.ac.ke/index.php/kjri/authorDashboard/submission/528
Username: skibet

If you have any questions, please contact me. Thank you for considering this journal as a venue for your work.

The Editor in Chief, KJRI