Examining responsibility allocation within the social care system for older people in rural Uganda: An ecological systems approach

Diana Erinah Nabbumba

Bachelor of Social Work and Social Administration, Makerere University (Uganda)

Master of Science in Social Sciences in Gerontology, University of Southampton (UK)

A thesis submitted in total fulfilment of the requirements for the degree of Doctor of Philosophy

John Richards Centre for Rural Ageing Research

La Trobe Rural Health School

College of Science, Health and Engineering

La Trobe University

Victoria, Australia

October 2021

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF GRAPHS

LIST OF ABBREVIATIONS

ADL	Activities of Daily Living
CBO	Community-Based Organisation
CDO	Community Development Officer
CHE	Critical Human Ecology
CRG	Critical Rural Gerontology
CSO	Civil Society Organisation
DFID	The UK Department for International Development
EoC	Ethics of Care
FBO	Faith-Based Organisation
FGD	Focus Group Discussions
HIC	High-Income Countries
HIV/AIDS	Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome
IADL	Instrumental Activities of Daily Living
IASCE	Irish Association of Social Care Educators
IDP	Internally Displaced Persons
JCSCP	The Joint Committee on Social Care Professionals
LIC	Low-Income Countries
LRA	Lord's Resistance Army
MGLSD	Ministry of Gender, Labour and Social Development
MIPAA	Madrid International Plan of Action on Ageing
NCOP	National Council of Older Persons
NDP	National Development Plan
NGO	Non-Government Organisation
NPAOP	National Plan of Action for Older Persons
NPOP	National Policy of Older Persons
NSPP	National Social Protection Policy
NSSF	National Social Security Fund
NUSAF	Northern Uganda Social Action Fund
OECD	Organisation for Economic Co-operation and Development
OVC	Orphans and Vulnerable Children
PEAP	Poverty Eradication Action Plan

PIS	Participant Information Sheet
PPI	Programme Plan of Intervention
PWDs	People with Disabilities
REC	Research Ethics Committee
SAGE	Social Assistance Grant for Empowerment
SCG	Senior Citizen Grant
SDIP	Social Development Sector Strategic Investment Plan
SOC	Selection, Optimisation and Compensation
SSA	Sub-Saharan Africa
TASO	The AIDS Support Organisation
TASO/IRB	The AIDS Support Organisation Institutional Review Board
UBOS	Uganda Bureau of Statistics
UN	United Nations
UNCST	Uganda National Council for Science and Technology
UNFPA	United Nations Population Fund
UNHS	Uganda National Household Survey
UNICEF	United Nations Children's Fund
VFG	Vulnerable Family Grant
VHT	Village Health Team
WHO	World Health Organization

ABSTRACT

The anticipated increase in the number of people aged 60 years and above in sub-Saharan Africa raises critical questions around who is responsible for providing social care for older people. This concern is timely in the context of growing demand for social care, uncertainty in relation to governments' provision of social care services, and multifaceted challenges to social care provision for older people in rural areas. However, there has been limited research exploring social care systems for older people in sub-Saharan Africa, including Uganda. This thesis aims to critically examine the allocation of responsibility within the social care system for older people in rural Uganda.

A transformative qualitative approach using ethics of care theory (EoC), critical rural gerontology (CRG) and critical human ecology (CHE) perspectives guided this study. The multiple methods adopted included the analysis of four national policy documents, in-depth semi-structured interviews with 21 key stakeholders and 19 rural older people receiving care, alongside focus groups with 40 rural caregivers. Participants were asked about the current social care services provided or received in rural communities, their perceptions of social care responsibility, their experiences and challenges relating to the provision of social care and their recommendations for improvement.

This thesis argues that responsibility for social care in rural Uganda both impacts and is impacted by other elements or phases of care and is shaped by care disruptions. The findings demonstrate that the formal social care system for older people in rural areas is inconsistent, underfunded, fragmented and unregulated, leaving families predominantly responsible for care. The lack of a clear policy framework and responsibility allocation at a macro level influences how stakeholders, informal caregivers and older people conceptualise and assume responsibility. This study makes a significant contribution to understanding and improving social care for older people in rural Uganda.

STATEMENT OF AUTHORSHIP

Except where reference is made in the text of the thesis, this thesis contains no material published elsewhere or extracted in whole or in part from a thesis accepted for the award of any other degree or diploma. No other person's work has been used without due acknowledgment in the main text of the thesis. This thesis has not been submitted for the award of any degree or diploma in any other tertiary institution.

All research procedures reported in the thesis were approved by the La Trobe University Faculty of Health Sciences Human Ethics Committee, under reference number HEC18466. Approvals were also obtained from The AIDS Support Organisation Institutional Review Board (TASO/IRB) (reference number: TASO REC/006/19-UG-REC-009) and Uganda National Council for Science and Technology (UNCST) (reference number: HS322ES) in Uganda.

Diana Erinah Nabbumba 25th October 2021

ACKNOWLEDGEMENTS

I express my gratitude to my supervisors, Dr Rachel Winterton, Professor Suzanne Hodgkin and Dr Jacqui Theobald, for their continued academic guidance and insight in shaping my thinking and writing. Without their unwavering support, this project would not have been realised. Thank you also to Dr Anne-Maree Sawyer for acting as the research panel chair and overseeing this project until the end.

I thank the Graduate Research School, Research Education and Development team and La Trobe University Bendigo library learning hub for guidance with my academic writing. To the John Richards Centre and La Trobe Rural Health School staff, thank you for providing a great environment for me to grow, feel welcome and belong. I am grateful to my colleagues and the Shut Up and Write crew for the support rendered throughout my candidature.

I am especially thankful to my research assistant, Aduk Euphrasia, who assisted me with data collection and transcribing. Your assistance and participation enabled me to reach a milestone in completing this project. I am also grateful to the organisations and participants who took part in this study. Thank you for your time and valued input in sharing with us your experiences and knowledge.

I am indebted to my spouse Ivan Rwakijuma for his steadfast support. Relocating with me to Australia was a very caring gesture I will always remember and cherish. To my children Ira and Myra, for your understanding when mummy needed time to study. You were my motivation to see me through this journey. I recognise and appreciate my mum, family, and friends for their continued support. I value the mentorship of Harry Bryce, for the encouragement and confidence he provided during this project. I also acknowledge professional editor Hazel Baker, who provided copyediting services according to the IPEd guidelines for editing research theses. Any remaining errors are my own.

This work was supported by a La Trobe University Postgraduate Research Scholarship and a La Trobe University Full Fee Research Scholarship.

DEDICATION

I dedicate this thesis to my late father, Ssalongo Edward Musoke Kisitu.

CHAPTER ONE : INTRODUCTION

1.1 Background to the research

This thesis examines the allocation of responsibility within the social care system for older people in rural Uganda. This research was primarily motivated by my personal experiences working with older people in Uganda. This journey began in my bachelor dissertation, where I researched child poverty in slums, only to find out that the most vulnerable children in urban slums were living with their grandparents, a scenario characterised by intergenerational poverty. Hence, I came to this study with the perception that older people, although needing care themselves, actively contribute to the social care system.

Coincidentally, at this stage, my grandfather also needed care. However, at that time, I was still pursuing my bachelor's degree, and my siblings and cousins were in school. My uncles and mother could not provide full-time care as they had obligations to their own families and careers, and some were living abroad. This experience prompted me to inquire in 2011 about professional care providers or care homes in Uganda. To my surprise, we did not have any. We settled for a housemaid who performed personal care, preparing meals and cleaning the house, and a nurse who occasionally addressed medical care needs like nursing, dressing wounds, and measuring blood pressure. My passion for working with older people had been cemented before my bachelor's degree graduation, and I secured a Commonwealth Scholarship to study for a Master of Science in Gerontology. Having completed my master's degree in 2013, I founded Wazee Caregiving Uganda, an organisation centred on providing social care for older people.

In my role with Wazee Caregiving Uganda, I had envisioned filling the gap in social care provision by starting with home visits and home-based care services in urban areas of the capital city, Kampala. However, it was my interaction with one of the clients at Wazee that caught my attention. The client noted that her children could pay for care and questioned how the older people in rural areas who could not afford to pay for care services were being supported. This question ignited my concern about social care services in rural Uganda and how people without care cope. Although I had dedicated my Thursday afternoons to volunteer with two groups of older people in the rural Mukono district in central Uganda, I knew that a larger-scale enquiry was required into the issue of caring for older people. During my volunteering sessions, older people shared their challenges, and we

brainstormed solutions. Together with other volunteers, we assisted some older people who were homeless, lonely, without meals and unable to farm. Older people in these groups formed associations and became each other's support systems. Once shared in the right environment, I believe that an issue is half solved and can be resolved when community members collectively use the resources available.

Through these experiences, my conceptualisation of care was broadened from an individualised view of personal care to a broader societal view. In other words, I could not claim to have offered care to an older person if that person still lived in an insecure and dilapidated house. Perhaps this fostered my approach to considering the ecological approaches in this study and the ambitions of targeting a larger geographical area of older people in rural areas. A small team at Wazee Caregiving Uganda could not solve these challenges, which led me to wonder what social care services for older people were available and who was or should be responsible. I believe that through evidence-based research, issues of marginalised groups in society can be amplified and advocacy for older people elevated. This research is also important and timely in the context of the population ageing and social care problems experienced in Uganda and globally.

1.2 Defining social care

Daly and Lewis (2000) provide one of the most holistic descriptions of social care, describing it as:

> Activities and relations involved in meeting physical and emotional needs of dependent adults and the normative, economic and social frameworks within which these activities are allocated and performed. (Daly & Lewis, 2000, p. 285)

Social care representation in the literature is varied due to its wide scope and complexity. There are several reasons for this. First, it has commonly been represented within professional fields, such as health care (Glasby, 2017; Vlachantoni, Robards, Falkingham, & Evandrou, 2016), social work (Glasby, 2017), care of older people and child care (Daly & Lewis, 2000; Ungerson, 2003), social protection or social security (Thelen, 2015) or cash transfers (Ungerson, 2003), with the care-centred concept being a unifying factor. Researchers argue that the variations occur due to the "unregulated" status of social care work that has not been licensed. Consequently, varying titles include "care worker-residential or community", "aged care worker" "personal care worker" "home support

worker" and "care assistant" (Hutchinson, 2017). Hence, while social care is regarded as a profession, various definitions among professional bodies exist. For example, in Ireland:

> The Joint Committee on Social Care Professionals (JCSCP) defines social care as the professional provision of care, protection, support, welfare, and advocacy for vulnerable or dependent clients, individually or in groups while, the Irish Association of Social Care Educators (IASCE) define social care as a profession committed to the planning and delivery of quality care and other support services for individuals with identified needs. (Lalor & Share, 2013, p. 7)

These definitions are limited to viewing social care within the boundaries of professional practice. However, care activities vary in different contexts. The first point to note is that most care is offered in informal, unprofessional settings. Second, social care rests at the intersection of dichotomies like paid and unpaid work, public and private domains, formal and informal provision and provision of cash and services (Daly & Lewis, 2000; Glendinning & Kemp, 2006; Kemp, Ball, & Perkins, 2013). However, dichotomising social care as either paid or unpaid, formal or informal, private or public, has been criticised for being too simplistic (Wiles, 2004). Third, social care is provided within a multiplicity of environments, for example, care homes, day-care centres, communities and homes (Glasby, 2017). This implies that scholars must consider the diverse meanings and arrangements of care to ensure a holistic exploration of social care.

Despite the complexities in defining care, the definition adopted in this study is relevant to exploring the allocation of responsibility for social care as it refers to macro level (structural arrangements) for the long-term care of older people. This includes consideration of the state, the family, and voluntary sectors alongside the care practices and processes at the micro-social level, as well as and how people deliver care in a given location. Understanding social care in rural sub-Saharan Africa (SSA) is important because the issues around global population ageing and rurality are even more pronounced in developing nations, which often lack formal systems of care.

1.3 Global population ageing and the social care problem

Global ageing trends raise significant concerns around who is responsible for providing older adults with social care, both in developed and developing nations. In this section, I argue that social care issues are more profound in rural areas of developing countries. Although both developed and developing countries experience challenges in increasing demand for care services due to population ageing, financing, staffing and changing

traditional norms around family responsibility, these challenges are more complex in developing nations.

Increasing global life expectancies increase social care demand due to rising frailty and dependency rates (Esping-Andersen, 2009; Savy, Sawyer, & Warburton, 2014). This global phenomenon is also associated with a simultaneous decline in fertility rates, resulting in the population aged 60 and above growing faster than younger groups (United Nations, 2017). Globally, the percentage of people aged 60 years and above is projected to increase by 65% from 962 million in 2017 to 2.1 billion in 2050 (United Nations, 2017). Population ageing has historically been a problem for developed countries, where the biggest populations of older people in the world reside. However, it has only recently emerged as an issue for developing nations. Populations are now ageing more rapidly in developing countries in Africa, Asia, Latin America, and the Caribbean. By 2050, 80% of older people will live in parts of the developing world, and in SSA in particular, the number of older people aged 60 years and above will reach 163 million by 2050 (United Nations, 2017). This anticipated increase in ageing populations in developing countries will increase the demand for social care services, thus requiring a more comprehensive exploration and response (Aboderin, 2017b; Skinner, Andrews, & Cutchin, 2017; WHO, 2017). In the context of the anticipated increase in ageing populations in low and middle-income countries, the question of who will care for older people is particularly pertinent.

While filial piety has traditionally been the key model of aged care provision in developing countries, it no longer guarantees such provision (Oppong, 2006; Van der Geest, 2016), as has also been observed in developed nations (Erhard, 2019; Vik & Eide, 2013). Changing norms around family responsibility for care are weakening family and traditional support networks (Aboderin, 2017b; Dhemba & Dhemba, 2015; Kago, Kavulya, & Mutua, 2017; Oppong, 2006; Van der Geest, 2016; WHO, 2017). In addition, increased poverty levels associated with economic shocks at a macro level like inflation and increased levels of formal unemployment impact household incomes, resulting in higher percentages of women in the paid workforce (Verick, 2014). While the increase in the female workforce is positively attributed to increasing levels of educational attainment, improved access to credit schemes and campaigns of gender equality (Verick, 2014), it also impacts family care resources by decreasing the numbers of informal caregivers in both developing and developed countries (Daly & Lewis, 2000; Esping-Andersen, 2009; Hodgkin, 2014; WHO, 2017; Zhou & Walker, 2016). Consequently, the informal care sector can no longer be

expected to provide care for the growing numbers of older people. This has impacted other sectors in developing African nations, placing pressure on community members, government, the voluntary sector, and international organisations like Help Age International, the United Nations (UN), and the World Health Organization (WHO) to contribute more resources towards social care provision for older people (Dhemba & Dhemba, 2015; Kloppers, Dyk, & Pretorius, 2015).

Governments within developed countries have developed various social care programs to address aged care needs. In high-income countries such as Australia, formal care is mostly provided by private commercial organisations (37.5.%), compared to government organisations (27.3%) (ABS, 2018). The federal government provides funding to support residential and community aged care through residential care homes, home care packages (Hodgkin, Savy, Clune, & Mahoney, 2020), and meals on wheels (Winterton, Warburton, & Oppenheimer, 2013). According to the Australian Bureau of Statistics, spouses and daughters are the main informal care providers, most of whom view their role as a family responsibility, followed by a perception that they could provide better care (ABS, 2018). Carers also noted emotional obligation, lack of other family members to take on the responsibility, the alternative care being more costly or the lack of other care arrangements as other reasons for providing informal care (ABS, 2018). Aged care includes assistance with personal care, household chores, property maintenance, meal preparation, mobility, transport, reading and writing, and cognitive and emotional tasks. In the United Kingdom, social care services include day centres, nursing and residential homes, meals and home care, assistance with personal budgets and direct payments to purchase care services (Humphries, 2015). In 2020, the Australian government spent $23.0 billion directly on aged care (Pagone & Briggs, 2020). While long-term care expenditure takes up only 1.5% of Australia's GDP, other developed countries like Sweden spend 5% of their GDP on aged care, and Denmark allocates 4.5% of its GDP (Dyer, Valeri, Arora, Tilden, & Crotty, 2020).

Developed countries have designed, implemented and modified various social care programs to address a perceived escalation of funding costs, which has led to significant changes in the way aged care is funded and delivered (Hodgkin et al., 2020). These reforms have led to the increased commodification and marketisation of care (Hodgkin et al., 2020; WHO, 2015) and increased family responsibility (Kröger & Bagnato, 2017). Government responsibility is also evident in some low- to middle-income countries. For example, in Uruguay, services for older people, including personal home care assistants, telecare and

free day centres are fully funded by the government (Bloeck, Galiani, & Ibarrarán, 2019). These encompass variations in private and public provision of aged care. For example, the Seychelles has a home care scheme, health care and social protection for all citizens, and public residential facilities. South Africa offers old-age pensions, private retirement village centres and publicly funded long-term care and individual private care homes (WHO, 2017).

However, governments assume limited responsibility in many developing countries, and social care remains unorganised and largely unidentified. There is also a considerable disparity between developing countries concerning government responsibility for social care provision. For example, in China, which is considered a developing country according to the World Bank and UN criteria of gross domestic product per capita, a small proportion of older people receive publicly funded care, and most older people meet their own care costs or rely on relatives to pay for their care (Hu, Li, Wang, & Shi, 2020). The social care system is comprised of home and community-based care services run by not-for-profit organisations and private companies, while residential care is supplementary (Hu et al., 2020). The government focuses on regulating the care market but only takes on care responsibility when the older people do not have other resources like pension or family caregivers (Hu et al., 2020).

Limited government intervention is also evident in some SSA countries like Ghana, Kenya, Namibia, Lesotho, Tanzania, Nigeria, yet many older people do not receive family care (WHO, 2017). In other African countries, like Lesotho, Zimbabwe and Namibia, existing nursing homes are businesses operating for profit and are neither owned nor managed by the government (Dhemba & Dhemba, 2015; Kloppers et al., 2015; WHO, 2017). Although government responsibility is limited, the social care services provided to older people offer a safety net when they require care and when family members cannot take on caring responsibilities.

Social care for older adults is most problematic in SSA's developing countries, which have no government-administered social care services. Therefore, care is mostly unorganised and often left to families and unregulated domestic workers (WHO, 2017). Faith-based organisations (FBOs) are the biggest care providers yet they face resource constraints (Dhemba & Dhemba, 2015; Kloppers et al., 2015). Institutional aged care homes are met with opposition because they are considered culturally inappropriate (Aboderin, Mbaka,

Egesa, & Owii, 2015; Musisi, 2015). Yet, these too face significant challenges. For example, a qualitative study in Namibia found that families often abandoned older people in privately managed nursing homes without paying for the services. This threatens private sector actors' role from expanding nursing homes as they are not viewed as profitable (Kloppers et al., 2015). Developing countries in Africa remain the most vulnerable globally as they are faced with extreme poverty, limited domestic resources to finance social protection, and inadequate infrastructure (Cox, 2020; UN, 2017). Further, political unrest, civil wars (Gresh & Maharaj, 2013) and the HIV/AIDS epidemic have claimed the middle generations who would previously have cared for the older people (Aboderin, 2017a; Kago et al., 2017). There are also limited numbers of social workers, doctors and nurses specialised in geriatric practice (Cirillo & Tebaldi, 2016; Namuli, 2015). Collectively, these factors produce inadequate government involvement and investment in care provision, and many developing countries have a limited, if not a non-existent, safety net to support older people's social care needs and compensate for reduced family support.

From a policy perspective, while most developed countries have social care acts that regulate the provision of care services and providers, many developing countries lack such regulatory frameworks. In 1990, the UK formulated the National Health Service and Community Care Act that provided 90% of publicly funded social care services. Reforms were introduced that led to the Health and Social Care Act of 2012 and the Care Act of 2014, both of which place responsibility on several organisations to advance integrated care (Humphries, 2015). In Australia, the Aged Care Act 1997 regulates aged care services (Gilbert, 2020). However, many developing countries lack policies to guide the provision of social care to older people. Some countries have adopted national policies of older persons and plans, like Tanzania in 2003, Mozambique in 2004, Lesotho, South Africa in 2006, Ghana in 2010, Kenya and Uganda in 2009 (Gresh & Maharaj, 2013; WHO, 2017). Although social care is one of many key issues that governments address in their policies, various scholars have noted that these policies have yielded few tangible outputs in practice (Aboderin & Hoffman, 2015; Dhemba & Dhemba, 2015; Gresh & Maharaj, 2013).

1.4 The social care problem in rural areas

While providing adequate social care for older people in rural areas is challenging in developed countries (Hodgkin, Warburton, Savy, & Moore, 2017), it is even more problematic in rural low-income countries (LIC) in SSA. Although they experience the

problems rural older people face in developed nations, they experience additional challenges associated with living in developing countries. Social care provision is problematic in the rural areas of developed countries as people are ageing more rapidly than in urban areas yet compared to urban areas they are faced with barriers to health and aged care provisions and a range of social disadvantages (Keating, 2008; Warburton, Cowan, Savy, & Macphee, 2015). Older people have lower socio-economic status and higher levels of physical ill health and discrimination (Winterton & Warburton, 2011). Often, geographical isolation and extreme weather conditions limit access to formal services, leading to social exclusion (Davis & Bartlett, 2008; Scharf & Bartlam, 2006; Walsh, O'Shea, & Scharf, 2019). Furthermore, rural areas face challenges in accessing, recruiting and retaining rural health and social care staff (Warburton et al., 2015; Winterton & Chambers, 2017), inadequate training (Skinner, 2008) insufficient financial resources and transportation of volunteers (Herron, Rosenberg, & Skinner, 2016). Across many African countries, the majority of older people live in rural areas (UN, 2017), where they experience difficulty accessing safe water and good sanitation (Wrisdale, Mokoena, Mudau, & Geere, 2017). They experience even more disadvantages as they have access to limited social and health services compared with their urban counterparts (Agyemang-Duah, Peprah, & Peprah, 2020; Alli & Maharaj, 2013; Vergunst et al., 2017). This is exacerbated by increasing rural-urban migration levels, resulting in older people being left in rural areas with even less care or poorer quality options for social care (Kloppers et al., 2015; WHO, 2017). Moreover, land tenure conflicts and land encroachment that continues to occur in rural areas in SSA have led to increasing rural marginalisation and impoverishment (Kalabamu, 2019). All these issues thus negatively impact the livelihoods and wellbeing of older people, and women are particularly disadvantaged, partly because they are largely excluded from land ownership (Gresh & Maharaj, 2013).

In addition, various sub-Saharan countries experience political instability resulting in forced displacement of people, increased protests and riots, and state-led discrimination, all of which lower growth rates further (Bello-Schünemann & Moyer, 2018). Rural areas experience even more disadvantages as they are more prone to drought and climate shocks, leading to food insecurity, another factor to affect older people (Mushavi et al., 2020). Amidst all these contextual challenges evident in rural populations of SSA, the extent to which formal and informal caregivers assume, are assigned or deflect responsibility for care provision remains unknown. Further, the process of how rural older people negotiate care and their experiences in receiving care remains unexplored. Uganda is a key example of a

developing country in Africa experiencing these multifaceted challenges in social care provision in rural areas, with limited regulatory frameworks guiding the social care of older people. Hence, there is a need to investigate who is responsible for Uganda's current social care system and what that social care system looks like. Therefore, this thesis focuses on how social care responsibility for older people is allocated in a developing country context, using rural Uganda as a case study.

1.5 Problem statement

In its document *Towards long-term care systems in sub-Saharan Africa* (WHO, 2017), the WHO argued the need to map existing social care services in sub-Saharan Africa, improve current initiatives and practices and develop indicators that could forecast long-term care needs. It stated:

> Synthesised information on long-term care experiences, policies, care models and financing approaches and evidence would capture the range of diversity in a manner that is easily accessible and useful to those who wish to implement long-term care systems in their settings. (WHO, 2017, p. 23)

However, no scholarly research has investigated social care services or models for older people in Uganda, including those in rural contexts. Scholars examining ageing in Uganda have instead focused attention on non-communicable diseases (Wandera, Kwagala, & Ntozi, 2015), dementia (Musisi, 2015), HIV/AIDS (Mugisha, Schatz, Seeley et. al., 2015; Mugisha et al., 2016; Mugisha. et al., 2016; Negin et al., 2016; Seeley, Dercon, & Barnett, 2010), and poverty (Golaz, Wandera, & Rutaremwa, 2017). However, Uganda as an example of a developing country in SSA is currently experiencing multifaceted challenges in relation to social care provision for older people in rural areas, and as such, this topic warrants close examination. Approximately 85% of older people in Uganda reside in rural communities, which are characterised by low incomes, limited social services, insufficient public transport and inadequate housing (Musisi, 2015; UBOS, 2017c). Income poverty rates are currently at 22.8% in rural areas compared to 9.3% in urban areas (MGLSD, 2015a). The HIV/AIDS pandemic and the Lord’s Resistance Army (LRA) insurgency, both ongoing since the mid-1980s, have claimed the lives of young adults, leaving grandchildren in the care of their grandparents. This has resulted in an increased caring burden for older adults, most notably older women (Golaz et al., 2017; Mugisha et al., 2015; Musisi, 2015;

Seeley et al., 2010; Ssengonzi., 2009). Consequently, older people in rural areas are more likely to head "skip-generation" households[1] than their urban counterparts (Kabuye, 2015).

Therefore, this dissertation will explore who is responsible for the social care of older adults from the perspective of diverse stakeholders, using Uganda as a case study, which has implications for other African developing countries with similar political and socio-economic contexts. Like most SSA countries, Uganda does not have a formally organised welfare system on which its senior citizens can fall back (Bilson, Nyeko, Baskott, & Rayment, 2013) and social care for older people in the country has emerged as a key policy issue. This is evidenced by its inclusion in the National Policy of Older Persons (2009), the National Plan of Action (2012), the Social Protection Policy (2015) and the Programme Plan of Intervention (2015) (MGLSD, 2009, 2012, 2015a, 2015c). It should be noted that there are no policy documents focusing specifically on social care. However, this research will analyse these related policies and examine the conceptualisation of social care responsibility at a national level.

Little is known about the formal social care services available to rural older Ugandans and who is responsible for providing these. While some qualitative research has identified sporadic institutionalised care home initiatives in Uganda, there is little evidence of whether they are still operating (Najjumba-Mulindwa, 2003; Njuki, 1999). Families have predominantly assumed aged care responsibility (Bantebya-Kyomuhendo & McIntosh, 2006; Golaz et al., 2017; Matovu & Wallhagen, 2020; Nzabona & Ntozi, 2015), yet their informal care practices also remain unexplored. Moreover, the varied responsibilities assumed by FBOs, NGOs, private companies, government and communities are also unknown. So too are the challenges they experience and their expectations of who should be responsible for care.

Consequently, the social care services available for older people and the geographical scope of these services in rural Uganda remain unidentified. As such, Uganda provides a valuable case study for this research, which will contribute directly to developing this evidence base.

[1] Skip generation households are comprised of grandparents and grandchildren with the middle-aged parents missing.

1.6 Aims and research questions

Using a qualitative transformative approach, this research aims to explore how social care responsibility for older people in rural Uganda is allocated and experienced across diverse levels of environmental context– policy, organisational and community. It is guided methodologically and conceptually by EoC theory (Tronto, 1993; Tronto, 1998, 2013), CRG (Skinner, Winterton, & Walsh, 2020), and CHE perspectives (Keating et al., 2020). The phases of care presented in the EoC theory, which comprises the stages of attentiveness, responsibility, caregiving and responsiveness (Tronto, 1993) and solidarity (Tronto, 2013), were used in the analysis to contextualise the findings.

The aims of this research were pursued by addressing four interrelated research questions:

1. How is responsibility towards social care for older people allocated in national policies in Uganda?
2. What are the perspectives of key stakeholders from government, non-profit and community-based organisations on responsibility for older people's social care in rural Uganda?
3. What are the lived experiences of caregivers of rural older people regarding responsibility allocation and caregiving?
4. What are the lived experiences of rural older people receiving social care?

This study is innovative as it is the first known study to explore the social care system in rural Uganda at various levels of environmental context and it will provide new knowledge about the current social care system for older adults in Uganda. This study is conceptually innovative because it is the first study to use EoC theory to understand social care systems for older people in the rural setting of a developing African country. This thesis also develops and introduces the concept of care disruption as a key consideration in applying and advancing the EoC theory to a rural developing country context. By doing so, this thesis provides an understanding of how social care responsibility is assumed or deflected and how this responsibility shapes and is shaped by the care needs, experiences, coping strategies and care expectations of older people, their caregivers, stakeholders, and policies. Rural gerontologists have noted the need to expand critical rural gerontology (CRG) to developing country contexts to examine long-term systems (Skinner et al., 2020). The adoption of CRG in this study thus aims to elucidate how structural and environmental factors alongside power structures shape rural ageing experiences in a low-income country, with particular attention to social injustice. This offers new evidence pertaining to the

resilience of older people, caregivers and stakeholders in taking on social care responsibilities despite the varied and complex challenges they experience. This study further offers practical recommendations and insights from stakeholders, caregivers and older people to solve challenges that worsen the social care problem for older people in rural Uganda.

1.7 Structure of the thesis

This thesis is comprised of nine chapters. Chapter Two discusses the conceptual and theoretical foundations of the thesis. Chapter Three explains the research methodology, which encompasses the philosophical foundations, methodological framework and a brief description of the study sites. It also presents the research design methods and analytical framework, and ethical considerations. Chapters Four to Seven present findings from the analyses. Chapter Four addresses research question one, which aims to analyse how social care responsibility is represented in policies. Using Trace analysis, it examines four Ugandan national policies relating to social care. It discusses the findings using arguments relating to EoC to establish how social care responsibility is conceptualised. Chapter Five presents findings from interviews with stakeholders from government, non-profit and community-based organisations. It addresses question two of this research, which explores social care responsibility through the stakeholder lens. Chapter Six addresses question three by examining social care responsibility from caregivers' lived experiences, drawing on focus group data. Chapter Seven presents the findings from interviews to answer question four of this research on older people's lived experiences in receiving social care.

Chapter Eight, the concluding chapter, presents a critical discussion of the study and its key findings. The chapter summarises the key study findings, then discusses and compares the key findings to existing arguments about aged care responsibility in relation to the ethics of care (EoC) theory and critical rural gerontology (CRG). The study's significance and its implications for theory, policy and practice are presented. The concluding section draws together the recommendations, the limitations and strengths of the study and proposes future research directions. In doing so, it acknowledges the intersection of the care theories and critical rural gerontology to understand social care responsibility allocation.

1.8 Conclusion

This chapter has provided an overview of why investigating social care for older people in rural Uganda is critical in the context of the socio-economic and political challenges

associated with social care provision for older people in developing countries and rural settings. I have defined the concept of social care and presented the research aims, the significance of the research and the thesis structure. In the next chapter, I present the theoretical underpinnings for this research and the historical foundations of social care in the Ugandan context.

CHAPTER TWO : THEORETICAL AND HISTORICAL FOUNDATIONS OF SOCIAL CARE

2.1 Introduction

The ethics of care (EoC) theory has been used in empirical research to critique the normative understanding of the ideals of responsibility, thus adding a moral dimension of care that advances our view of social care beyond practice and care processes (Sihto, 2020). This chapter aims to demonstrate that EoC theory is relevant to understanding care responsibility in a rural context in a developing country. I begin by introducing the theory and reviewing the concept of responsibility within the ethics-of-care model. This is followed by an exploration of the positioning of EoC in welfare states. The chapter then explores the historical context of social care in Uganda with regard to EoC. Finally, the chapter discusses critical rural gerontology (CRG) and critical human ecology (CHE) as important perspectives in understanding social care responsibility for older people in a rural developing country context, and across different levels of environmental context.

2.2 Ethics of care

EoC is the most commonly used theoretical perspective in research on care (Ibnouf, 2020). Tronto defines care as

> …a species activity that includes everything that we do to maintain, continue and repair our "world" so that we can live in it as well as possible. The world includes our bodies, ourselves and the environment, all of which we seek to interweave in a complex, life-sustaining web (Tronto, 1993, p. 103).

This broad definition allows for the consideration of care for oneself, others and the environment. This thesis draws on key concepts in care ethics to explore social care for older people in rural Uganda. In doing so, it focuses on the concept of responsibility to enhance our understanding of not only "who cares," but also the type of care, the motives to care and the activities and relationships associated with responsibility. Held (2006) argued that the ethics of care primarily focus on the moral obligation to meet the needs of people for whom we are responsible. The theory was developed based on Carol Gilligan's (1977) research on the psychology of moral development. She argued that women had a unique view of morality and approached morally related problems differently from men (Gilligan, 1977). Gilligan (1977) argued that women saw morality principally as a matter

of responsibilities that arose from their relationships with other people. Men considered morality in terms of their rights that evolved from quasi agreements between egocentric equals that previously had no obligation to each other. She challenged the dominant male-centric models to research decision-making and morality and the depiction of individuals as autonomous, free-thinking agents who are completely rational, claiming that women made moral judgements based on the context of care and responsibility (Gilligan, 1977). Therefore, the fundamental reason for making a moral judgement is to practise choice and the readiness to assume responsibility (Gilligan, 1977). The development of the ethics of care in the twentieth century was, therefore influenced by feminist thought. Feminist care theorists have continually noted that care responsibility for older people, children or the sick falls heavily on women in the private sphere (Gilligan, 2013; Sevenhuijsen, Bozalek, Gouws, & Minnaar-McDonald, 2003; Tronto, 2015b). Critics of the EoC theory have remarked on its absolute focus on care as a traditionally gendered women's task; however, care theorists argue that they make the previously unacknowledged value of care more visible as they (and the theory) give voice to the subjugated group (Kittay, 2011). Although this thesis questions the gendered roles in caregiving, it focuses on a broader ecological system of social care that explores *responsibility* for care. Scholars have previously urged that scholars explore the more varied cross-cutting relationships, forces and processes that shape how care is posited, prioritised and recognised in policy and society. Hankivsky (2014) discussed the importance of considering intersectionality as a theoretical resource in developing the ethics of care. Over time, the EoC theory has evolved thanks to major contributors like Tronto, who developed the phases of care. I discuss these in the next section in terms of how they inform this research.

2.2.1 Responsibility within the phases of care

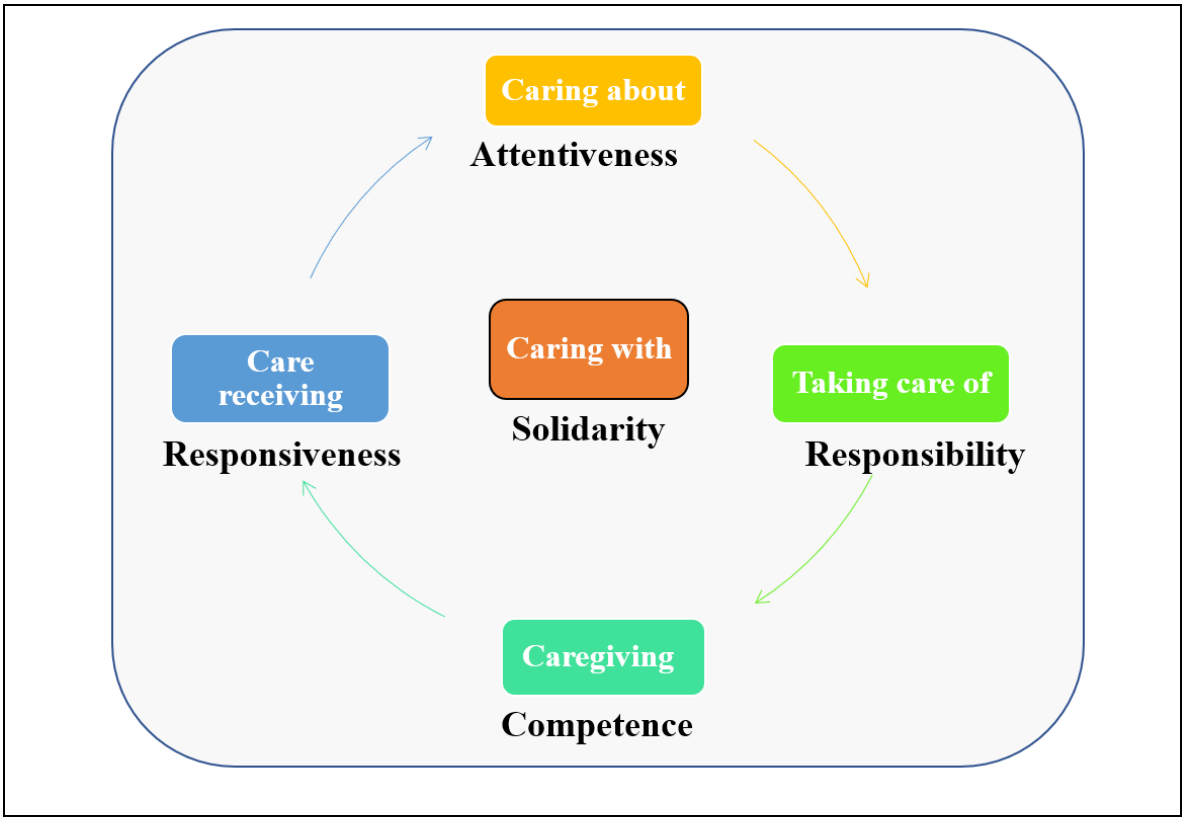
The EoC theory has broadened beyond its original feminine focus of ethical decisions in the private sphere of the household towards public, political realms and globally in informing moral thought about care (Held, 2006). As depicted in Table 2.1, Tronto (1993) proposed four cyclical phases of caring (Tronto, 1993, p. 105) that align with four elements of care (Tronto, 1993, p. 127). An additional fifth element is caring *with*, which aligns with the elements of trust and plurality (Tronto, 2013).

Table 2.1 Phases of care

	Phase of care	Element
1	Caring about	Attentiveness
2	Taking care of	Responsibility
3	Caregiving	Competence
4	Care-receiving	Responsiveness
5	Caring with	Solidarity

Tronto (1993) argued that the phases of care are cyclical, as shown in Figure 2.1. Hence this thesis views responsibility within this model as both influencing and being influenced by other elements. *Caring about* involves an assessment that entails identifying people in need of care, recognising the conditions that trigger care needs, as well as daily needs and moral orientations (Sevenhuijsen, 2000; Tronto, 1993). The second element is *taking care of*, which encompasses assuming responsibility for the recognised need and determining the course of action to respond to it.

Figure 2. 1 Phases of care (Tronto, 2013)



Responsibility is viewed as being relational, based on relationships that often involve people in need and those who respond by engaging in direct caregiving. Hierarchy of care theorist Goodin (1995) elaborated on how this responsibility is ascribed to stakeholders by bearing in mind the assumptions that:

a) The primary responsibility of care is to self.
b) Family members, friends and those holding a special relationship are immediate secondary carers.
c) The community then has shared responsibility for all its members.
d) Government has the responsibility to care. If not able, the international community takes on this role.
e) We have general duties to care for people in need.

Applying the hierarchy of care model to developing countries is problematic, particularly when global care workers leave their immediate family relatives who are themselves in need of care to work in foreign countries (Nguyen, Zavoretti, & Tronto, 2017; Yeates, 2012). Where there is a limited mandate for people to care, it is generally important to explore the responsibility hierarchies and the context or processes within which they thrive, this research considers the Ugandan context.

People who assume responsibility for care are expected to engage in *caregiving* (Tronto, 1993; Tronto, 2014), the third phase of care that highlights the moral competence of the caregiver to engage in actions to meet another person's need for care. Tronto (2013) noted that care is a practice initiated with a thought that needs to be manifested into action. Thus, caregivers are expected to provide quality adequate care that meets all care needs. However, limitations in resources, even if combined with willingness or knowledge to perform caregiving, can lead to inadequate care (Tronto, 1993; Tronto, 2015b). The fourth element of responsiveness is concerned with the phase of *care-receiving*, where conditions of vulnerability and inequality are present (Tronto, 1993). Care theorists emphasise that those providing the care should ensure that caring does not create dependencies on the carer and caregivers who assume responsibility need to be aware of the possibilities of abuse that could arise with vulnerability (Tronto, 1993). Hence, for care to be responsive, it should react to the person's needs, which requires close attention, listening and understanding, and being receptive (Tronto, 2015b). *Caring with* is the last phase of the care cycle, and underscores the element of solidarity (Tronto, 2013). Solidarity encompasses the moral qualities of plurality, trust, respect and communication (Sevenhuijsen, 1998; Tronto, 2013). It calls for a collective approach that addresses care needs based on democratic commitments and principles of equality, freedom and justice that promote a caring democracy (Tronto, 2013). A caring democracy is seen to answer the questions around responsibility, including "Who is caring in society?" "Do those individuals accept these

responsibilities?" "Are they properly compensated?" (Tronto, 2015a). Care theorists call for the investigation of diverse care needs, existing caring practices and institutions in our communities to facilitate creating social organisations that can respond to diversity (Tronto, 2015b). Care theorists thus acknowledge the importance of understanding the interdependencies, relationships and interconnectedness that characterise care (Suitor et al., 2017).

This thesis focuses on the second element of responsibility, that is, the second phase, *taking care of*, and its relationship with the other phases and elements of care. Specifically, this thesis draws on EoC theory to argue that responsibility impacts and is impacted by the other elements/phases of care and shaped by the complexities in different ecological environments, which I refer to as care disruptions. Before responsibility can be assumed, one needs to observe closely the presence of care needs and assess how those needs could be met.

I employ EoC theory across the chapters of this thesis to comprehensively analyse (1) how perspectives and experiences among various stakeholders are associated with social care responsibility and (2) the interface of responsibility with other elements of the care phases. In EoC, care responsibilities are allocated according to ideologies related to domesticity, professionalisation, institutionalisation and marketisation (Tronto, 2013). Various care theorists have also analysed the ethics of care, conceptualisations of social care and particularly responsibility allocation within the social welfare model (Chung, Hrast, & Rakar, 2018; Daly & Lewis, 2000; Engster, 2019; Sevenhuijsen et al., 2003; Tronto, 2010). The next section discusses the concept of responsibility in relation to care in developed and developing countries, highlighting the variations in the ethics of care and the limitations of applying EoC in rural developing nations.

2.2.2 Responsibility allocation through welfarism

Several care theorists have explored the intersection of ethics of care and welfare states (Engster, 2015, 2019; Nguyen et al., 2017; Tronto, 2015a). One of the channels through which care is considered in policy agendas is welfare policies and aged care regulations (Sevenhuijsen, 2003). In line with contemporary research on welfare states, this body of research draws on the concepts of institutionalism, communitarianism, marketisation, familialism, individualism and voluntarism (Daly & Lewis, 2000; Esping-Andersen, 2009) to explore responsibility allocation in various countries. These concepts will provide a

background for analysing the allocation of responsibility in Uganda. The use of these concepts is vital as they embed responsibility allocation in the types of care provided and care environments.

Globally, care ideologies govern how older people are cared and provided for. Most developed countries have established welfare systems that provide financial care through the provision of welfare payments. Institutionalism represents the formation of government institutions and the management of welfare and development. Here, the state is responsible for aged care by providing social cash transfers, social insurance and direct care delivery programs, including residential aged care (Robertson, Gregory, & Jabbal, 2014) and care in these settings is regulated and formalised. In social democratic welfare regimes, mostly Nordic countries like Sweden, Denmark, Finland and Iceland, institutionalism is the predominant ideology behind social welfare management, evidenced by their commitment to providing publicly funded universal aged care (Warburton & Jeppsson Grassman, 2011). However, researchers note that institutionalised care is now facing cutbacks in many developed countries like Sweden (Szebehely, 2020; Wiles, 2004), with corresponding shifts in care responsibility from the state to individuals, communities, volunteers and the market (Daly & Lewis, 2000; Esping-Andersen, 2009; Hodgkin, 2014). In Finland, the shift in responsibility from the public to the private sphere is viewed as a solution to challenges in the aged care sector to reduce government spending (Sihto, 2020).

Care theorists have also noted the increasing influence of neoliberal ideology, which frames care as an individual responsibility (Sevenhuijsen et al., 2003; Tronto, 2017), in line with neoliberalism's promotion of marketisation and favouring small government and private enterprises (Bergman, Johansson, Lundberg, & Spagnolo, 2016; Daly & Lewis, 2000; Robertson et al., 2014). The notion of individual responsibility inherent in neoliberalism translates into arguments for individuals to organise and pay for their own social care (Tronto, 2017; Yeatman, Dowsett, Fine, & Gursansky, 2008) rather than relying on the state (Yeatman et al., 2008). In liberal welfare regimes like the USA, Canada, UK, New Zealand and Australia, the ideology of neoliberalism has become increasingly influential in the provision of care to older people. For instance, in Australia, the government is placing increased responsibility on individuals through policies that favour independence, self-determination and individual choice (Cash, Hodgkin, & Warburton, 2013; Glendinning & Kemp, 2006; Ungerson, 2003; Xiao et al., 2014). Australia has moved to a delivery model heavily reliant on marketisation (Hodgkin et al., 2020), resulting in a multi-billion dollar

publicly funded industry subcontracted to for-profit and not-for-profit organisations (Cousins, 2020). While care ethics assume collective responsibility, liberal individualism emphasises self-reliance (Held, 2006), resulting in care responsibility being devolved to family members. The growing trend of under/de-regulating and commodifying care causes caregivers and care recipients to be exploited, disempowered, and vulnerable (Rummery, 2011). Often those with fewer resources will have the poorest quality of care with responsibility devolved to the individual and family (Tronto, 2015a).

In mixed-welfare states, where multiple agencies meet welfare needs, voluntarism represents the ideology of relying on the involvement of voluntary organisations in the distribution of social welfare. This is manifested by devolving care responsibility to not-for-profit organisations and community support groups (Nguyen et al., 2017; Skinner, 2008; Winterton et al., 2013). Hence voluntary and not-for-profit organisations take up varying degrees of responsibility for aged care (Herron et al., 2016).

Contrary to the morals reflected in both institutionalism and individualism, communitarianism stresses community responsibility for the care of individuals and encourages the provision of care at the neighbourhood level, that is, within the locality of the older recipient (Zhou & Walker, 2016). Accordingly, communitarianism often enables older people's capacity to age in place (Andrews & Phillips, 2005; van Groenou & De Boer, 2016; Wiles, 2004). Communitarianism presumes that the sense of belonging in a community offers a moral justification for communities to take on responsibility, which is vital in shaping their self-identity and behaviour (Sevenhuijsen, 1998). Services primarily funded by the state, such as home care, day care, recreational activities, transportation, and meals on wheels (van Groenou & De Boer, 2016; Wiles, 2004; Winterton et al., 2013; Zhou & Walker, 2016), often rely on volunteer friends and neighbours to be successfully delivered (LaPierre & Keating, 2013). In South-East Asian welfare regimes, particularly those developed by Japan and Chinese societies, communitarianism is dominant and based on Confucian concepts (Warburton & Jeppsson Grassman, 2011). Elements of communitarianism are also evident in Africa, as evidenced by the concept of ubuntu, which describes a person’s quality and identification with the community. Bishop Desmond Tutu, a South African Anglican cleric and human activist, conveyed the notion of ubuntu, noting,

"My humanity is intrinsically related to that of other persons" (Tutu, 1999). Obuntu[2] views community needs as being superior to those of the individual and that collectivism and communal responsibility are essential in addressing societal needs with the associated values of empathy, generosity, dignity, mutualism and community commitment (Tutu, 1999). Care responsibility is assumed to follow communal relationships and is reciprocal, entailing mutual dependencies (Gouws & Van Zyl, 2015).

Familialism is an ideology that assigns the principal responsibility for individuals to the family (Esping-Andersen, 2016) and is dominant in conservative welfare regimes like Germany, France, Belgium and Austria and the southern European welfare regimes of countries like Italy, Spain and Portugal (Warburton & Jeppsson Grassman, 2011). Familialistic societies promote family dependence in situations where care is required (Connolly, Kiraly, McCrae, & Mitchell, 2017; van Groenou & De Boer, 2016). By viewing families as the first response to older people's care needs, familialism in these societies often considers care an obligation, rather than a responsibility that is met voluntarily (Sihto, 2020). In these patriarchal frameworks, care is mostly regarded as a feminine responsibility instead of a democratic framework that views care within the human ethic (Gilligan, 2013). This sense of duty to care is also evident in Confucian societies, where caring responsibilities in families and communities are determined based on gender. The men's care work promotes official positions of protection and production, while women are left in the domestic realms, which are undervalued in Confucianism (Zhang, 2020). Care within families is heavily reliant on intergenerational relations and solidarity (Hodgkin, 2014).

The theorisation of care ethics has been grounded in the western societies of Europe and North America, drawing on care as practised in the Global North (Raghuram, 2016). Care theorists have thus argued that care ethics need to be considered beyond the Global North by considering the diversity of care practices globally. Although the literature on care for older people has progressed over the last decades, there is limited application of theories to understand how care responsibility is allocated in developing countries, particularly in SSA low-income countries. Most research applying an ethics-of-care perspective in Africa is limited to policies (Sevenhuijsen et al., 2003), and research on care practice has been carried out mostly in South Africa (Gouws & van Zyl, 2014; Hanrahan, 2015; McKenzie, 2016;

[2] I am aware that the concept of Ubuntu is largely referenced in the literature. However, as a Muganda, the concept of Ubuntu translates to Obuntu and resonates with the study participants in central Uganda. Hence, this study will refer to "Obuntu."

Schneider, 2020). Welfare states are very limited among the developing nations in Africa; as a result, there is limited investigation of empirical contexts in the Global South and rural contexts create gaps in the ethics-of-care scholarship. Additionally, while scholars note that the connotations and practices of care are ambivalent in the Global South (Nguyen et al., 2017), they do not explain those points of ambivalence. It is therefore critically important to provide a history of social care in Uganda in order to understand the contextual underpinning of how responsibility for social care is conceptualised and understood.

2.3 The historical evolution of social care in Uganda

Examining how care for older people has evolved in Uganda is important in understanding the current state of social care for older people in its rural areas and how care responsibilities are allocated. The impact of colonial and post-colonial influences in shaping the ethics of care in the country is explored by highlighting the historical contexts of care. Colonial backgrounds have been noted to affect the meaning of care and how it is practised (Raghuram, Madge, & Noxolo, 2009; Urban & Ward, 2020). As the subsequent discussion indicates, the evolution in Uganda's social care is characterised by a decline in the dominance of kingdom and a reduction in the power held by traditional and cultural leaders alongside changes in post-colonial cultural norms. Further, these changing cultural norms in Uganda have been influenced in part by historical factors such as industrialisation, evolving religious beliefs and civil conflicts.

2.3.1 Pre-colonial era (before 1894): The political-cultural context

During the pre-colonial era, powerful traditional leaders dictated social care provision for older people, based on norms and traditions, which included compelling extended families to provide care in Uganda. Many traditional Ugandan societies were headed by kings based on hereditary principles within organised structures known as “kingdom states”. These states included Buganda, Ankole, Toro and Bunyoro among the Bantu ethnic group and they covered most of the central and southern parts of modern Uganda. In Northern Uganda, age-set clan systems such as the Lugbara, Langi and Acholi were stateless but politically organised through self-governing villages (Rubongoya, 2007; Tamale, 2018).

The exercise of political power in the pre-colonial era was rooted in the authority vested in kings and bore little relationship to the current democratic system of government (Rubongoya, 2007). The governance of these highly centralised kingdoms ensured care for

older people through their complex structures. For example, in Buganda, the king appointed administrative and clan chiefs who, in turn, reported to the clan and lineage-based councils; further down the hierarchy were village councils and local councils (Rubongoya, 2007). The choice of clan-heads was often based on their political-cultural abilities to meet society's needs and demands. The clan organisation ensured familial and collective responsibility in caring for older people who were ill, homeless, requiring support to cultivate their land for food as well as the provision of support and comfort when a relative died (Ouma, 1995). The provision of care reflected local culture and traditions, and was based on values of reciprocity, social cohesion, personal intimacies and altruism, equity and social justice (Ouma, 1995). This highlights the heavy influence of familialism and some elements of institutionalism through collective responsibility.

Pre-colonial societies were generally patriarchal, and men were authoritarian and dominating in the political, social and economic realms, wielding power and control over women. It has been noted that women's engagement with political processes was very limited during the period but that they were consulted before political decisions were made (Lebeuf, 1963). Women's power role in the informal realms of pre-colonial society accorded them primary caring responsibilities for their relatives, including older people—a convention passed on across generations. The kings, chiefs and traditional leaders who held power decreed and reinforced these customs, thus ensured social care provision by women for older people in these societies (Rubongoya, 2007).

2.3.2 Colonial rule (1894-1962): political-religious context

During the period of British colonial rule, colonialists and missionaries introduced formal social care arrangements. It has been argued that this served to weaken traditional care systems (Sejjaaka, 2016) and distort the complex indigenous Ugandan political-cultural structures of power and governance. This era witnessed the imposition of religious beliefs, alongside western political institutions and objectives on Ugandan societies (Okoth, 1992). The arrival of Christian and Muslim missionaries in Uganda also undermined recognition of traditional authorities as legitimate rulers, not least because the colonial guarantors gave the missionaries considerable power to establish Uganda as a British protectorate (White, 1999). As a result, traditional rulers had to align with a particular religion, such as Protestantism, Catholicism or Islam, to maintain their political-cultural influence and relevance (Rubongoya, 2007). However, existing and divergent independent political systems within Ugandan societies made it challenging for the colonialists to consolidate

Uganda into one governmental entity. In response, the British imperialists introduced the divide-and-rule strategy of indirect rule and the formation of formal public domains, separate from the informal, traditional political structures (Sejjaaka, 2016).

Deformation of the traditional support systems characterised the colonial era and the mutual social support systems are now deemed to have been destroyed due to three distinctive processes of colonisation, as outlined below (Ouma, 1995).

- First was the introduction of a bureaucratic British protectorate government that expediated the decline of traditional power, thus crippling local populations' ability to solve their affairs. Consequently, this undermined the kinship system of protecting and providing for the old and the sick.
- Second, the introduction of money weakened existing mutual aid support schemes and bartering, which had accommodated the values of reciprocity and altruism. This introduction of commercialised work weakened the traditional norms and customs of caring for older people. The sale of labour was prioritised over community service in helping the aged and sick. Collective responsibility was undermined as new responsibilities and obligations of taxation and foreign merchandise were introduced.
- Third, promoting a distinction between work and home meant that people had to work in industries like mines, plantations or commercial centres that focused on cash crops rather than food crop production away from their homes. People spent more days in economic work away from relatives, which decreased even more the ability to care for older people and led to a steady diminution of extended family relationships (Ouma, 1995).

Provision of care for older people was viewed as more suitable in public hospitals and as a state responsibility (Ouma, 1995). The colonial administrators also introduced remedial welfare measures mainly for settler communities (Gray, 2016). The ancient social work practices in Uganda were thus rooted in the colonial and post-colonial social welfare systems that focused on service delivery and individual remedial services. Central development and welfare committees were established, which appointed sub-committees to deal with rural development and welfare issues like water supplies and nutrition. These local standing committees coordinated and informed policy formulation by the government (Jeffries, 1943).

Against this, the colonial period came to be regarded as an era of female empowerment. The establishment of missionary schools meant women's social and economic position in the colonial economy was improved (Meier zu Selhausen, 2014). Women engaged in paid work with increased literacy, mainly taking on caring professions as nurses, teachers, and midwives, thus breaking away from their pre-colonial status. Women's empowerment also promoted more equal relations between men and women and between generations (Meier zu Selhausen, 2014). According to Prevost (2010), the emancipation of women in this era is also credited with the shared spiritual and social clubs frequented by married African and Anglican British women. In these spaces, Christian values were promoted and male-centred hierarchies were challenged. The colonial era also witnessed the opposition of ideologies concerning women's work outside the domestic context as women became more independent and free and could delegate caring tasks (Bantebya-Kyomuhendo & McIntosh, 2006).

2.3.3 Post-colonial era (1962-1986): The formation and distortion of policies and institutions

Uganda's independence in 1962 marked the formal end of the colonial era with the Buganda King, Sir Edward Muteesa II, becoming the first president of Uganda and the formation of the Buganda government. However, throughout the post-colonial period, the shift of political regimes led to uncertainties and deformation of social care structures alongside crippling policy development. By 1967, traditional rulers and local legislators were abolished, sending the president into exile. A professional civil service was established and controlled by the Public Civil Services Commission, prompting the provident fund for wage earners in the mid-1960s (Ouma, 1995). The first Ugandan Constitution was established in 1962 and went through a series of amendments, favouring the first prime minister, Milton Obote. Uganda went through six changes in political leadership between 1979 and 1986, a period often referred to as "a lost decade" or the "Uganda crisis" (Sejjaaka, 2016) because it was characterised by dictatorship alongside the expulsion of Asians from Uganda and a short rule of the fourth president of Uganda; Yusuf Lule, which lasted approximately 60 days. The political instability distorted policymaking and service delivery structures (Ouma, 1991), leading to the cessation of social support systems; many families lost their breadwinners (Ouma, 1995) and government and non-government social welfare services were crippled (Bukuluki, Mukuye, Mubiru, & Namuddu, 2016).

2.3.4 The National Resistance Movement era (1986 to present): Reformation and development of policies

During the contemporary period, the political stability and dominance of a single political party influenced developments in relation to informal and formal care provision for older people and related social policy. According to Ouma (1991), the input of political leaders the policy process mirror political ideologies. Since the acquisition of political power by President Museveni in January 1986, different reforms and restorations were made to human rights that later led to the consideration of social care for older people in the Uganda constitution and policies. For example, in May of 1986, the first bill was tabled to create the Uganda Human Rights Commission, which was established in December of the same year (Rubongoya, 2007). In 1993, the traditional monarchies were restored. Although only cultural, not political, powers were given to the kings, the traditional customs of pre-colonial Uganda were reinvigorated. By 1995, the Ugandan Constitution was enacted and promulgated (Asiimwe, 2014). Additionally, a Local Government Act was established in 1997 that reflected the World Bank's recommendations to shift control from central government ministries to local institutions (Rubongoya, 2007). However, through the 1990s, conflict stemming from the rise of the Lord's Resistance Army (LRA) led to insurgencies in Northern Uganda, which disrupted family and social networks, including the death and relocation of relatives and traditional customs (Corbin, 2021). In 2006, the peace agreement signed between the rebels of the LRA and the Ugandan government halted the conflicts, and the restoration of Northern Uganda was under way (Rubongoya, 2007).

Although social security initiatives were evident through the National Social Security Fund (NSSF), the NSSF itself was criticised for not providing social support and care (Ouma, 1995). Notably, the NSSF did not include long-term care services like home care services or nursing homes (Njuki, 1999). This meant that older people fell back on the fragile traditional welfare system for social care. However, commitments were outlined in the National Resistance Movement (NRM) party manifesto in 2006, when it considered older people in relation to three areas. First, the NRM proposed reviewing the constitution to include the representation of older people in parliament. Second, it proposed the provision of drugs for older people at health centres and, third, it proposed to fully operationalise The National Plan of Action for Older Persons (Museveni, 2016). The Senior Citizen's grant, a program clustered under the Social Assistance Grants for Empowerment (SAGE), was formulated to fulfil this manifesto (Museveni, 2016). Older people, therefore, receive 25,000 Ugandan shillings each month (approximately US$7, AUD$10 and £5) from the

SAGE program. President Museveni has been praised for initiating the broadest agenda of policy reforms across various sectors, including economics, health, decentralisation, education, social development and social welfare in Uganda's post-colonial history, making the president's office innovative in policymaking (Rubongoya, 2007). However, it was not until 2009 that the National Policy for Older Persons (NPOP) (MGLSD, 2009) was formulated.

The historical contexts of social care and responsibility throughout the colonial and post-colonial periods have significant implications for the ethics of care in the current care practices and responsibility allocations of social care within the systemic levels of rural Uganda. Colonialism, political instability and civil wars were key challenges that contributed to the disruption of care in Uganda's history. Therefore, as I explore responsibility allocation, I argue for the consideration of the complex situational and environmental challenges and disruptions that shape social care responsibility, subsequently having a significant impact on elements in the phases of care (attentiveness, caregiving, responsiveness and solidarity). My study is important in highlighting how the way in which care is practised, the broader structural system of care, and the contexts of caring in a developing country, namely Uganda, within SSA are different from developed nations. In the next section, I make the case as to why CRG theory is important in exploring care responsibility in a developing rural context.

2.4 Care responsibility and Critical Rural Gerontology (CRG) theory

This study draws on concepts from CRG to understand care responsibility for older people in rural contexts. Critical rural gerontologists seek to understand and challenge ageing stereotypes in rural ageing environments (Burholt & Scharf, 2019; Skinner et al., 2020; Skinner et al., 2017; Skinner & Winterton, 2018). A critical lens can shine a light on how the various elements and circumstances of ageing in a rural area shape older people's lived experiences within a complicated multi-level set of practices (Skinner et al., 2020). CRG aims to:

1. interrogate the impact of broader macro-level trends and processes on ageing in rural communities and older people in rural communities

2. question the construction or positioning of rurality within processes and structures that empower or disenfranchise diverse older people while simultaneously considering how processes and constructions of demographic ageing shape rurality
3. question the scope and capacity of diverse rural communities to support population ageing (Winterton, Walsh, & Skinner, 2020, pp. 354-356).

This study contributes to the literature by employing a critical lens to position the claims and debates of EoC in the rural context of a low-income country and rural gerontologists have recently noted the need to expand CRG to the contexts of developing countries (Skinner et al., 2020). This approach will contribute to innovations in policy and practice to address the growing problem of caring effectively for older people in rural settings of low-income countries. Care theorists maintain that being attentive to differences in values around the meaning and practice of care in different geographical settings can enhance solutions towards solving some tensions in normative forms of care (Raghuram, 2016). Hence, incorporating the exploration of rural contexts expands our understanding of the complexity of care processes, factors and values that shape care systems and environments. These environments are considered in detail within the CHE perspective, a key theory in CRG and one that I discuss next.

2.4.1 Critical human ecology

In applying a critical lens, this thesis draws upon concepts from critical human ecology (CHE) (Keating et al., 2020). Basic human ecology theory recognises and incorporates human relationships to environments from micro to macro levels. The micro environment is the immediate environment, which is comprised of the interactions between the individual and their closest surroundings such as family, physical (i.e., home, natural environment) and social (i.e., neighbours, friends and family members) environments (Keating & Phillips, 2008). The macro environment is comprised of economic, cultural and social contexts, policies, programs and services (Keating & Phillips, 2008).

At its base level, human ecology theory has been used to advance research, practice and policies for ageing-in-place initiatives (Greenfield, 2012). It has also been used to explore the perspectives of providers and beneficiaries of rural home support (Sims-Gould & Martin-Matthews, 2008), and spousal caregiving (Cash, Hodgkin, & Warburton, 2017). Christensen (2010) used an ecological framework to analyse the care profession and social work practice from a transnational perspective in relation to Sweden, Denmark, and

Germany. This model has since been applied to develop a community ecological model of wellness for older rural people (Winterton et al., 2016) and explore the establishment of contested rural ageing spaces (Skinner & Winterton, 2018, p. 19). More recently, critical human ecology has been used in rural research beyond the Global North, in such developing countries as Malawi and India (Keating et al., 2020).

A critical approach in human ecology asserts that older adults are not passive beneficiaries in their environments (Keating & Phillips, 2008). Similarly, I argue that the consideration of micro-macro environments aligns with the representation of care in the private-public spheres. Therefore, CHE is a suitable lens to employ in this dissertation to explore how different levels of environmental context intersect to influence perceptions of responsibility for social care in rural Uganda. Key assumptions and principles underpinning CHE theory include:

1. Environments interact with and influence each other. Macro global contexts have a differential impact on other contexts, shaping local places and local lives.
2. People have varying capacities to make choices and to act upon or adapt to their environments. There must be shared responsibility for supporting those with limited agency.
3. Older persons are not homogenous.
4. The voices of marginalised groups are often rendered inaudible and should be heard, creating evidence informed by their perspectives (Keating et al., 2020, pp. 59-61).

Consequently, applying the CRG, and CHE perspectives alongside EoC theory will enhance our understanding of how structural, environmental, and individual factors interact to structure care responsibility for rural older adults in developing nations at diverse levels of context. It will also illuminate how rural older people/families experience complexities negotiating social care for older people in multidimensional rural spaces.

2.5 Conclusion

This chapter has discussed the importance of applying the EoC theory and CRG and CHE perspectives in this study. This thesis draws on the EoC to argue that responsibility impacts on and is impacted by the other EoC elements/phases of care to model the current social care system for older people in rural Uganda. By incorporating the CRG perspective, this thesis contributes to the literature by employing a critical lens to position the claims and debates of EoC in the rural context of a low-income country. Thus, it expands our understanding of the complexity of care processes, factors and values that shape care systems and social care responsibility. The CHE perspective enhances the research further

through the exploration of social care responsibility across public institutions, voluntary organisations, private companies, families and individuals. This chapter also reviewed responsibility allocation in various welfare states, which is mostly evident in developed nations. Hence, this thesis argues the need to explore social care responsibility within and beyond familialism and communitarianism in a developing country like Uganda, which does not have a well-developed welfare system. This chapter also examined the historical context of care in Uganda by highlighting how social care responsibility allocation has evolved and been shaped by its historical, cultural, religious, and political environments. The next chapter discusses the methodological approach employed for this study.

CHAPTER THREE: METHODOLOGY, RESEARCH DESIGN AND METHODS

"No society can long sustain itself unless its members have learned the sensitivities, motivations, and skills involved in assisting and caring for other human beings" (Bronfenbrenner, 2001, p. 6969).

3.1 Introduction

In the previous chapter, I explored the theoretical and conceptual literature relevant to this study. In doing so, I highlighted the gap in the application of ethics of care (EoC) and critical rural gerontology (CRG) in rural developing countries to understand social care responsibility allocation. To address this gap, this study incorporated EoC theory and CRG across the four stages of the research process as analytical tools to interpret data. It is against this background that this chapter describes the methodological approach of this study. It discusses and provides a rationale for using a transformative research paradigm, explains the philosophical foundations of the research and states how critical human ecology (CHE) theory (Keating et al., 2020) informed the research design. These approaches allow this researcher to determine how inequalities and power struggles inform the allocation of social care responsibility in the current social care system for older people in rural areas in Uganda.

3.2 Research paradigm

A research paradigm is the understanding of what one can know about something and how one can gather knowledge about it (Guba & Lincoln, 1994). This research is situated in a transformative paradigm that aims to improve social justice among people of culturally varied groups (Mertens, 2008; Mertens, Holmes, & Harris, 2009). Transformative research requires researchers to address inequalities by prioritising the voices of marginalised people in the pursuit of social justice and equality, which also reflects a human rights approach (Mertens et al., 2009). The transformative paradigm therefore directs researchers to critically consider how historical, cultural and economic contexts support power relations that promote oppression (Mertens, 2016).

I argue that the concepts relevant to this study, CRG and EoC align with this transformative approach. Indeed, care theorists claim that analysing care responsibility is integral to revealing injustice (Noxolo, Raghuram, & Madge, 2012) by questioning the principles of fairness, equality, rights (Held, 2006) and trust (Tronto, 2010, 2013). Similarly, critical rural gerontologists are interested in how power structures empower or disempower older people in rural communities (Skinner et al., 2020). Since CRG research challenges unequal power relations and injustices at both the macro and micro levels, study findings can potentially translate into social action to improve older people's lives in rural areas (Burholt & Scharf, 2020). At the very least, all three concepts are essential in highlighting power struggles related to responsibility allocation across both macro and microenvironments and underscores pathways towards social justice.

Various researchers in the fields of ageing and social work have undertaken transformative research (Cash et al., 2017; Mertens & Ginsberg, 2008; Sedgley, Pritchard, & Morgan, 2011), including in Africa (Kamanzi, 2011; Mertens, 2016) and EoC studies (Parsons et al., 2021). As rural older Ugandans are considered in the literature as highly vulnerable and marginalised (Golaz et al., 2017; MGLSD, 2009, 2012, 2015a; Wandera, Ntozi, & Kwagala, 2014), this approach is certainly appropriate for this study. In the first chapter of this thesis, it has already been established that rural older Ugandans face the combined disadvantages of being older, residing in a developing country and residing in rural areas. In the next section, I discuss the philosophical underpinnings of this thesis.

3.3 Philosophical foundations

Philosophical foundations are sets of assumptions or beliefs describing a person's worldview and help to direct the planned study (Denzin & Lincoln, 2005; Spencer & Snape, 2011). The transformative paradigm's philosophical foundations include ontological, epistemological and axiological assumptions (Mertens, 2007; Mertens et al., 2009).

3.3.1 Ontological

Ontology is the study of being (Crotty, 1998; Guba & Lincoln, 1994) and seeks to establish the nature of reality (Creswell & Poth, 2016; Mertens, 2008) or the nature of social entities (Bryman, 2012). Mertens (2008) states that the transformative paradigm regards our knowledge of reality as socially constructed (Mertens, 2008). As such, the truth is deemed to be subjective, based on participants' multiple views (Creswell & Poth, 2016). However,

not all versions of reality are equal, and it is argued that power differentials shape social relations with those who are marginalised and considered to have less power (Mertens, 2008; Mertens et al., 2009). This perception of reality is usually aligned with prominent social, cultural, political, ethnic and gendered positionalities, which oppress some people in society while privileging others (Mertens, 2016). Further, people's different roles and responsibilities, experiences and social status shape their interpretations of reality and knowledge (Bryman, 2012; Mertens, 2013; Spencer & Snape, 2011). It follows then that social practices as both rules and principles govern what we say and do, and are known to shape care responsibilities within the wider community (Pease, 2020). In this study, I assume that key stakeholders, caregivers and older persons hold different knowledge and perceptions about the current state of social care in rural areas of Uganda, including who is and who should be responsible for social care provision. Moreover, this reality is constantly being reconstructed and revised.

Furthermore, I believe that actors are attentive to care based on their rationales and morals, which made it important for me to interrogate diverse views. Justifications of care provision are often embedded in moral standards, either imparted during upbringing or developed later in life through interaction with other people and institutions. Care theorists also assert the importance of analysing the ethics of care in order to understand the governing norms, ethical standards and values that shape normative judgements in policies and government institutions and in how social problems are addressed (Fitzgerald, 2020; Gilligan, 2013).

3.3.2 Epistemological assumptions

Epistemology focuses on ways of learning and knowing reality, including how the researcher knows that knowledge is real (Spencer & Snape, 2011). The epistemological assumption informing this study is critical constructionism, which is concerned with examining how power relations can influence the way people give meaning to reality (Cohen, Manion, & Morrison, 2007; Heiner, 2002). The social constructivist epistemological position aims to interpret the social world from the perspective of both participants and researchers (Spencer & Snape, 2011), which entails going into the field to bridge the distance between researcher and participants (Creswell, 2018). In the present study, it was deemed critical to go to the places where care responsibilities were assumed and where care was provided, thus meeting the need to consider the power-knowledge relationship between the researcher and participants (Hartman, 2000) and to continually engage in reflexive processes to enhance my openness to participants' knowledge.

Transformative epistemology is characterised by an understanding of culture and trust-building between the researcher and their participants, emphasising the use of participants' language of choice and consideration of cultural norms in the research process (Mertens & Ginsberg, 2009; Mertens, 2007). In this study, the researcher used heterogeneous samples that reflected older people's social diversity in rural Uganda by including those individuals 'at risk' of being deprived of social care, namely those who were chronically ill, disabled and/or homeless.

3.3.3 Axiological assumptions

Axiological assumptions question the researcher's ethical and moral behaviour (Mertens, 2018; Mertens et al., 2009). Ethical behaviours entail principles of no harm to participants, acquiring informed consent, ensuring privacy and confidentiality, and no deception to participants (Bryman, 2012). Within the transformative paradigm, principles of respect, beneficence and justice are fundamental (Mertens et al., 2009). These principles guided the present study and are embedded in the National Statement in Ethical Conduct in Human Research (2007), which provides the framework for human ethics-related research in Australia. They are also reflected in the *National Guidelines for Research involving Humans as Research Participants in Uganda* (UNCST, 2007). These values and ethics are further reflected in the ethical considerations section (3.10) of this chapter, which discusses how the various principles and consideration of cultures were observed and respected in the field.

3.4 Methodology

According to the transformative paradigm, a researcher can adopt a qualitative inquiry which allows varied perspectives on a phenomenon to be examined (Mertens, 2007). In this study, qualitative research was chosen to understand and interpret social care responsibilities and experiences in social settings and to recognise the meanings that people attach to these phenomena (Denzin & Lincoln, 2011). This qualitative method of inquiry is different to quantitative methods that set out to test theories and hypotheses. Qualitative approaches are generally inductive and set out to develop an in-depth understanding of an issue (Patton, 2002). According to Spencer and Snape (2011), qualitative research is essential in understanding social problems that policies set out to address. Consequently, research takes place in the real-world setting instead of within the controlled experimental design settings pertinent to quantitative studies (Patton, 2002). Having identified only

limited existing literature on social care for older people in Uganda, this research considered an inductive, real-world exploratory approach as best.

This qualitative study aimed to understand the current state of social care in Uganda by examining the perceptions of key stakeholders and exploring caregivers' and older people's lived experiences, which would not have been possible using a deductive approach. The focus instead was to engage with participants to understand how they ascribe meaning to experiences. It aimed to critically examine the current state of social care and explore who was identified as having responsibility for the care of rural older Ugandans. In the next section, I present the study site, discuss the complexity of the rural contexts that show how vulnerability and marginalisation exist and justify that these sites provided valid case studies for this transformative research.

3.5 Study sites

Uganda is a developing country in East Africa that lies across the equator, about 800 kilometres inland from the Indian Ocean, as shown in Figure 3.1. Uganda is landlocked, bordered by the Democratic Republic of Congo in the west, Kenya in the east, Rwanda in the southwest, Tanzania in the south and South Sudan in the north. Administratively, Uganda is divided into northern, central, western, and eastern regions (UBOS, 2016).

Figure 3.1 Map of Africa showing the location of Uganda (Google Maps 2019)

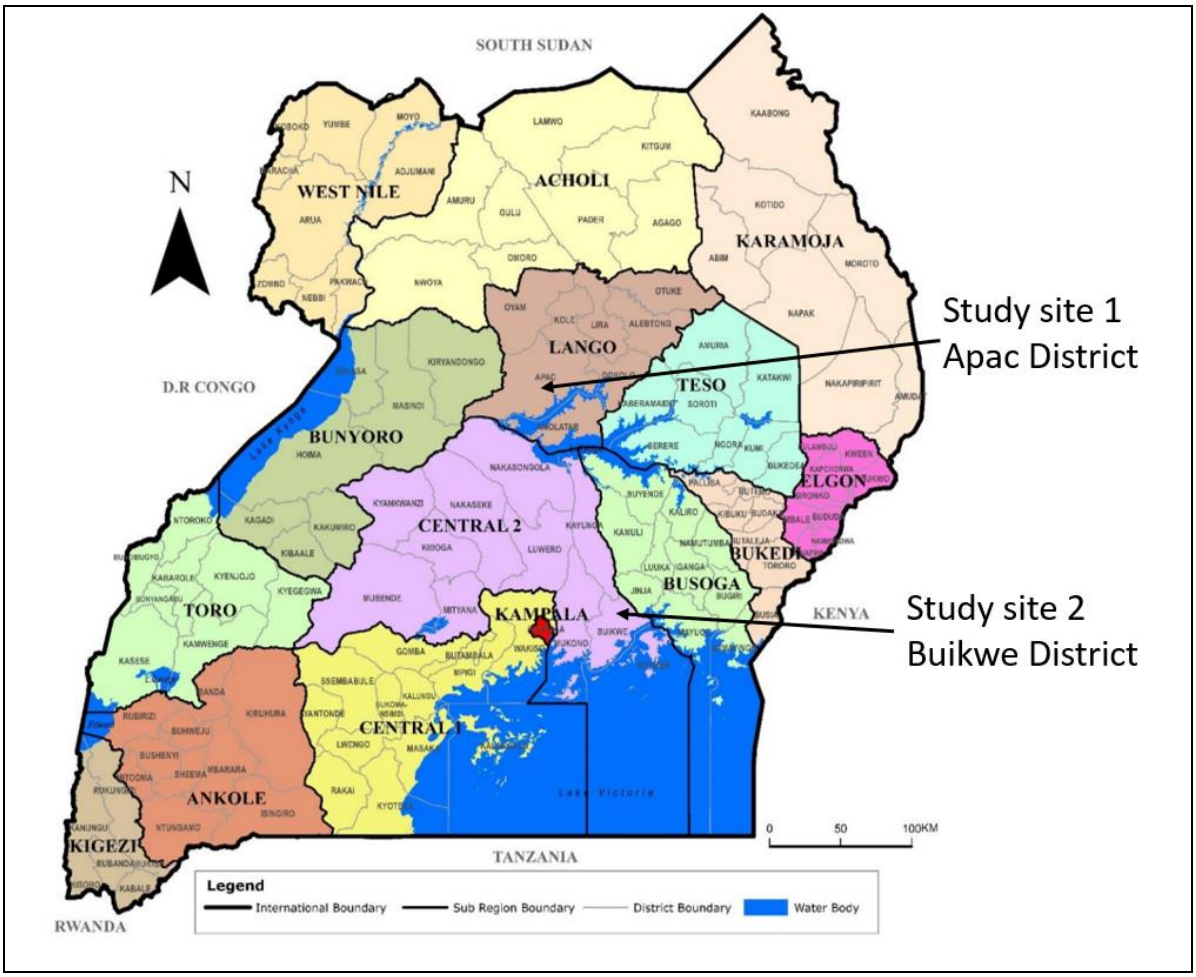
Uganda has two major ethnic groups: the Nilotic of Northern Uganda and the Bantu of central/southern Uganda (see Figure 3.2). In this study, two rural study sites were selected to capture cultural diversity and variations. As critical human ecology (CHE) perspectives suggest, cultural values present in the macrosystem impact interaction across systems (Keating et al., 2020). Studies have shown that cultural values, beliefs and attitudes influence older people's perceptions of social care and the experiences of caregivers and practitioners (Fang, Sixsmith, Sinclair, & Horst, 2016; Giunta, Chow, Scharlach, & Dal Santo, 2004; Scharlach et al., 2006; Söderman & Rosendahl, 2016). Further, informal care by families and communities is influenced by cultural values that promote filial obligations and intergenerational support in care provision (Aboderin, 2017a; Aboderin & Hoffman, 2015; Esping-Andersen, 2009). Consequently, scholars in nursing, social work and gerontology have advocated for culturally competent practice (Damskey, 2000; Lor, Crooks, & Tluczek, 2016; Rothman, 2018). Hence, this study needs to establish how care varies or is similar among Ugandan cultures to expose the differences in care practices, the inequalities and the power relations that could exist among ethnic groups to better inform EoC and CRG in a developing sub-Saharan country.

Figure 3.2 Division of Ugandan regions by ethnicity/culture

3.5.1 Study Site One: Apac district

Apac district is home to the Nilotic ethnic group, located in Lango sub-region in Northern Uganda, as shown in Figure 3.3. It is approximately 230 kilometres north of Kampala (the capital of Uganda) by road, and 87 kilometres from Lira (a regional town where the field team resided during data collection). Apac district is divided into three constituencies: Mazuri and Kwania counties and Apac municipality. This research was carried out in the Akokoro sub-county of Mazuri county. A sub-county is an administrative unit of the district within the local government structure. A senior administrative secretary manages the sub-county, and a Community Development Officer (CDO) heads the Department of Older and Disabled People.

Figure 3.3 Map of Uganda showing study sites



Approximately 97.6% of the people in Apac live in rural areas (UBOS, 2017a). Older residents of Apac have access to the government-implemented Social Assistance Grant for Empowerment (SAGE) pilot scheme, which has provided social protection for older people since 2010 and is administered in only a few Ugandan districts. The SAGE has two components−the Senior Citizen Grant (SCG) and the Vulnerable Family Grant (VFG) −and provides regular income support to older persons funded by Irish Aid, UK Aid, UNICEF and the World Bank (MGLSD, 2015a). At the time of this research, 1,146 older persons in Akokoro sub-County were benefiting from SAGE (UBOS, 2017a). However, the impact of these programs on older people's social care was unknown. This region is prone to drought, had suffered war conflicts for the previous two decades and had refugee camps for people from Congo and South Sudan. It had been affected by the LRA civil wars that lasted over two decades in Northern Uganda and had several internally displaced persons (IDP) camps (Carpenter, Slater, & Mallett, 2012). Moreover, it is a district intermittently affected by conflicts and cattle rustling (UBOS, 2017c). These situations of unrest and disaster, as well

as implementation of the SAGE program, were similar to those experienced in Western Uganda; thus, Akokoro sub-county offered a good illustration of these compounding conditions, making it a suitable study site.

3.5.2 Study Site Two: Buikwe district

Buikwe is a rural district located in the central sub-region of Uganda, as depicted in Figure 3.3. The majority of the population residing in Buikwe district belong to the Bantu ethnic group. Central Uganda has a hot and wet climate and at the time of this research had been relatively peaceful for the previous two decades. It had very few IDP camps and no cash transfer or social programs for its older people. It was, however, severely impacted by the HIV/AIDS epidemic, leaving many older people negatively affected due to increased care responsibility for grandchildren whose parents died from the disease (Mugisha et al., 2015). Buikwe district is divided into one county, two municipalities, eight sub-counties and four town councils. Approximately 4.5% of the Buikwe South county population was aged 60 years and above (UBOS, 2017b). Previous research conducted by Njuki (1999) and Najjumba-Mulindwa (2003) identified a care home called Nkokonjeru Providence Home, which was established and managed by the Catholic Church. Before 2009, Nkokonjeru was in Mukono district. However, following the restructuring of districts in 2009, the home is located in Buikwe district, in Ngogwe sub-county. It was of interest in this research to establish whether this formal care arrangement still existed, in order to better understand the current formal social care services available to older rural Ugandans.

3.6 Research design

The design of this qualitative study is aligned with CHE (Keating et al., 2020). The research questions correspond with the macro and micro levels of CHE theory, which is also similar to the public and private spheres of care outlined in EoC theory. This allows the use of critical approaches to interrogate variances in care responsibility between and within ecological environments.

The first two research questions interrogate both policy and stakeholders in institutions within the macroenvironment of the CHE framework.

- RQ1. *How is the concept of responsibility towards social care for older people represented in national policies within Uganda?*

- RQ2. *What are the perspectives of key stakeholders from government, non-profit and community-based organisations on responsibility for older people's social care in rural Uganda?*

The last two questions address the experiences of older people within their immediate microenvironments (informal caregivers):

- *RQ3. What are the lived experiences of caregivers of rural older people regarding responsibility allocation and caregiving?*
- *RQ4. What are the lived experiences of rural older people receiving social care?*

3.7 Methods triangulation

The transformative paradigm recognises that using a single research study method to determine the need for social transformation could produce narrow results (Mertens, 2007). Multiple methods are increasingly used in Australian and international research on ageing (Cash et al., 2017; Hodgkin, 2008; Kamanzi, 2011). As such, this study adopted a multiple-methods approach, using different qualitative methods to gather data about social care for older people in rural areas of Uganda from various groups perceived to hold different levels of power and positions, including policymakers, key stakeholders, caregivers and older people.

This multiple-method research design enabled triangulation in order to bring together various data sources from multiple sources, people and places (Denzin, 2012; Flick, 2004). It was anticipated this would enable deeper understanding and explanations of social care experiences and how responsibility was assumed. Within each of the four research stages outlined in the subsequent sections, three primary forms of data collection were employed, including policy analysis, in-depth interviews and focus group discussion.

3.7.1 Stage one: Policy analysis

At Stage One, national policy documents related to older Ugandans' social care were reviewed and analysed to address the first research question: How is responsibility towards social care for older people allocated in national policies within Uganda? This analysis aimed to critically explore how they conceptualised social care responsibility for older people. The policy documents examined were publicly accessible on the Ministry of

Gender, Labour and Social Development (MGLSD) website and published in English. The stated aims of the policies and action plans are summarised in Table 3.1.

Table 3.1 Policies included in the study

Policy document	Main focus/aim
1. National Policy of Older Persons (MGLSD, 2009)	This policy was intended to guide decision-makers, development partners, planners and implementers of programs for older persons by focusing on priority areas affecting older people.
2. National Plan of Action for Older Persons 2012/13-2016/17 (MGLSD, 2012)	This document operationalised the preceding National Policy of Older Persons (MGLSD, 2012).
3. National Social Protection Policy (MGLSD, 2015a)	This document described the Ugandan context of social protection and provided the basis for a universal approach to respond to risks and vulnerabilities among diverse groups of the population.
4. Program Plan of Intervention (MGLSD, 2015b)	This document operationalised the preceding National Social Protection Policy (MGLSD, 2015a)

It is essential to note the absence of a national social care policy for older people in Uganda. The four policy documents listed above represent the policies most related to the concepts of care, psychosocial support or social care for older people. It is also important to acknowledge that all policies in Uganda were (and still are) formulated at a national level. Therefore, no specific policies were or are created by district or municipality local governments specifically targeting rural or urban populations.

Consequently, conventional policy analysis frameworks adopted by various scholars in the western world, such as McClelland and Smyth (2014), Patton (2016) and Young and Quinn (2002), could not be followed for this research. This is because policy development relating to social care for older people in Uganda is still in its infancy and still being implemented. As the above table indicates, the first policy for older persons was formulated only in 2009 and the latest in 2015. In recognition of this, the analysis was conducted by focusing on the first step, called "tracing" in the Trace method (Sevenhuijsen, 2004). In Trace analysis, the objective is to use the EoC as a framework for analysing policy documents that deal with care, as an analytical lens through which a normative framework and problems can be identified and assessed (Sevenhuijsen, 2004). The EoC theory is viewed as a particularly useful approach to analyse public policies, as it raises various questions that in turn enable a rethinking of public policy and the creation of concrete recommendations (Švab, 2007).

The Trace method has been applied in various EoC policy studies to explore notions of care responsibility in Finland (Sihto, 2020) and independence and equality in countries like Slovenia, the Netherlands and South Africa, which have a variety of socio-economic and political climates (Hankivsky, 2004; Sevenhuijsen, 2004; Sevenhuijsen et al., 2003). The Trace method includes four steps, namely, tracing (as mentioned above), evaluating, renewing and concretising (Sevenhuijsen, 2004). This policy analysis in this study focused on the first stage, by tracing the normative frameworks within which the concepts of social care and responsibility were applied in the policy documents. Tracing is essential to this thesis as it contributes directly to answering the overall research question of social care responsibility allocation. Given that this multiple-methods study explored the conceptualisation of social care and responsibility from the perspective of stakeholders, caregivers and older people, the second, third and fourth Trace method steps were not appropriate. For example, the renewal step requires proposing alternative definitions of care, and the concretising step requires drawing up concrete measures and division of responsibility. These cannot be achieved at this stage of the research.

As pointed out by Sevenhuijsen (2004), texts in policies both describe and construct the reality of care in society. Therefore, identifying the definition of social care and conceptualisations of social care responsibility in Ugandan social policies will enhance our understanding of how stakeholders, caregivers and older people define social care, the care practices that encompass social care and perceptions about how they actually experience social care responsibility in a rural society, all of which are described in subsequent stages of this thesis. Tracing also entails identifying values, strategies and institutional framework, while analysing any inconsistencies that shape responsibility. The findings from this analysis are presented and discussed in Chapter Four of this thesis.

3.7.2 Stage Two: Stakeholder semi-structured interviews

Stage Two of the study addressed research question 2: What are the perspectives of key stakeholders from government, non-profit and community-based organisations on responsibility for older people's social care in rural Uganda? Stakeholders providing programs and services are situated within the macro environment of the CHE framework (Keating & Phillips, 2008). In relation to ethics of care, these key stakeholders shape public caring services, practices and processes through varied institutional arrangements, either public or third-sector (Nguyen et al., 2017). Interviews with 21 diverse government stakeholders at both national and local levels (within the Apac and Buikwe case study

districts) were conducted in June and July of 2019. Interviews are a primary data collection tool used in qualitative research to access people's perceptions and meaning making (Punch, 2013). These interviews were in-depth and semi-structured and the questions were open-ended (Bryman, 2012; Watson, McKenna, Cowman, & Keady, 2014). This enhanced flexibility during the interview process and enabled the use of various probes and follow-up questions to gain greater depth and detail (Legard, Keegan, & Ward, 2003).

Stakeholders were purposively selected to participate in semi-structured interviews for this study due to their particular knowledge, namely, their roles in providing care, implementing social care projects, or advocating for older people's social care needs. Participants were recruited from both national and local organisations (specific to the study sites in Apac and Buikwe districts) (See Table 3.2 below).

Table 3.2 Stakeholder administrative levels and sectors

Stakeholder	**Number of participants**	**Sector**	**National/local level**
Gerontologists	3	Public	National
Local council	1	Public	Local – Buikwe
Community Development Officer (CDO)	1	Public	Local – Apac
Parish Chiefs	4	Public	Local – Apac
Manager of care home	1	Voluntary	National
Manager of Community-Based Organisation (CBO)	1	Voluntary	National
Manager of Association of Older persons	1	Voluntary	National
Managers of Faith-Based Organisations (FBOs)	2	Voluntary	National
Religious leaders	2	Voluntary	Local (Apac and Buikwe)
Leader of local Older Persons Association	2	Voluntary	Local (Apac and Buikwe)
Managers of private care companies	2	Private	National
Private Researcher	1	Private	National

They were also drawn from public, private and volunteer-based agencies. Stakeholders from the public sector included gerontologists from the MGLSD and local government authorities in charge of older people's affairs at village, parish, sub-county and district levels. Stakeholders from the private sector comprised representatives from private care companies and a researcher from a privately registered company. Stakeholders from the voluntary sector included CBOs, FBOs and other associations.

Potential participants' names, contact numbers and email addresses were obtained from published lists from both FBO and government websites. Lists for local communities were not available on websites; hence the gatekeeper at the MGLSD identified the CDOs in the selected sub-counties. A participation invitation letter (Appendix Eleven), Participant Information Sheet (PIS) and a consent form (Appendix Four) were sent via email informing participants about the study, and they were later contacted by phone call to schedule a meeting. Of the 12 invitations sent out, nine responded by either a phone call or email. Interviewed stakeholders also recommended other participants who met the study's inclusion criteria, hence, the snowballing sampling technique was also used (Ritchie, Lewis, & Elam, 2013). Organisations that did not specifically target older people were excluded.

Face-to-face interviews were conducted in English using an interview schedule (Appendix Seven) to guide the flow of the interview. Participants were questioned about topics including the perceived social care needs of older people in rural areas, aged care responsibility, the current state of social care in rural areas, existing providers of social care, challenges faced in social care provision in rural areas and recommendations to improve the social care system. Interviews were recorded with permission from participants and lasted between 30 and 60 minutes. Upon completion of the interview, each participant was thanked and reassured of confidentiality.

3.7.3 Stage Three: Informal caregivers focus groups

At stage three, four focus groups with caregivers were conducted to explore the role of caregivers within the microenvironment of older people. These focus groups addressed research question three: What are the lived experiences of caregivers in providing social care to older people in rural Uganda? Group interactions facilitated data production and produced insights which would have been less forthcoming with individual interviews (Punch, 2013). For example, focus groups enabled interaction between participants through the group process. They also facilitated access to more caregivers' experiences, attitudes, perceptions and ideas relating to social care provision in a relatively short time.

Two focus groups were conducted in Apoi village (Akokoro sub-county in Apac district), and two in Ngogwe sub-county (Buikwe district). Separate focus groups were held for women and men because scholars have noted that mixed-sex focus groups are often

dominated by males unless the topics of discussion were viewed as female-specific (Hollander, 2004). Feminist care theorists have noted that direct care responsibility is mostly assigned to women and argue for care to be viewed as both a male and female responsibility (Gilligan, 2011; Tronto, 2014). Therefore, obtaining the voices of male caregivers and identifying what care practices they took responsibility for was essential for this study. Hence, performing separate focus groups of men and women also enabled comparison of findings across gender (Krueger & Casey, 2014). The focus groups examined key differences in caregivers' responsibilities by gender, including the challenges faced, coping mechanisms adopted and the knowledge of existing social care services in rural Uganda.

3.7.3.1 Access to study sites and participants

Qualitative researchers often find it challenging to gain access to participants in cross-cultural qualitative studies (Liamputtong, 2008). With this in mind, we undertook a range of strategies to overcome these challenges. Before accessing the study participants, the field team (driver, research assistant and I) had to introduce ourselves to the CDO and community leaders. With guidance from community gatekeepers,[3] we located the local community leaders' offices. We met parish chiefs in Apac district and Local Council Chairperson III in Buikwe district. The local councils are administrative units at the sub-county and village level while parish chiefs carry out administrative and management work at the parish level, within the local government system. Permission given by these leaders offered reassurance to the community members that the research was legitimate and did not pose any harm to participants.

Despite considerable planning for recruitment in the lead up to the focus groups, the process occurred differently when we were actually in the field. In Apac district, on the day data collection was to take place, most community members had gone to a burial. This overturned our plans to conduct the focus groups during a public community meeting, where the study's purpose could be explained to community members. Instead, the community gatekeeper had to inform community members about the study from the burial grounds. People interested in participating in the study came to the meeting point in the trading centre under a tree, near the acting local council chairperson's home. Similarly, in Buikwe, instead of community members who were caring for older people converging at

[3] Community gatekeepers were people in the community who the Community Development Officers assigned to the research team to assist our navigation through the community and assist in the recruitment process. Each study site had one gatekeeper.

the local council chairperson's home at the agreed time (9am), as originally planned, the local facilitator had to use a megaphone to call caregivers who had gone farming to assemble for the recruitment meeting.

To be eligible, participants had to be aged 18 years or above and caring for someone aged 60 years or above. Many of the community members across both study sites were willing to participate in the study. However, a manageable group size of approximately 6-12 participants per group, which is highly recommended, had to be implemented (Lewis, 2003). People who had refused or were unable to give informed consent, or who had communication difficulties that limited their ability to participate in the study, were excluded. Additionally, where more than one person represented a household in both male and female caregivers' groups, only one person was selected.

Forty caregivers participated in the four focus groups, as detailed in Table 3.3. In Apac district, 11 male and eight females participated, while in Buikwe district, 10 males and 12 females participated. Focus group discussions lasted between approximately one and a half and two hours. A charting exercise was carried out during all focus groups that required participants to document their caring responsibilities and the recording was paused as participants took turns to fill out the chart. The actual voice recording took an average of 50 minutes each in both study sites and across all focus groups.

Table 3.3 Characteristics of caregivers

	Buikwe		Apac		Total	
Characteristics	**N**	**Percentage**	**N**	**Percentage**	**N**	**Percentage**
Sex						
Male	9	43%	11	58%	20	50%
Female	12	57%	8	42%	20	50%
Total	**21**		**19**		**40**	
					0	
Marital status					0	
Married	15	71%	10	53%	25	63%
Not married	5	24%	9	47%	14	35%
Widow	1	5%	0	0%	1	3%
Total	**21**		**19**		**40**	
Age of caregiver						
18-60 years	15	71%	15	79%	30	75%
61 years and above	6	29%	4	21%	10	25%
Total	**21**		**19**		**40**	
Relationship						
Spouse	4	19%	2	11%	6	15%
Grandchild	3	14%	6	32%	9	23%
Adult child	5	24%	4	21%	9	23%
Daughter-in-law	3	14%	4	21%	7	18%
Sibling	1	5%	0	0%	1	3%
Hired help	1	5%	0	0%	1	3%
Relative	1	5%	0	0%	1	3%
Neighbour	2	10%	1	5%	3	8%
Multiple carers	1	5%	2	11%	3	8%
Total	**21**		**19**		**40**	

The PIS and consent form (see Appendix Five) was read out to participants, and written consent was obtained. A focus group guide (see Appendix Eight) was used to facilitate discussion, which included caregivers being first asked about their caring responsibilities. The charting exercise was introduced where all caring roles were listed (see Appendix Ten), and each participant was requested to rank tasks performed from highest to lowest. Participants shared stories of their lived experiences in providing social care to older people in rural Uganda, their challenges in delivering that care and how they coped. They expressed interest in how other caregivers in the focus group discussion solved their problems, which potentially created a positive learning experience through the different interactions and examples discussed. Lastly, respondents were invited to offer recommendations on how these problems could be solved and their views on an ideal future social care system for older people.

3.7.4 Stage Four: Older care recipient semi-structured interviews

To answer research question four (What are the lived experiences of older people in receiving social care in rural Uganda?), 19 face-to-face interviews were conducted with older people (those aged over 60) in selected sites in Apac and Buikwe districts who were receiving care at the time of the interviews. Engaging older people directly enabled exploration of responsibility and social care at the individual level in the microenvironment. The interviews were in-depth and semi-structured (Bryman, 2012), which enabled older people to talk about their lived experiences in receiving care. Furthermore, in-depth interviews with older people offered validation of the data gained from other stages of the research process.

Participants were recruited through the caregivers who had participated in the focus group discussions. The selection of older participants was purposive, based on a generated sample frame (Ritchie et al., 2013), which involved obtaining the names of all older people cared for by the caregivers who participated in the earlier focus group discussion. A generated sample frame was appropriate because it enabled the information from the caregivers to be validated. For example, older people could comment on the activities performed by their caregivers, which enabled comparison with stakeholder data relating to their caring responsibilities. The sample size was heterogeneous to enable a range of experiences to be captured. Variations in age, gender, education, household composition, duration of stay in the rural space, health status and marital status were vital to this study to ensure a heterogenous sample of participants with different care and ageing experiences. The primary criteria were age, sex, duration of receiving care and any disability (Table 3.4). The secondary criteria comprised whether the older person had a chronic illness and when that person was last hospitalised. Some older people diagnosed with a contagious, acute, or chronic disease that would limit their participation in the study or cause risk to the research team were excluded from the research. One older person was too ill to speak, one had an infectious disease, and another had been taken to hospital the morning of the interview. Two other older people had communication difficulties that limited their ability to participate; all these cases were excluded from the study.

Table 3.4 Demographic characteristics of participants

	Pseudonym	Age	Gender	Marital status	Education	Duration in locality	Region	Household occupants	Subjective health
1	Nafuna	63	F	Widow	None	39 years	Central	1 grandchild	No complications
2	Nandutu	72	F	Widow	None	56 years	Central	6 grandchildren	Paralysed arms and legs and backache
3	Kalema	83	M	Not married	None	53 years	Central	Alone	Toothache and body pain
4	Namataka	70	F	Married	None	30 years	Central	1 grandchild	Leg pain and sinuses
5	Namusisi	64	F	Widow	P.7[4]	20 years	Central	9 grandchildren	Pain in legs, arms, back and cough
6	Namimbi	69	F	Widow	None	69 years	Central	2 grandchildren	Pain in hands and legs
7	Ntege	89	M	Widower	P.7	89 years	Central	Alone	Paralysed feet and ulcers
8	Nambuya	67	F	Separated	P.7	15 years	Central	2 grandchildren	No illnesses
9	Watuwa	89	M	Widower	None	5 years	Central	Daughter, son-in-law and 1 grandchild	Injured legs from a fall
10	Awor	80	F	Widow	None	67 years	Northern	8 grandchildren	Body ache
11	Apiyo	70	F	Widow	None	30 years	Northern	Son, daughter-in-law and 2 grandchildren	High blood pressure, body pain
12	Adong	78	F	Widow	None	63 years	Northern	Daughter-in-law and 6 grandchildren	Blood pressure, diabetes, back pain, poor sight
13	Elem	68	F	Widow	P.7	68 years	Northern	2 sons, daughter-in-law and 2 grandchildren	Painful swollen throat and body ache
14	Auma	92	F	Widow	None	75 years	Northern	Son, daughter-in-law and 4 grandchildren	High blood pressure and ulcers, body pain
15	Bilal	82	F	Widow	None	40 years	Northern	10 grandchildren	Mild paralysis
16	Ojara	78	M	Married	None	78 years	Northern	Spouse, son and 4 grandchildren	Headaches
17	Alum	70	F	Widow	P.5	1 year	Northern	1 son, 1 daughter and 3 grandchildren	No illnesses
18	Layet	68	F	Widow	P.6	44 years	Northern	5 grandchildren	Body pain-legs and head pain
19	Aryemo	63	F	Widow	S.2	46 years	Northern	13 grandchildren	High blood pressure

[4] The Uganda education system has a 7-year structure of primary education, which is equivalent to elementary school and considered compulsory. The next level of education is secondary education, comprised of four years of lower secondary and two years of upper secondary education.

Caregivers sought permission from the older people they were caring for to allow the researcher to interview the older people individually in their homes. Where caregivers returned with positive responses, interviews were scheduled. The researcher sought informed consent by reading out the PIS and consent form (see Appendix Six) and verbal consent was obtained to ensure the older person actually wanted to participate. While it was initially intended to conduct interviews with older people in their homes, this was not possible for some participants in Apac district due to impassable roads owing to bad weather conditions. Therefore, it was decided that these participants could instead be interviewed at the meeting point in the village centre where the focus groups were carried out. In Buikwe, all interviews were carried out in participants' homes or under a nearby tree in the compound. Interviews were conducted using an interview schedule (see Appendix Nine), lasting between 2l and 35 minutes. Participants were asked about the challenges they experienced, coping strategies, available social care services, and an ideal social care system for older people in rural Uganda. Interviews in Apac district were conducted in Langi by the research assistant, while I conducted interviews in Buikwe district in Luganda.

Pseudonyms were assigned to each participant to reflect their gender, ethnic group and clan. It is essential for readers from Uganda not to relate these names with traditional meanings because they are only fictitious names to ensure confidentiality and privacy for the participants. Although the study site of Buikwe district is predominantly occupied by the Baganda people, during data collection for older people, it was identified that some participants were from the Bagishu ethnic group. The Bagihsu had migrated from Mbale district in Eastern Uganda, which shows the cross-cultural diversity of the study sites. These participants were all fluent in Luganda, so the language of communication was not affected.

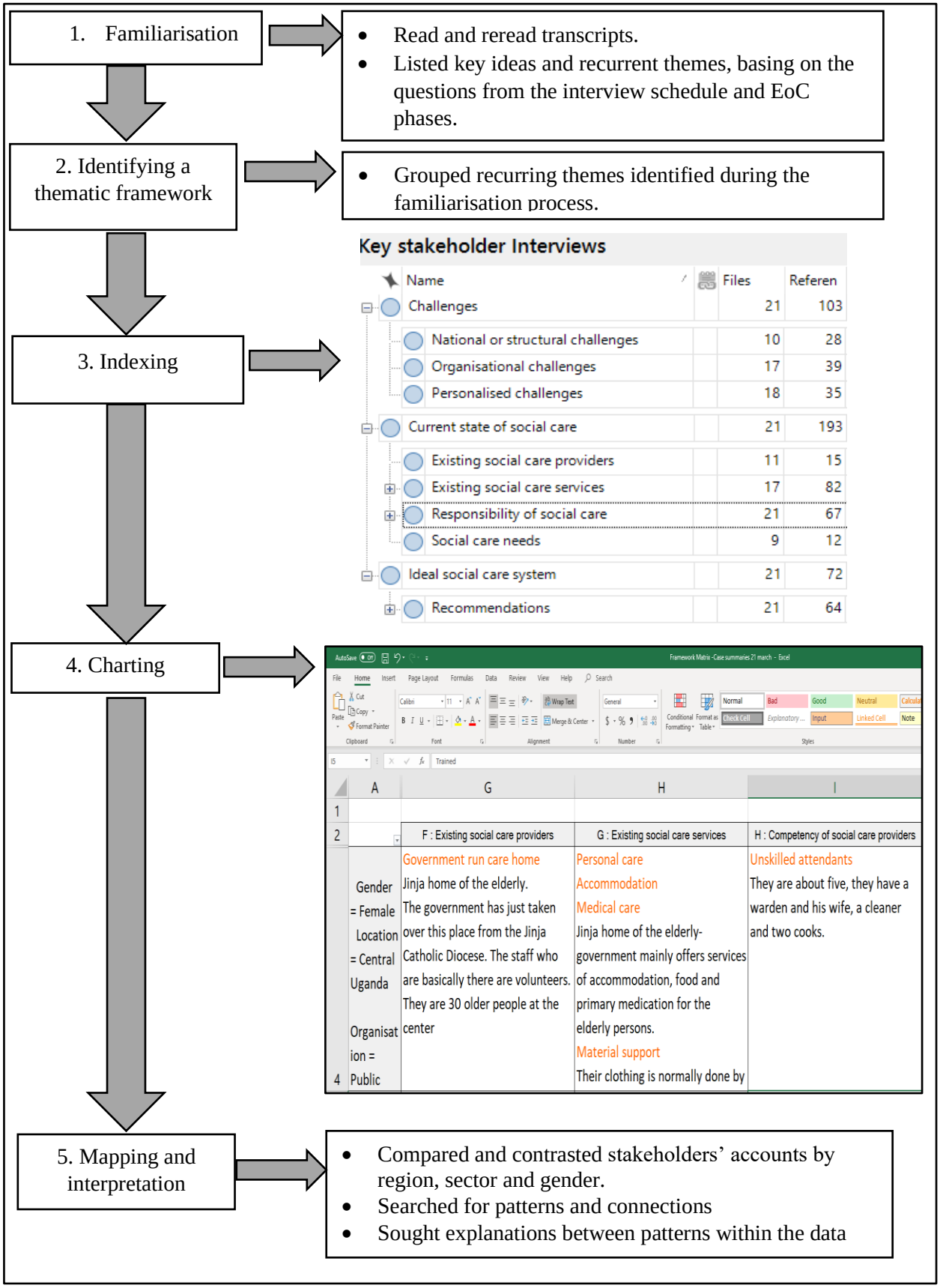
3.8 Data analysis

Focus groups and interviews were all audio-recorded, transcribed verbatim and entered into the QSR NVivo 11 Plus qualitative data analysis program. Interviews were translated during transcription by the researcher and research assistant. This decision was based on the assumption that the Australian project supervisors could not use Langi and Luganda transcripts and that transcribing in the local languages and then translating the transcripts to English would be too time-consuming.

Across the three stages (stakeholder interviews, focus groups with caregivers and interviews with older people), analysis was completed using deductive thematic analysis with QSR NVivo 12 Plus. Deductive analysis is where data is analysed according to an existing framework (Patton, 2002). The first step entailed familiarisation, where three transcripts were first read and the first cycle of coding undertaken (Saldaña, 2013), making notes in the margins of the transcripts. Similar codes from all the three transcripts were grouped under each research question and categories established. At this point, the second cycle of coding was undertaken whereby all transcripts were coded into QSR NVivo, creating a coding frame of key themes in the data associated with the phases of care. This ensured that the whole transcript was indexed, and no data was lost or left uncaptured (Ritchie & Lewis, 2003).

The analysis of stakeholder interviews was undertaken slightly differently from the other analyses. Charting was completed by running a framework matrix query in QSR NVivo 11 and creating case summaries of coded quotes. These summaries were then edited and compared with the transcripts to ensure that the participants' original terms and language were accurately retained. The case summaries were exported to Microsoft Excel (an example is shown in Figure 3.4). The visualisation of data into a chart enhanced understanding and interpretation of the whole data set. The last stage of the framework analysis was mapping and interpretation (Ritchie & Lewis, 2003). At this point, filters were applied to the case summaries, enabling the comparing and contrasting of respondents' accounts across gender, regions, and sectors. Data was then critically interrogated in relation to the EoC and the CRG perspective.

Figure 3.4 The framework technique applied in this study



The entire research team, including supervisors, reviewed the framework matrix, the conceptual framework and the emerging themes. The conceptual framework was then revised, some sub-themes were merged and others were renamed, creating a second set of themes which are presented in Chapter Five.

Within the focus group data, the care responsibility charts (see Appendix Ten) were translated into English and analysed using Microsoft Excel to establish any difference in caring responsibilities between gender and geographic location. The rest of the data was analysed using deductive thematic analysis (Patton, 2002) with QSR NVivo 12 Plus, as explained earlier in this section. The analysis of the interview transcripts in northern Uganda involved contacting the research assistant to clarify my interpretation of the study findings. This was because some of these transcripts included words in the local language that could have multiple interpretations. Therefore, establishing the context in which the native word was used enhanced accuracy in interpretations. The contributions of each focus group participant were analysed separately so that their information was retained and discussions between participants were captured. The findings of this analysis are presented in Chapter Six.

The analysis of findings from older care recipients also used deductive thematic analysis (Patton, 2002) with QSR NVivo 12 Plus, as explained earlier in this section. The interpretation and explanation of findings presented in Chapter Seven were drawn in relation to the care phases/elements of EoC. Data saturation (Patton, 2002) was reached when no new responses or relationships between cases emerged during the analysis.

3.9 Rigour

Conducting this study within a transformative paradigm allowed for the use of multiple data collection techniques, theories and interdisciplinarity approaches drawn from social work, psychology, anthropology, economics and sociology. This methodological approach thus enabled an in-depth study and exploration of varied perspectives from actors at different levels of the ecological systems framework. This enhanced validation of findings, establishing credibility, rigour, trustworthiness and confidence in the truth of the findings. The use of multiple approaches has been argued to provide a mechanism for testing the reliability and validity of findings where the same themes, issues, challenges and contestations emerge across different stages of the research process (Bond, Peace, Dittmann-Kohli, & Westerhof, 2007; Denzin, 2012; Moran-Ellis et al., 2006; Patton,

2002). For example, older people and caregivers reported delays obtaining government financial support associated with the SAGE program. Questioning stakeholders about this finding provided explanations for this delay, which related to the challenges in relation to financing—an issue also noted in the analysis of the policies. Triangulation, therefore, enabled the identification of conflicting perceptions between participants and added depth to the findings (Flick, 2004; Patton, 2002). The thick descriptions and use of verbatim quotes enhanced the validation of my interpretation of what participants said.

In addition to triangulation, peer debriefing during data collection, analysis and reporting assisted in ensuring the credibility of the research (Guba & Lincoln, 1989; Spall, 1998). Peer debriefing with the research team was done at all stages during the research process. The engagement with my supervisors enabled rigorous exploration of ethical considerations, methodological support and assistance during fieldwork in solving challenges. During the analysis stage, discussions with supervisors about the themes emerging from the data and writing up enhanced the trustworthiness of this research. The panel progress committee chair and oral presentations allowed for external checks on the research, during which scholars from the La Trobe Rural Health School asked questions about the methods, meanings and interpretations of the findings. Archiving of the raw data improved the dependability of this research. In accordance with university records and archives policies and procedures, the raw data was securely retained to permit a review audit, should one be deemed essential.

3.10 Ethical considerations

Ethical approval was obtained from the La Trobe University Human Ethics Committee (reference number: HEC18466) on 23 November 2018 (see Appendix One). Approvals from The AIDS Support Organisation Institutional Review Board (TASO/IRB) (reference number: TASO REC/006/19-UG-REC-009) (see Appendix Two) and the Uganda National Council for Science and Technology (UNCST) (reference number: HS322ES) (see Appendix Three) were also obtained. Obtaining ethics approval in Uganda took longer than anticipated based on unforeseen additional requirements by the TASO ethics board. This process involved gaining approval from a Research Ethics Committee (REC) before filing with the UNCST.

3.10.1 Ethics and principles

Informed consent was gained at the beginning of each interview where PIS forms were read aloud to the participants in English, Lango or Luganda as appropriate. Some participants signed consent forms, and those who could not read or write provided thumbprints instead of signatures. Each participant was given a copy of the PIS, consent form and withdrawal of consent forms. Consent to participate was required from the older person to ensure that they were undertaking voluntary participation in the research and were not being coerced by their caregiver to participate. Consent to audio record interviews and focus groups was sought before commencement. Participants were informed they could stop the discussion or interview and withdraw from the research or withdraw their data within four weeks. Fortunately, no participant withdrew his or her consent or data from the study.

Participants in focus groups were allocated pseudonyms before recording to ensure anonymity. Demographic information, including gender, age, group and residency (northern or central), was written down but not included in the recording to ensure confidentiality of the information provided. Any identifiable data and information were available only to the research team and not shared with local authorities or gatekeepers. On certain occasions, either visitors or family members interrupted the interviews. We had to adjust accordingly, which meant first pausing the interview for a while, and seeking ongoing consent.

The researcher and research assistant ensured no harm was caused to the participants during or after the research. Participants were requested to inform the gatekeeper and call the research team if they experienced any distress, felt upset, depressed or worried to ensure no harm was inflicted on participants. A support person or trusted family member or friend of the older person was requested to remain available in another room to offer support in case it was needed. A break was given to the participant when requested until she/he was able to proceed. Fortunately, no cases of distress came up throughout the study. The role of the trusted family member was important not only in providing support but also in ensuring minimal interruptions throughout the interview. For example, in Ngogwe sub-county, the support person attended to other community members who wanted to see the older person as I carried out four interviews in Buikwe district. In another instance, the support person also attended to the grandchildren of the interviewee, preparing meals and performing some house chores to enable their participation. Another incident involved the

support person making the older person more comfortable by changing his sitting position. Others offered interviewees drinks. All this reduced the pressures on the interviewees, enabling them to concentrate in the interview. Caregivers and older people were given a transport refund to cover the costs of travelling to the meeting point so that no financial harm was inflicted on participants.

3.10.2 Cultural sensitivity

This research was conducted in cross-cultural sites, hence respect for cultural norms was at the forefront of the design of interview questions and the whole data collection process to ensure no harm for the participants (Liamputtong, 2008), including older persons and caregivers. The researcher and research assistant also ensured that they were dressed appropriately, with no short dresses or skirts, and avoided wearing trousers, which are viewed as inappropriate for women. The researcher also had a long cloth (traditionally known as *lesu*) wrapped over her dress. While conducting focus group discussions in both study sites, the sitting arrangement was crucial due to the gendered norms and practices that characterised the ethnic groups. It is a cultural norm among the Langi (Nilotic Luo ethnic group in northern Uganda) and Baganda (Bantu ethnic group who live in central Uganda) for women not to sit at the same level as men. The researcher and research assistant demonstrated cultural sensitivity by sitting on the mat, like other women, while the men sat on the benches. While conducting focus groups with women in both counties most women preferred to sit on the mat. These cultural beliefs and practices also portray the gendered social relations within these societies where men hold more power in decision-making.

Another cultural sensitivity issue was courtesy. It is the norm for people in the community to greet one another as they pass by. Notably, younger members greet older people first. We first greeted the local people we found at the trading centre as we waited for the mobiliser to arrive. Further, the researcher and research assistant engaged people who had come to the meeting point in conversation as we waited for more people to arrive. In a sense, the research team commenced building trust and rapport before the formal research was conducted, and some of these people became participants in the study. Similar to previous cross-cultural research in rural contexts that noted a variety of norms around time consciousness and punctuality (Laverack & Brown, 2003), participants in this study had a different concept of time. For example, even though the mobiliser had communicated to the community members in Ngogwe Sub-County of the research team's arrival at 9 am, it is a daily norm for people to undertake gardening and collect food and firewood. Hence a

public address system was used to call people to gather for the information session and participant recruitment. The research team had to exercise patience and wait for community members to arrive. The number of willing community members to participate in the study was overwhelming and some people came even after the focus groups had begun, hence some people were kindly requested to go back to their homes.

Liamputtong (2008) stresses the need for researchers to exhibit culturally appropriate communication and willingness to be open to different ways of doing and being. As I was an outsider who did not identify as Nilotic and was not familiar with the Lango language, I endeavoured to learn essential greetings. For example, “Ibutu aber: good morning,” “apwoyo: thank you,” “irio aber: good evening,” “itye ni ngo: how are you?” In the central region, kneeling is culturally appropriate in Buganda while greeting elders; therefore, the researcher conformed to this practice on certain occasions and demonstrated some humility by waving at community elders. By adapting to these cultural practices, the research team exercised cultural competency in research.

3.11 Reflexivity

Critical reflection is regarded as an essential practice in social work (Gardner, 2014; Theobald, Gardner, & Long, 2017), including working with older adults (Hughes & Heycox, 2005) and in conducting qualitative research (Band-Winterstein, Doron, & Naim, 2014; Berger, 2015; Houghton, Casey, Shaw, & Murphy, 2013; Jootun, McGhee, & Marland, 2009). Critical reflection entails questioning our interactions with our own cultures and social structures to offer a deep understanding of how individual assumptions, beliefs, history, social context and experiences influence our understanding of the world (Gardner, 2014). Reflexivity is vital in qualitative research as it can enhance the study's accuracy, trustworthiness and credibility of findings by acknowledging the researcher’s knowledge, biases and values (Berger, 2015). According to Houghton et al. (2013), rigour in qualitative research involves highlighting how the researcher’s interests and history brought them to the investigation. In the research process, scholars have noted power imbalances between the researcher and participants' relationship (Karnieli-Miller, Strier, & Pessach, 2009). Therefore, critical reflexivity is also important in recognising and responding to power differentials between researchers and their participants, including how they shaped participants' research experience and expectations. Despite the best preparations for fieldwork, the research process had to be continuously adjusted to manage

the challenges experienced. Furthermore, as I discuss below, I was required to manage the differences of being an outsider in one study site, yet an insider in another.

3.11.1 Outsider vs insider

The data collection process in northern Uganda was guided and mostly performed by the research assistant, who was an insider. The research assistant and the community were members of the same tribe, spoke the same language and were familiar with the landscape and main roads leading to the study site. A collaborative relationship with the research assistant and community mobilisers was maintained through good communication, which enabled effective management of the research team while in the field. During the interviews, the research assistant made notes, which I read and followed, notifying her where further probing was required. In some instances, decisions in solving problems in the field also involved consultation with my supervisors. In central Uganda, I was the insider, speaking the same language as the participants and aware of the cultural expectations when interacting with elders; this made it easier to build rapport with participants.

3.11.2 The environment of interviews and focus groups

In both study sites, interviews and focus groups with older people were mostly carried out under a tree near the main road or in a person's house compound. It had been anticipated that interviews would be carried out at community public facilities, however, there was no room close by that could be used. Adjustments were made to the meeting places on both sites, making it easier for participants to travel. For example, in Apoi cell in Apac district, the focus groups were held under the tree near the home of the older people's councillor[5] where older people usually meet. In Ngogwe, the chairperson of the older persons' group permitted the focus groups to take place under a tree in his compound (front yard). It posed some challenges with the audio recording because of its close proximity to the main road with vehicles and motorcycles occasionally passing. We also had to keep shifting the sitting arrangement to avoid too much sunshine during the sunny days. And when it rained, the interviews had to be stopped and moved to the car so that the time was not lost when it was raining. While this slightly affected the quality of some recordings, the quality of engagement with participants was enhanced because they were comfortable with the research location.

[5] The councillor represents older people on the District Council of Older Persons, which then reports to the National Council of Older Persons at a national level.

3.11.3 Participants who could not read and write in their native languages

It was anticipated that some participants would not be familiar with English; therefore, all tools were translated into their local languages. However, some participants could not read or write in either Lango or Luganda. In these cases, to ensure participants gave informed consent, forms were read aloud for them and verbal consent was first sought. They were then encouraged to sign the consent forms using ink and their fingerprints. This strategy was also used to sign for the transport refund issued to participants to ensure the accountability of funds allocated for the study.

3.11.4 Impassable feeder roads from rural areas

After a torrential rain downpour while in Apac district, the village road was impassable, very slippery and flooded. The car fell in a pothole in the middle of the road; hence, we requested the gatekeeper to send some community members to assist us. However, they needed assurance that money would be paid to them before rendering their support. On agreeing, the community members got us out of the pothole; however, the car was damaged, which required immediate attention. Therefore, some welding was done, as it made noises on our way back. An alternative route was requested from the mobiliser which we used on our way back the following day. With the uncertainty about the conditions of the roads to older people's homes, caregivers were requested to bring the older persons in their care to the meeting point near the mobiliser's house and different time slots were allocated to them. In doing so, we adapted to the local conditions in the field to ensure successful completion of the data collection process.

3.11.5 Challenges for cross-cultural research in managing expectations

Participants wanted more money for transport refunds than we had initially budgeted for them. We had to negotiate with them to accept the original amount because the researcher was a student, and we came to an agreement. In Apac, participants expected that a project was going to be implemented in their village. In Buikwe, participants expected that our research team had come from the government to include them on the list of cash transfer beneficiaries which the government implements in other pilot districts. The research team made it clear that an academic study was being carried and no promises were made to establish a project for them.

3.12 Conclusion

This chapter has established the importance of the transformative approach in understanding social care responsibility allocation, and how this informs the philosophical and research design. I introduced the study sites and offered justification of the study areas in relation to the varying levels of vulnerability and socio-cultural contexts. This chapter has presented the four stages of the data collection process and discussed how the data was analysed, using the EoC and CRG as analytical tools to interrogate the findings. This section highlighted key questions that guided the cross-examination of data to establish how the findings fit or challenge the existing theoretical perspectives in relation to a rural developing country context. The ethical considerations during the study, the reliability of the study and reflections of the research process were also described. The next chapter presents the findings from the policy analysis that examined responsibility allocation for older people's social care in Uganda's national policy documents.

CHAPTER FOUR: SOCIAL CARE RESPONSIBILITY ALLOCATION IN UGANDA NATIONAL POLICY DOCUMENTS

"A policy is a temporary creed liable to be changed, but while it holds good, it has got to be pursued with apostolic zeal." (Mahatma Gandhi)

4.1 Introduction

This chapter addresses the first research question, exploring how responsibility for social care for older people is allocated in Ugandan national policy documents (both policies and plans). It is important to examine such policies because they influence who we think should be responsible for the social care of older people. Policies also influence the distribution of power and resources (Keating et al., 2020), which will either foster or limit responsibility uptake towards care by different stakeholders and in rural areas. Consequently, it aids our understanding of how older people obtain access to resources generally, and in this research, forms of social care in rural Uganda. The interaction between macro-level trends and policies, individuals, communities and organisations can influence people's perceived and actual rights and responsibilities concerning ageing in a rural place (Skinner & Winterton, 2018). Thus, an analysis of policy documents is important in building our understanding of how responsibility has been conceptualised and assumed in rural Uganda.

The examination of policy documents through the first step (tracing) of the Trace analysis offered a new and innovative perspective on the central values, strategies, and normative frameworks that underpin responsibility allocation in Uganda's national policy documents. This examination filled a research gap in understanding how the ethics of care traverse the private and public spheres from a policy perspective. Further, it enhanced knowledge of how responsibility is allocated to different actors and how justice and responsibility inter-relate to create power relations arising as a result of the policy documents analysed. Care theorists acknowledge that responsibility is an element in the care process that assumes a central place in the normative considerations of policymakers (Sevenhuijsen, 2004).

Tracing entails analysing various features in the policy documents that do not follow a systematic path. In the next section, I begin by providing a background to the policy

documents and the legal and policy framework that support them. This involved the text production element of tracing to establish the rules in writing the policy, who influenced the production of the text and the power relations at play. I go on to explore the conceptualisation of care to ascertain how it was defined and elaborated in the policies, searching particularly for the connection between human nature and care. I then explore the allocation of responsibility, examining the role of the state and its relationship with private agencies and individual citizens. Lastly, I present the findings about the strategies proposed to improve social care provision in Uganda.

4.2 Contextualising the policy documents

The historical context presented in Chapter Two described the slow progress associated with adopting formal care institutions in Uganda that later saw the formulation of policies. The Ugandan Constitution of 1995 encompasses a central focus on maintaining the welfare of older citizens. While attention to care for older people was first seen in Ugandan policy documents from 2009, the concept of "social care" was incorporated in national policies only in 2015. Consequently, it must be noted that policy related to social care is very new in Uganda.

The four national policies examined in this chapter were all published by the Ministry of Gender, Labour and Social Development (MGLSD). They are the only existing policy documents with a real focus on care for older people. They include:

1. The National Policy of Older Persons (MGLSD, 2009)
2. The National Plan of Action for Older Persons 2012/13-2016/17 (MGLSD, 2012)
3. The National Social Protection Policy (MGLSD, 2015a)
4. The Programme Plan of Intervention (MGLSD, 2015b)

The first policy targeted in this research is the National Policy of Older Persons (MGLSD, 2009) (referred to hereafter as the NPOP), the first policy in Uganda that focused on addressing older people's issues. It was spearheaded by the MGLSD with the central theme of *"promoting ageing with security and dignity" (MGLSD, 2009)*. The rationale for formulating this policy was to "promote and contribute to attaining the development goals" (MGLSD, 2009, p. 16). These development goals are stipulated in the National Development Plan (NDP) (2010/11 – 2014/2015) and include reducing income poverty and inequality, improving human development and increasing GDP growth aimed at

transforming Uganda society from a peasant to a modern and prosperous country within 30 years (NPA, 2010). The NDP followed the Poverty Eradication Action Plan 2004/5 – 2007/8 (PEAP) (MoFPED, 2004). The NPOP is consistent with other national policy documents like the PEAP, The Social Development Sector Strategic Investment Plan (SDIP) and the Vision 2025 agenda, which are long-term national development frameworks. These frameworks aim to achieve development goals by addressing exclusion and inequality challenges that impede development by empowering vulnerable groups and improving access to basic services, social amenities, and infrastructure, including older people (MGLSD, 2009).

The second policy document is The National Plan of Action for Older Persons 2012/2013-2016/2017 (referred to hereafter as the NPAOP), that operationalises the NPOP. The NPAOP's overall objective is *"to empower older persons with information, knowledge and skills for increased participation in development programmes for an improved standard of living" (MGLSD, 2012, p. 6).* The NPAOP lists 15 priority areas of focus to address issues faced by older people, including psychosocial support and care for older persons, economic empowerment, social security, health care and lifestyle for older persons, food security and nutrition, HIV/AIDS, gender, elder abuse, education, training and lifelong learning, water and sanitation and capacity building for service delivery. Each priority area has specific interventions proposed and an action log frame that states the key actors, output and outcome indicators and critical assumptions. This analysis will focus on psychosocial support and care for older persons.

The National Social Protection Policy of 2015 (hereafter referred to as the NSPP) is the third policy document included in the analysis. It aims to empower *"all citizens to participate in and benefit from the social and economic transformation in the country" (MGLSD, 2015a, p. iii)* and is one of the most recent government initiatives designed to address the needs of vulnerable groups. Although the NSPP does not focus entirely on older people, it includes older people as a key vulnerable group in Uganda that require social care. The NSPP runs under the theme of *"income security and dignified lives for all"* and is depicted as an integral component of the Uganda Vision 2040 *(MGLSD, 2015a).* It must be noted here that although this analysis draws on concepts like social protection and social security, the major focus of this thesis is on social care.

The last policy document included in this analysis is the Programme Plan of Intervention (hereafter referred to as the PPI), which aimed to operationalise the NSPP between 2015/16- 2019/20. One of the PPI's key objectives was to *"enhance holistic social care and support services to individuals and families at risk of social exclusion, abuse and neglect" (MGLSD, 2015b, p. 22).* The policies are related to previous documents that aim to promote the development of the country. The NSPP and PPI note that:

> The National Development Plan (NDP) also highlights social protection as one of the key strategies for transforming Uganda from a peasant society to a modern and prosperous country. The Uganda Vision 2040 underscores the importance of social protection to address risks and vulnerabilities (MGLSD, 2015a, p. 7; 2015c, p. 5).

4.3 Legal and policy framework

In exploring the topic of text production in the tracing step of the Trace Framework (Sevenhuijsen, 2004), I found that the legal and policy frameworks within which policies are developed provide an understanding of the influences behind the formulation of these policies. Aged care policy in Uganda has been shaped by foreign organisations due to the presence of foreign aid and the formulation of the policies analysed for this research was influenced by approaches championed by regional and international organisations. Indeed, the documents demonstrate that external international and regional legal frameworks informed the development of the relevant Ugandan policies. For instance, the NPOP notes:

> This policy is formulated within the framework of the following old-age specific international instruments, United Nations Plan of Action on Ageing (1982); United Nations Principles for Older Persons (1991); United Nations Proclamation on Ageing (1992); The Madrid International Plan of Action on Ageing (2002); and The Yaounde Declaration on Ageing (2006). In addition, this policy is consistent with the international instruments for the promotion of human rights (MGLSD, 2009, pp. 15-16).

These instruments are direct and obligate the Ugandan government to undertake measures to uphold the rights of vulnerable groups of older people, women, people living with a disability, or those discriminated against based on economic, social or cultural factors. The central focus of the NPAOP aligns with the implementation of the Madrid International Plan of Action on Ageing (MIPAA), as it noted:

> The Development of the National Plan of Action is an important step that the Government of the Republic of Uganda has made towards implementing the Madrid International Plan of Action on Ageing (MIPAA) adopted by the Second World Assembly on Ageing in 2002 (MGLSD, 2012, p. ii).

The influence of foreign policies and initiatives is evident, as the MIPAA was developed by the UN to influence global policy action on ageing in the 21st century, focusing on

developing nations (Sidorenko & Walker, 2004). It includes three priority areas, namely, older people and development, enhancing supportive and enabling environments and promoting health and wellbeing in later life (Walker, 2005). The MIPAA is acknowledged for its role in increasing debate about older people in national policy documents and offers essential points of reference in national, regional and global campaigns (Walker, 2005), as is the case in Uganda.

Closer to home is the regional body of the African Union, which also influenced policy development. According to the NSPP,

> The African Union Social Policy Framework (2008) calls on Member states to recognise that social protection is a state obligation, with provisions in national legislations. The above policies, laws and obligations demonstrate government's commitments and obligations to provide social protection to all citizens (MGLSD, 2015a, pp. 9-10).

The provision of social protection is depicted as obligatory for the countries in the African region and is viewed as a response to regionalisation pressures and obligations. The government's commitment to addressing older people's needs is based not only on the Uganda constitution that provides welfare for all citizens. The NSPP refers to the Uganda Constitution Objective VII by noting, *"the State shall make reasonable provision for the welfare and maintenance of the aged" (MGLSD, 2009, 2015a).*

In the next section, I highlight the conceptualisation of social care with the analysed documents to better understand the complexities of referring to social care only in the Ugandan context, and the dyad classification in social protection evident in the policy documents analysed for this research.

4.4 Conceptualising social care

Examining the object of care, its definition and the connection between care and human nature was the essential first tracing step of tracing (Sevenhuijsen, 2004). When considering the dimensions and phases of care (Tronto, 1993; Tronto, 2013), responsibility cannot be assumed or assigned without first acknowledging care needs. Care as a continuous process begins with "caring about", followed by "taking care of" (Tronto, 2013). Hence this study needed to establish what policymakers regard as social care for older people and who should be cared for. Defining social care is a first step towards understanding how responsibility is allocated in the relevant policies to different actors. The NPOP refers only to the psychosocial care and support of older people. However, the concept of social care,

which was first introduced in the NSPP (2015), was positioned within a social protection approach. The concept of social care is also used in the PPI; it can thus be identified only in the last two documents, both developed in 2015. The NSPP definition differentiates between social care and social security in the Ugandan context:

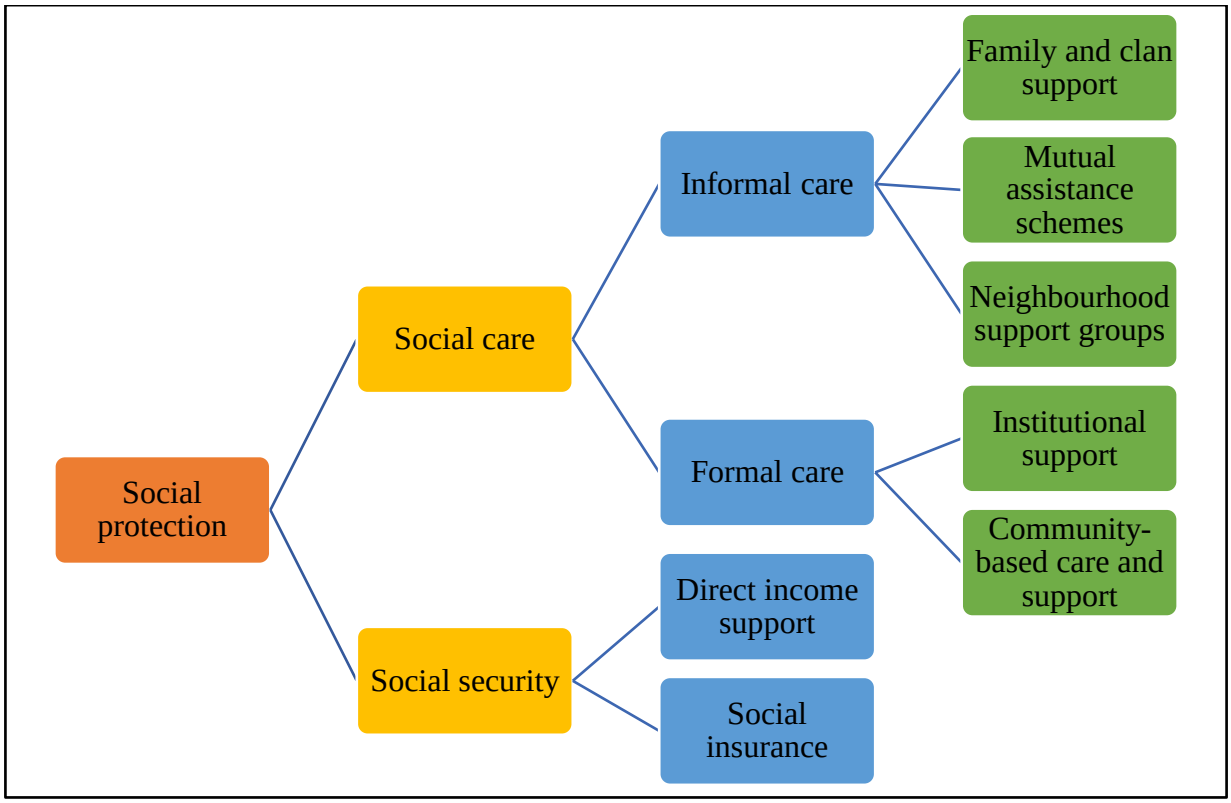
> Social care and support services are a range of services that provide care, support, protection and empowerment to vulnerable individuals who are unable to fully care for themselves. In the Ugandan context, the social protection system comprises two pillars: social security and social care and support services. Social security refers to protective and preventive interventions to mitigate factors that lead to income shocks and affect consumption. (MGLSD, 2015a, p. 1).

This analysis offers three crucial insights into the understanding of social care in Uganda:

1. First, unlike the NPOP, where care is viewed only from a psychosocial approach, the NSPP expands social care to include psychosocial support, personal care, rehabilitation, respite care, protection services, provision of information and referral (MGLSD, 2015a). Therefore, it offers a holistic approach to care by involving preventative social care services that provide a safety net and respite care that considers the provision of care when the primary caregiver is away.
2. Second, older people's social care is also presented in binary form − "formal and informal care" − as shown in Figure 4.1. Informal care includes "family and clan support systems, local credit and savings groups, mutual assistance schemes and burial groups" (MGLSD, 2015a). Existing formal social care and support services include *"institutional support to vulnerable PWDs [people with disabilities] and older persons and community-based care and support for older persons" (MGLSD, 2015a, p. 20).* From this excerpt, it can be seen that social care representations emphasise the "place of care provision", including family, communities and institutions. Identifying this binary categorisation is significant in exploring who is responsible for one or both categories of care. However, specific services and activities associated with both informal and formal care are neither mentioned nor detailed in these documents.
3. The third insight covers the conceptualisation of social care as empowerment, financial protection and support to vulnerable groups. This conceptualisation is essential in understanding how the social care problem in Uganda is framed, the rationale for addressing social care for older people, and how it impacts responsibility allocation.

In the next section, I examine these concepts further to enhance understanding of why attention is paid to social care for older people within the policy documents analysed.

Figure 4.1 Classification of social care in Ugandan policies



4.4.1 Social care for vulnerable older people

The policies analysed orient social care around addressing the concept of vulnerability, which is simultaneously significant in empowering older people to address their care needs themselves. The NPOP defines vulnerability as *"a state of being or likely to be in a risky situation where a person is likely to be in a significant physical, emotional or mental harm that may result in their human rights not being fulfilled" (MGLSD, 2009, p. 32).* This definition presents a broader framing of social care that draws attention to the dire circumstances that intensify the need for care. The NPOP also highlights the vulnerability associated with rurality, as it is notes that *"the majority of older persons live in rural areas where poverty is rife, economic opportunities are limited, ill health is common, and health services are inadequate" (MGLSD, 2009, p. 10).* The policies also reference gendered vulnerabilities in a society affecting older women compared to older men. The NPOP revealed these gender inequalities, noting that,

> Historical and social-cultural dominations of men in most societies have continued to have an effect on women's access to social, cultural, economic, and political opportunities. Age affects women and men differently but impacts more on older women than men due to the different roles. Due to unequal household power relations, widows tend to be marginalized in terms of access, ownership and control over household resources. (MGLSD, 2009, p. 12)

This quote points towards the asymmetric power relations that limit female civic participation. This patriarchal system is also seen to oppress older women socially and culturally and construct gender roles where older women are discriminated. The NPAOP presents a detailed list of potentially vulnerable older people, including *"physically and mentally incapacitated, chronically sick, homeless, widows and widowers, caregivers of orphans and vulnerable children and economically active poor" (MGLSD, 2012, p. 5).* These categories reveal the target groups of older people whom policymakers consider most vulnerable and therefore require more care and support compared to the rest of the older population in Uganda.

The NSPP also highlights the circumstances that make older people vulnerable to the point of requiring support and social care, as it states:

> Those without support experience difficulties such as the inability to take care of their personal needs and isolation. Their susceptibility to ill health coupled with the high costs of drugs and the absence of specialists on diseases associated with ageing exacerbates their vulnerability. This is compounded by the impacts of HIV and AIDS, including the loss of their would-be caregivers. (MGLSD, 2015a, p. 12)

The above quote exposes older people's vulnerabilities expose moral, social and structural challenges and reveals the dire situation of the health care sector in handling age-related issues; in particular, it shows that older people have challenges in accessing specialised health care, yet some have narrow care networks.

Having explored the older people for whom care should be provided, in the next section I examine the benefits stated in policy documents and why older people should be cared for.

4.4.2 Social care as empowerment

All four policy documents situate social care within a normative framework of citizenship that focuses on economic growth through empowering vulnerable groups. The NPOP is seen to highlight the negative connotations attached by service providers to older people as dependent, inactive and unable to choose or control their care. For example, the NPAOP references the Uganda National Household Survey (UNHS) 2009/2010 report, where it noted that *"service providers of many poverty eradication initiatives believe that older persons cannot participate, have no productive role, and are merely passive recipients of support" (MGLSD, 2012, p. 9).* This statement demonstrates that service providers regard older people as a problem homogenous group that cannot assume individual responsibility and it fails to articulate the diversity of older people and their needs. However, the policies

simultaneously illustrate that older people are considered to make social contributions to their societies. The NPOP and NPAOP note:

> In Uganda, older persons contribute immensely to the creation of wealth, support and care for children, including HIV/AIDS orphans, creation of social cohesion and conflict resolution in their communities and the nation as a whole. Older persons make valuable contributions to society as guardians of traditions and cultural values which are passed on from generation to generation. In cognisance of the valuable contributions older persons make, the Government is committed to enhancing their potentials by establishing a framework to address their needs and rights. (MGLSD, 2009, p. 9; 2012, p. 1)

From this excerpt, it can be deduced that the attentiveness towards older people's needs and rights in receiving care is associated with their active social and economic participation in society, reflecting a neoliberalist ideology. The policymakers took this further by also promoting the neoliberalist position of personal power and individualism, a concept defined in the NPOP as:

> The process of giving voice to the disenfranchised and allowing the poor and vulnerable have access to the tools and materials they need to forge their destinies by allowing every household the possibility of becoming the producers of their own welfare rather than consumers of others' charity. (MGLSD, 2009, p. 31)

The analysis demonstrates an assumption that the provision of social protection will contribute to national development and economic progress. Social care is presented as a key strategy within the social protection approach in contributing to economic development. The NSPP noted that:

> Social protection supports the attainment of middle-income status. Provision of income security and basic care and protection for the most vulnerable citizens is essential for stimulating local economies, supporting political stability as well as building and protecting the human capital necessary for sustained growth and development. (MGLSD, 2015a, p. 4)

This indicates a desire to reach international economic competitiveness and improve the productivity, participation, and citizenship of older people, among other vulnerable groups while acknowledging the influence of the global care economy. They highlight in the PPI that *"governments all over the world have recognised that social protection is an inevitable intervention for supporting the population to maintain a minimum level of consumption in case of unforeseeable shocks" (MGLSD, 2015b, p. 20).*

This excerpt highlights social protection as a necessary safety net required to maintain citizens' minimum welfare levels and one that could prevent them from falling below the

poverty line. The anticipated benefits for vulnerable older people and national economic progress in these neoliberalist ideologies are evident.

The next section examines who then should be responsible for providing social care to achieve these stated benefits.

4.5Social care responsibility allocation

The tracing step involves examining the division of responsibilities between the state, private companies and individual, as it entails vital dimensions of normative frameworks (Sevenhuijsen, 2004). The analysis identified responsibility allocation to families, community, state, transnational organisations and collective responsibility through multi-stakeholder partnerships.

4.5.1 Social care as a family and community responsibility

All four policy documents allocate social care responsibility primarily in the informal sector, particularly to families. For example, the NPOP emphasises the need for a *"family and community-based care approach for older persons in accordance with socio-cultural setup. This recognises that the family is the primary source of care and support to the older persons" (MGLSD, 2009, p. 20).* This quote reveals that the policymakers held opinions that the family and community are the best social settings in which care should be provided. This delegation to families and communities is also justified by arguments relating to the quality and responsiveness of care. For example, the NSPP noted that:

> Traditional support systems are valuable and beneficial social protection mechanisms as they define personal and collective identity. They are institutions of the first instance for support to vulnerable persons which provide immediate, more effective, culturally familiar support. (MGLSD, 2015a, p. 21)

Similar to the EoC perspective and ubuntu philosophy, policymakers acknowledge that care is relational. The care provided by families is considered to be more humane in recognising older people as both individuals and belonging to a particular society, which in turn could promote personalisation and reciprocal interactions within the broader society. However, in the context of Uganda, which has more than 56 different tribes, this statement also reveals the consideration of the many cultural identities or ethnic orientations involved in caregiving and the many identities that encompass shared norms, values, history and customs around caring for older people.

However, despite highlighting their responsibility to care for older people, the policies similarly acknowledge that traditional support systems and family and kinship networks have significantly deteriorated and are on the verge of extinction. The PPI noted several structural challenges that weaken existing informal care systems, including:

> (i) socio-economic conditions, leading to individualistic tendencies focusing on the nuclear family as opposed to the extended family, which has, in turn, weakened the social solidarity that was a strong pillar for traditional social protection.
> (ii) armed conflict, civil strife and land wrangles, which have led to the disintegration of families and communities.
> (iii) migration in search of jobs and other economic opportunities, especially in urban areas; and
> (iv) weakened clan leadership, which used to be custodians of the traditional values and norms, leading to a breakdown in social cohesion (MGLSD, 2015b, p. 15).

Thus, the policies acknowledge that families and communities are constrained in taking on sole responsibility for social care. It is evident that changes in the cultural, political, socio-economic contexts within which care is provided contribute to challenges and interruptions. However, despite acknowledging the many problems families face, the policies still allocate responsibility primarily to them. For example, one of the priority areas of focus in the NSPP is described as follows:

> Government shall promote traditional and informal social protection initiatives to ensure that families and communities provide support and care for vulnerable groups such as widows, orphans, abandoned children, persons with severe disabilities, the chronically ill and older persons. (MGLSD, 2015a, p. 41)

The solutions across all four policy documents rely heavily on the family's role to remain primarily responsible for social care.

4.5.2 Social care as a state responsibility

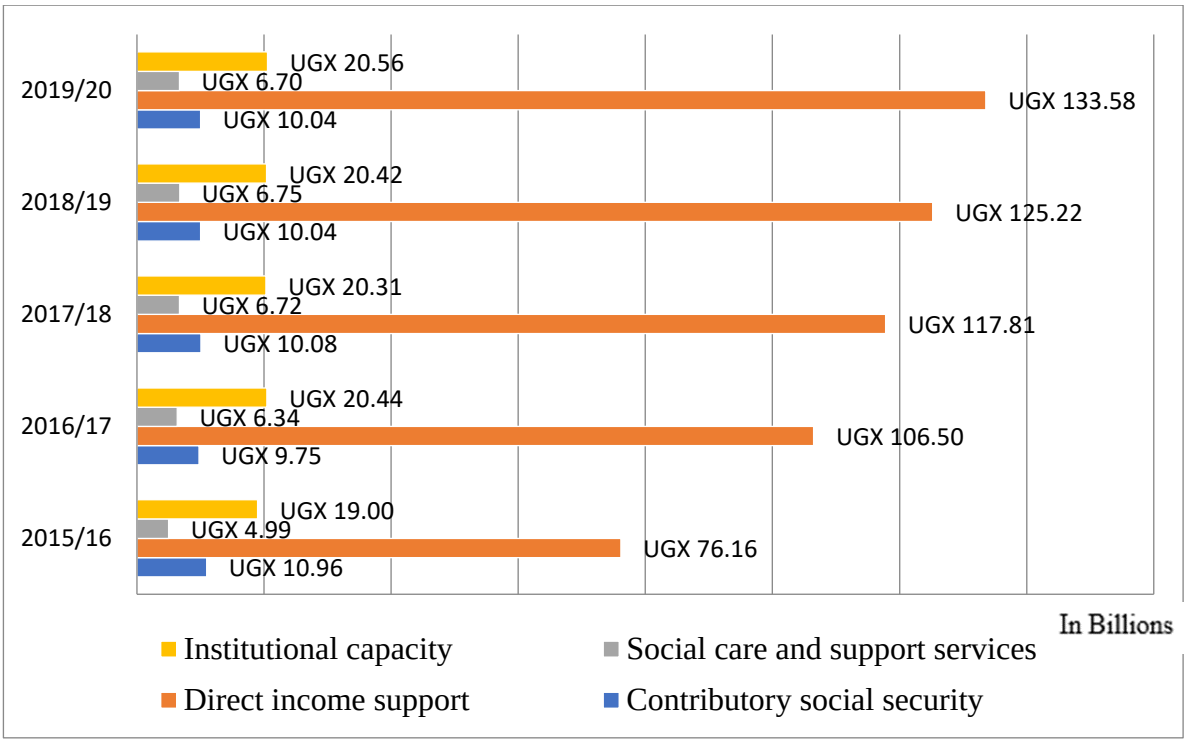
As stated earlier in this chapter, all the policy documents analysed for this research indicated that the central government's attentiveness to older people's social care needs was encompassed within social protection and was largely based on other policy frameworks referenced in the documents. The NSPP states that the government's commitment is to all citizens, *"the above policies, laws and obligations demonstrate government's commitments and obligations to provide social protection to all citizens" (MGLSD, 2015a, p. 10).* The universalisation of the government's responsibility is also identified through the principles. The policies list a variety of principles, such as *"a rights-based approach, equity, participation, inclusion, gender responsiveness, dignity, social choice, adaptability, transparency and accountability" of the NPOP (MGLSD, 2009, p. 19)*, and the NSPP's

"individual, family and community involvement, human rights-based approach to service delivery, timeliness, reliability and sustainability, universalism and inclusiveness, transparency, accountability, gender responsiveness equity and dignity" (MGLSD, 2015a, p. 26). The principle of universalism is problematic in these policies as it does not align with other statements in the same documents that refer to targeting the most vulnerable and the financial incapacity of the government to implement universalistic interventions.

While policy documents reveal a government's commitment to addressing older people's needs, they simultaneously highlight the government's limitations in fulfilling this responsibility. The PPI notes, *"the human and financial resources required by government institutions both at national and local government levels are very limited." (MGLSD, 2015c, p. 59).* To elaborate on this at the national level, the NSPP declares that *"there are low staffing levels and inadequate government resources to deliver social care and support services. Consequently, the demand for the services significantly outstrips supply" (MGLSD, 2015a, p. 19).* The same policy also declares that "social care and support services are handled by the Community-Based Services Department in the Local Governments which has inadequate human resource and logistical capacity for effective service delivery" (MGLSD, 2015a, p. 21). Therefore, the policies indicate that both the central and local governments are inadequately resourced to provide social care services.

While the financial and human resource constraints are noted across the later policy documents (those of 2015), these challenges can be traced back to the disparities in the budgetary allocations between social care and social security, which fall under the umbrella term of social protection. For instance, the PPI reported budgetary disproportions, which I illustrate in Graph 4.1.

Graph 4. 1 Cost for implementation according to the PPI of 2015 (MGLSD, 2015c).



Note: The graph was constructed by the author from the text in the PPI.
UGX is Uganda Shillings

Graph 4.1 shows that direct income support is allocated the highest financial resources in each financial year, followed by institutional capacity and contributory social security. Social care services were allocated the fewest resources. This could explain the financial constraints experienced in the local and central governments regarding the implementation of interventions for social care, which interferes with adherence to these principles.

The analysis also revealed inconsistencies in the reporting of the policymakers. The PPI notes that the *"government shall provide the primary source of funding with different ministries leading implementation in line with their respective sector mandates"* (MGLSD, 2015c, p. 35). Despite this statement, a contradiction is evident in the sources of funding, which show that the majority of funds come from the development partners accounting for 68% of the total funding costs, as shown in Table 4.1.

Table 4. 1 Source of funding of PPI (000s UGX)

	2015/16	2016/17	2017/18	2018/19	2019/20
MTEF Budget under MoPS	213,000	213,000	217,000	217,000	217,000
MTEF Budget under MFPED	614,500	633,500	652,500	706,500	706,500
MTEF Budget under URBRA	6,655,000	6,655,000	6,655,000	6,655,000	6,655,000
MTEF Budget under MoH	706,000	726,000	950,000	990,000	990,000
MTEF Budget for SCG	9,000,000	17,590,000	29,150,000	40,340,000	52,920,000
MTEF Budget for Social care	3,823,550	4,851,276	5,154,102	5,282,760	5,223,930
MTEF Budget for Salaries of CDOs in LGs	14,808,960	14,808,960	14,808,960	14,808,960	14,808,960
Development Partners	76,200,000	98,010,000	97,330,000	93,430,000	89,350,000
Grand Total	**112,021,010**	**143,487,736**	**154,917,562**	**162,430,220**	**170,871,390**
Funding Gap	-	-	-	-	-

Note: Adapted from the PPI (MGLSD, 2015b, p. 36).

Hence, the Ugandan government is not the primary social protection financer. Later in the same policy, it is noted that *"PPI will require additional government resources both in the medium term and long term. The PPI may attract inadequate funding for its implementation"* (MGLSD, 2015c, p. 58). The same document further states that *"unforeseen weaknesses in public financial management and accountability systems can expose social protection programmes to fiduciary risk"* (MGLSD, 2015c, p. 59). The financing of social protection by development partners external to Uganda shows the indirect responsibility of these partners.

4.5.3 Responsibility of transnational organisations

In the context of governmental resource constraints, the role of international development partners in social care provision was evident in the policy formulation process of all the analysed documents and the NSPP and PPI acknowledge the role of UK AID, Irish Aid, UNICEF and the World Bank in that process (MGLSD, 2015a, p. iv; 2015b). This finding positions transnational organisations as global political actors in formulating and implementing the policy documents that were analysed. However, the extent of consultation and engagement in decision-making is not specified. What is dominant in these policies is financial involvement through public-private partnerships, another neoliberalist strategy evident in the NSPP, which noted that the government would *"promote public-*

private partnerships in the delivery of social care, support and protection services" (MGLSD, 2015a, p. 29). This notion is further emphasised in the financing strategies where the NSPP stated, *"in the short and medium-term, Government shall finance some aspects of social protection in partnership with Development Partners. The private sector will provide resources for social protection through corporate social responsibility"* (MGLSD, 2015a, p. 41). The government is seen to reduce public funding and responsibilities while emphasising the role of the private sector.

However, the dependence on development partners disclosed across all the policies analysed raises questions about the sustainability of policy interventions. The PPI revealed this as a key risk in financing its implementation, noting, *"a change in aid policy of development partners that leads to withdrawal of support, could significantly affect the implementation of the PPI"* (MGLSD, 2015b, p. 58). This statement reveals that the funding from development partners was at risk of being discontinued, which will weaken the domestic policies. This risk also highlights the constraints in the provision of public social care, which could explain why other stakeholders in NGOs and the private sector are allocated responsibility.

4.5.4 Social care as a collective responsibility of actors

According to the policies analysed, NGOs are given responsibility for social care provision only when the family and community fail to meet older people's care needs and to supplement government interventions. For instance, the NPOP notes that *"the policy will emphasize community-based management of older persons. However, in exceptional cases where the immediate families may not be in existence, stakeholders will be encouraged to establish homes for the landless and homeless older persons"* (MGLSD, 2009, p. 20). This statement portrays the NGOs' purpose as a safety net to intervene only when families, community and government do not intervene. However, the role of institutions that should determine the need for care and to link older people to various stakeholders is overlooked.

However, the policies analysed do recognise the efforts of the NGOs in assuming responsibility and providing care services, as well as the significant challenges that NGOs and CBOs experience while fulfilling these responsibilities. The PPI asserted:

> Most of the social care and support services in the country are offered by non-state actors such as NGOs and CBOs, but their services are patchy, inconsistent and uncoordinated due to inadequate financial and human resource capacity to provide comprehensive services to vulnerable groups. (MGLSD, 2015b, p. 21)

This quote highlights the challenges associated with the social care systems, given that the purported main stakeholders are depicted as inadequate in providing care. This will likely have implications for older people who may fail to secure care with family, government or community, as NGOs are equally financially constrained.

The plurality of responsibility noted in policy formulation through consultation and implementation does not translate to direct care responsibility allocation. In all four analysed policy documents, policymakers acknowledge the participation of line ministries, civil society organisations (CSOs), local authorities, faith-based organisations (FBOs) and older people themselves in the consultation process through a series of workshops and consultative meetings. The documents further reveal a multi-sectoral and multi-ministerial approach towards policy implementation. Implementing both the NPAOP and PPI is viewed as a shared responsibility of government, private and non-state actors (MGLSD, 2015b). However, the NGOs, the private sector, cultural institutions and FBOs are viewed as an auxiliary, providing care only when families, communities and governments fail. The PPI states, *"the civil society, private sector, traditional institutions and religious institutions will complement Government in the provision of social protection services"* (MGLSD, 2015c, p. 34). Therefore, the division of direct care responsibility among stakeholders in the public sphere remains unknown.

At the same time, the NSPP promotes a collective responsibility, placing it back on families, communities, government sectors and other actors. The PPI also notes that "society has a moral responsibility to care for the vulnerable members" (MGLSD, 2015b, p. 15), which indicates a value-laden assumption that citizens will have the resources to care for minority groups. Simultaneously, the state seems to deflect care (minimising social provisions and benefits) from being its responsibility to that of the citizens. Given such diversity in responsibility allocation, it is important to examine the institutional framework to understand who is responsible for coordinating other stakeholders and makes decisions.

4.5.5 The institutional framework and power structures

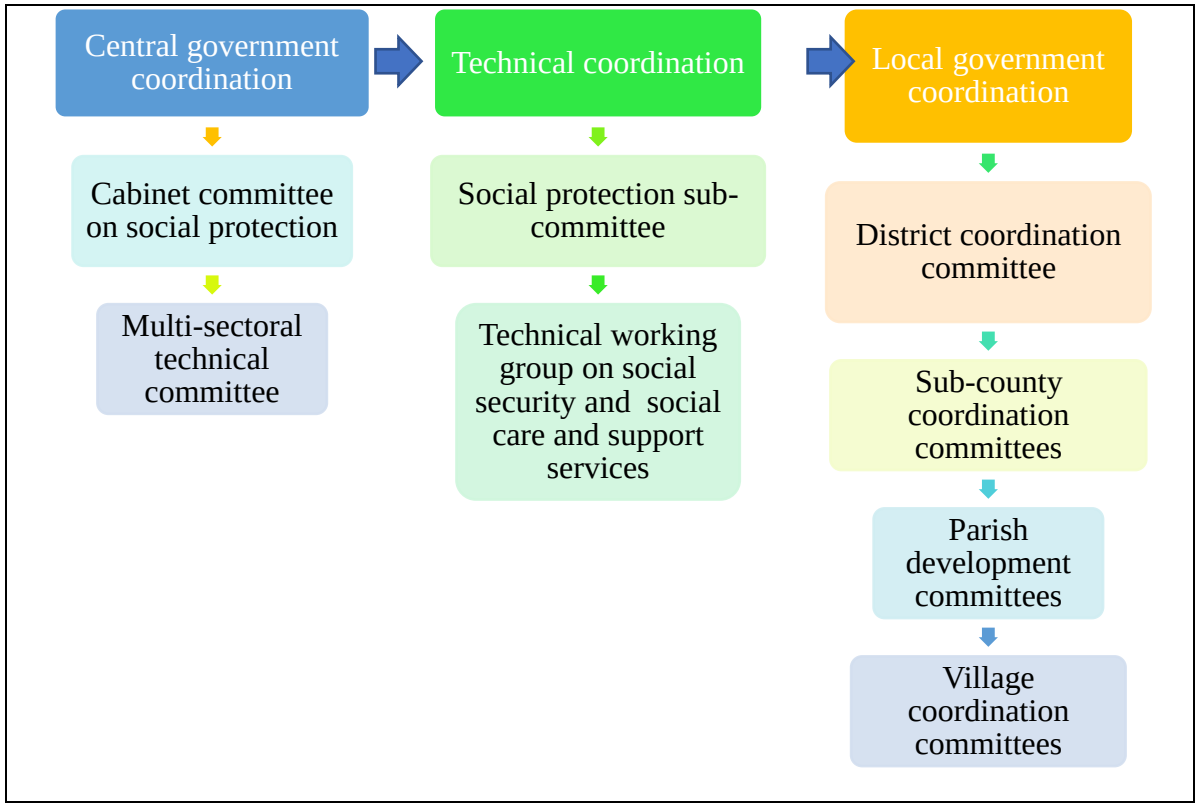
The NSPP highlights weak coordination of services delivered by CSOs, leading to wastage of resources and duplication of services, yet with minimal impact on the population (MGLSD, 2015a). Other challenges experienced by the government in taking on responsibility are further noted in the PPI, which states, *"the services provided by*

government are limited to residential care and support, underfunded and poorly monitored and evaluated" (MGLSD, 2015c, p. 21). The PPI indicates responsibility for implementing social care services falls on both central and local governments, as it notes:

> The Ministry of Gender, Labour and Social Development shall lead on the implementation of direct income support programmes and delivery of social care and support services. Local governments shall carry out the implementation of all aspects of social protection at the community level through established service delivery structures. (MGLSD, 2015c, p. 34)

The requirement to report indicates the tendency of bureaucratic reporting to dominate power structures. The PPI appears to offer a comprehensive coordination mechanism, as illustrated in Figure 4.2, to solve challenges in the provision of care services, yet this mechanism creates grounds for further power imbalances.

Figure 4.2 Coordination mechanisms specific to social care provision



Note: Developed this figure from the text on pages 29-34 in the PPI (MGLSD, 2015c).

The organisational framework shows three levels of coordination that need to be achieved— central government, technical, and local government level—indicating a top-down hierarchical approach. The need for lower-level committees (rural administrative structures) to report back to top-level committees highlights bureaucratic tendencies in implementation. In contrast, the high-level committees offer management and leadership

to subordinate committees. This indicates that the coordination teams are not at the same level, as the central government coordination team has power over the local government coordination team.

The analysis of these documents revealed that the leadership of ministers and permanent secretaries of the MGLSD was vital in implementing the NPAOP and the PPI. Hence, the MGLSD holds more power over other ministries and actors. The PPI states:

> This Technical Working Group shall be comprised of representatives from MDAs [ministries, departments and agencies] and CSOs [civil society organisations] implementing social care and support services programmes. This working group shall support development, implementation, monitoring and evaluation of social care and support programmes. It shall be coordinated by the MGLSD and report to the social protection sub-committee. (MGLSD, 2015c, p. 33)

The above coordination tool does not translate to care coordination, whereby different service providers organise each client's care specifically. Rather, this structure relates to a hierarchical reporting mechanism and decision-making about care and older people's issues in policies. At the lowest coordination level, the PPI states, *"the village coordination committees will consist of the LC1 chairperson, community associations, CBOs and representatives of target groups"* (MGLSD, 2015c, p. 33). The representatives of older people hold more power than other older people in various villages in rural Uganda, as they decide the issues to be presented before the village coordination committee. However, the power dynamics between families and communities are unknown.

4.6 Proposed strategies towards social care

Examining the solutions proposed in the policies to solve the problem is another important topic in the tracing stage (Sevenhuijsen, 2004) in terms of shaping expectations and responsibility allocation. The analysis shows similar strategies to those used to enhance holistic social care provision in the policy documents of 2009/2012 and 2015 that primarily target family, community and service providers. The only two strategies identified as different in the policy documents focus on improving older people's participation in the NPOP and NPAOP and promoting public-private partnerships in the NSPP. The strategies presented in the NPOP and the NPAOP focused on ensuring that older people actively participate in four key areas of experience: sharing, intergenerational activities, older people's associations and recreational and leisure activities. Specifically, the strategies are: *"Encourage experience sharing among older persons; Promote the formation of associations of/for older persons; Promote recreation, culture, leisure and sports activities*

that target older persons; Promote intergenerational activities" (MGLSD, 2012, p. 11). While these strategies propose more societal engagement and participation of older people in sports and recreation, there is an unrealistic critical assumption related to the lack of age-friendly leisure, sports and recreational places in rural communities. The only strategy present in the NSPP that is not included in the NPOP, NPAOP and PPI relates to public-private partnerships, namely, *"promote public-private partnerships in the delivery of social care, support and protection services"* (MGLSD, 2015a, p. 29). This inclusion seems to be associated with the development partners' role in formulating and financing social protection policy and interventions. However, no national or local private partners are suggested or mentioned.

All other strategies proposed in the four policy documents revolve around promoting family and community-based care and support for older people and building the capacity of social care and support service providers. For instance, the NPOP suggests, *"promote family and community-based care for older persons' developing curricula on counselling, guidance and care for older persons; training service providers in counselling and guidance for older persons; mainstreaming training needs of older persons in relevant training programmes"* (MGLSD, 2009, p. 26; 2012, p. 11). The NSPP and PPI also refer to similar strategies, as follows:

Government shall enhance social care and support services through the following strategies:

- Promote community-based response mechanisms for supporting vulnerable people.
- Expand the scope and coverage of care, support and protection services.
- Build the capacity of social care and support service providers.
- Strengthen the capacity for delivery of social care and support services at all levels.
- Promote specialised social care and support services. (MGLSD, 2015a, 2015b).

All this indicates that strategies are targeted towards ensuring that families, communities and service providers fulfil their responsibility towards social care for older people. The focus on professionalising social care work is evident, with later policies shifting from only training individuals to increasing the efficiency of human resources and systems more broadly through increasing capacity in human resources, scope and speciality.

4.7 Discussion

This chapter has explored how social care responsibility for older people is allocated in Uganda's national policies. The Trace analysis has highlighted the challenges, risks and contradictions that influence the conceptualisation of social care and responsibility allocation, leading to what I refer to as care disruptions. It also revealed that all four policy documents emphasise that family and community are and should be primarily responsible for older people's social care needs. While the central government claims to be responsible and attentive, it devolves responsibility to the local governments through decentralisation. The NGOs are noted for providing most social care services, yet the policies assign them complementary responsibility, only when families and communities fail. Although transnational organisations are seen to assume some indirect responsibility through global public-private partnerships, their involvement is limited to funding social protection programs. Therefore, older people are also responsible for their own care and are expected to contribute to society and national development. The analysis also revealed paradoxical statements in the policies' ideology, the reasons for formulating the policies and framing the social care problem, the principles underpinning the policies, and the limitations experienced by all responsible actors in explaining how responsibility is allocated.

The responsibility of transnational organisations is evident in policy formulation and financing, the dependence on donor funding to actually implement social protection programs for older people in Uganda. The foreign influence is evident in the implementation of the MIPAA, international and regional commitments towards human rights for older people, adherence to international and regional sanctions, the desire to achieve middle-income status, and transnational organisations' role in financing the NSPP and other social protection programs. These development partners are affiliated with countries including Sweden, Denmark and the United Kingdom. The funding from transnational organisations provides short-term piecemeal solutions rather than long-term outcomes yet they promote westernised ideologies. Policymakers in Uganda accentuate the neoliberalist notions of individuality by portraying social care provision as empowering; this is to promote active citizenship with expectations that older people will contribute to their social welfare and the country's economic and social development. Scholars have noted that very powerful actors like the World Bank, the International Monetary Fund and bilateral international donors have promoted this neoliberal agenda in Uganda (Wiegratz, Martiniello, & Greco, 2018). Indeed, the central government is seen to distance itself from financial spending. It decentralises its fiscal responsibilities to local governments and

promotes public-private partnerships, expecting private companies to engage in social care provision. The same scholars have noted that privatising responsibility out to family networks in Uganda is evident in the over-reliance on kin and informal social support (Wiegratz et al., 2018).

The policies attribute responsibility to the state which alludes to principles of universalism and inclusiveness, yet at the same time implements an inconsistent strategy of targeting the most vulnerable. The limitations in resources and the countless vulnerabilities can explain the need to prioritise social care for the most vulnerable older people. However, in Uganda's context, where formal social care services are either limited in scope or non-existent across most geographical locations, targeting only the most vulnerable implies that those who are less vulnerable but require care are excluded and their care disrupted or left with unmet needs. Therefore, a reconsideration in formulating a range of care programs and services for all older people is essential in establishing other stakeholders' responsibility and participation in care for older people in Uganda. This could mean that older people who can afford to pay for their care have access to well designed and high-quality care services. I argue that to achieve social justice, all older people should have equal access to social care services. The ethics-of-care lens emphasises the need to rethink vulnerability as a part of daily living, an inherent dimension in human life (Sevenhuijsen, 2004). Tronto (2015b) noted that care is multifaceted, and people will have diverse care needs, all of which are important and need to be taken seriously. This calls for different care arrangements based on needs and resources. After all, social justice aims to enhance equal participation of all citizens where all needs are met, where welfare rights are viewed as basic rights (Held, 2006).

Furthermore, the inclusion of the principles of accountability and transparency in the policies is flawed, given the history of corruption in public management. The trend of corruption is evident in the current regime's historical context (Asiimwe, 2014; Rubongoya, 2007). Hence using the sentence "unforeseen in public financial management and accountability systems" in the PPI is an understatement. Although the pilot schemes of the SAGE program initially targeted older people aged 65 and above in approximately 64 districts, this program has also been criticised for providing poorly targeted financial support that excludes many older people and is arguably corrupt and lacking in transparency (Bukuluki et al., 2016). Between 2012 and 2013, economic sanctions were

imposed on the Ugandan government due to allegations of embezzlement of foreign assistance from all previously stated countries (Bukuluki, 2013). For example, a forensic audit by the Office of the Auditor General in Uganda revealed that more than UGX 60 billion (about US$24.5 million) meant for the Peace, Recovery and Development Programme (PRDP) for post-conflict Northern Uganda was misappropriated by the Office of the Prime Minister (OPM) (Bukuluki, 2013). Government resources are still improperly accounted for and used for unintended purposes, and consequently, the value of foreign aid is not always realised (Bukenya & Hickey, 2019; Kaluya & Elliott, 2018; Ssentongo & Okok, 2020). Scholars have noted that the current government's values of state-society exchange, accountability and trust were undermined by "personalisation of politics," corruption and a deficit in democratic legitimacy, suppression of freedom and orchestrated human rights violations (Asiimwe, 2014; Rubongoya, 2007). One Ugandan social work scholar has noted that corruption interferes with the quality of service provision, worsening the vulnerability of marginalised groups (Wamara, 2017).

The policies noted that families and communities provide culturally appropriate care to older people, justifying why significant responsibility is allocated to the micro level. This assertion draws on Obuntu principles of solidarity, togetherness, consideration of kinship and the family atmosphere of care. The Obuntu principles of society responsibility, emphasise the communal expectation and moral obligation of society to care for each other to achieve societal prosperity. Older people are also expected to participate in intergenerational activities, promoting their relationships in their families and communities, and continue caring for themselves and their dependents. Here, the care for others supersedes the care for oneself. Hence, older people are expected to perform their roles in society towards orphans and vulnerable children (OVCs) despite their own vulnerability and often extreme poverty. Care theorists argue that active citizenship that is not backed up by government funding can jeopardise social cohesion (Eggers, Grages, & Pfau-Effinger, 2019). A threat to social cohesion that could have implication for caring with, the solidarity and plurality care phase care presented by Tronto (2013). Some care theorists argue that viewing care within a cultural context implies that less responsibility is taken up by the state, NGOs or private companies (van Nistelrooij & Visse, 2019). This is evident in the case of Uganda, where no particular responsibility towards direct care responsibility is allocated to any actor. According to Tronto (2010), the fact that those who should be engaged in the care process are not explicitly named is an indication that institutions are not caring well.

Since Uganda's policymakers allocated primary responsibility to families and communities despite acknowledging their inadequacies in taking on sole responsibility for social care, care disruptions are inevitable. It is evident that cultural, political, socio-economic contexts within which care is provided in Uganda are challenging. Policies have noted the risk of transnational organisations withdrawing the funding, which disrupts care, especially when government, as noted earlier, does not have the resources to continue funding interventions. Another fiduciary element relates to the significant discrepancies in budgetary allocations between social security and social care when social protection interventions are being implemented. This financial variation highlights institutional challenges as social care programs are implemented with extremely constrained budget allocation. However, the financial discrepancies could relate to the role of donor organisations that determine and prioritise the interventions they finance. Moreover, top-down approach constrains the decision-making capacity and efforts of local governments as they depend on the central government's funding. NGOs were also noted to be financially constrained and where higher poverty levels characterise rural communities compared to urban areas, as older people experience abject poverty. The challenges relating to human resources specialised in ageing issues were identified as key challenges in delivering social care services across all the analysed policies. This implies that complex care needs remain unmet as only limited personnel have the skills to take on complex care responsibilities. I argue that all the challenges, risks, changes, limitations and contradictions evident at a macro level in the analysed policies can manifest across the caring process, impacting other phases of care, like caregiving and care-receiving, both formal and informal. Hence the concept of care disruption(s) needs to be incorporated into the ethics of care, particularly the care phases.

4.8 Conclusion

This policy analysis explored through an ethics-of-care lens how social care and responsibility allocations are conceptualised in Ugandan national policies. It revealed policymakers' attentiveness towards older people's needs, where social care is framed within a vulnerability framework, targeted towards the most vulnerable groups. Care disruptions are inevitable across both the private and public spheres, as the policies noted constraints in financial and human resources. These constraints potentially impact on the uptake of responsibility and caregiving, thus shaping the responsiveness to care needs. The findings demonstrate that government seems to mostly "care about" and, while conceptualising social care within neoliberalism and Obuntu ideologies, does not take on

responsibility. The policies demonstrate a hierarchy of care, giving primary responsibility to the family and communities, then the government, followed by NGOs. The allocation of responsibility in the analysed policies has implications at different ecological levels and subsequent care stages (caregiving and care-receiving). The analysis revealed a lack of definitive allocation of task responsibilities towards care, leaving a gap in our understanding of the various care services provided by stakeholders. Therefore, it is important to bridge this knowledge gap and analyse the current providers taking responsibility for social care service provision. This exploration is described in the next chapter.

CHAPTER FIVE: SOCIAL CARE RESPONSIBILITY THROUGH A STAKEHOLDER LENS

"Do what you can, with what you have, and where you are." (Theodore Roosevelt)

5.1 Introduction

The previous chapter explored how social care and responsibility allocation are conceptualised at a macro level in Uganda's national policies, using EoC theory. Analysis of these policy documents revealed a primary reliance on families to take the main responsibility for care, with the policies simultaneously encouraging individual responsibility of older people themselves through promoting concepts of active participation. The policies accentuate the limitations in government funding and hence imply that the family, community and/or civil society organisations (CSOs) will take responsibility for older people's social care. However, no definite responsibilities were allocated to other stakeholders in the public, voluntary and market sectors, which could potentially lead to care disruptions. It was evident that overall, there was little clarity in the policies about the extent of stakeholder engagement in and responsibilities for social care provision nationally, including in rural Uganda. These policies also revealed the higher numbers of older people residing in rural areas, who were extremely vulnerable compared to their urban counterparts.

However, none of the analysed policy documents described current social care models and services available for older people in rural areas or highlighted the stakeholders required to assume responsibility for these models or services. To date, there has been little research into the social care systems available to older people in rural Uganda. Given limited government funding and limited policy direction on social care for older people, it is vital to understand how stakeholders assume responsibility and shape the current social care system.

Consequently, this chapter explores the second research question by examining stakeholder perspectives on responsibility for the social care of older people in rural Uganda. Interviews were conducted with 21 stakeholders at both national and local operational levels. National stakeholders included public servants from the Ministry of Gender, Labour and Social Development (MGLSD), private companies, researchers, associations and FBOs. Local

stakeholders encompassed local and religious leaders from the two case study regions (Akokoro sub-county in Apac district and Ngogwe sub-county in Buikwe district). In consideration of the Critical Human Ecology (CHE) approach framing this thesis, this chapter also adds to our understanding of the macro environment, which comprises economic, cultural and social contexts, policies, programs and services. Following the analysis of policies in the previous chapter, this chapter focuses on the various stakeholder care programs and services to explore how caring responsibilities for older people are assumed in rural Uganda.

First, the chapter presents the social care services provided by stakeholders who assume responsibility, emphasising both geographical and care inconsistencies in the rural Ugandan social care system for older people. This exploration shows how stakeholders assume responsibility and the types of social care for which they feel responsible. The subsequent themes provide a critical exploration of the rural context, focusing on how other elements of EoC influence responsibility. The second theme presents findings about why stakeholders assume responsibility, which is directly in line with the EoC element of attentiveness. Here, the stakeholders describe the challenges they experienced in assuming responsibility, leading to the third theme, which aligns with the element of competency in EoC theory. The fourth theme pertains to the perceptions of stakeholders regarding anticipated care responsibilities (who ought to be responsible?), which is associated with "caring with", the final phase of the EoC. This chapter adds to the EoC discussion by exploring how responsibility is assumed by or devolved to other stakeholders. I argue that responsibility assumed by stakeholders is continually disrupted due to limited funding and skill sets, resulting in inconsistent delivery of social care services in Northern and Central rural Uganda.

5.2 Description of social care services for older people in rural Uganda

As the subsequent sections demonstrate, there is a range of stakeholders providing social care services to older people in rural places. However, the state of social care provision is characterised by geographical discrepancies, inconsistent provision and varying levels of competency and funding, as illustrated in Table 5.1 is based on findings from stakeholder participants, which include the care services they provided and those they knew about. During the interviews, stakeholders mentioned other social care providers who I followed up through snowballing sampling techniques and hence were also included in this study.

While government, private and voluntary stakeholders at a national level claimed that social care services were available to both rural and urban populations, this did not necessarily translate to the study sites. Discussions with stakeholders from the FBOs and local government indicated that social care services were inadequate at the study sites. For example, in the Akokoro sub-county in northern Uganda, only financial support, material support and pastoral care were mentioned, while in the Ngogwe sub-county in central Uganda, only material and pastoral care were provided.

Table 5.1 Attributes of different types of social care provided by stakeholders

Type of care	**Provider** (who is responsible for providing the care)	**Frequency** (how often care is provided)	**Financing** (who funds the care)	**Qualification of providers** (level of training of care staff)	**Social care services provided at study sites**
Residential care homes (only 2 care homes identified)	Government	Consistent	Government	Unskilled	None
	Faith-based organisation		Well-wishers Catholic church	Skilled and semi-skilled	
Community-based care (1 identified)	Faith-based Organisation	Consistent	Donors	Skilled, semi-skilled and unskilled	None
Home care services (2 companies included)	Private companies	Inconsistent	Adult children	Skilled and semi-skilled	None
Financial support/ cash transfers (Only the government in a few districts in northern Uganda)	Government	Consistent	Government Foreign partners	Unskilled	Northern
Community development	Government	Consistent	Government Foreign partners	Unskilled	Northern
Material support (Common among local churches)	Faith-based Organisation	Inconsistent	Government Congregation Corporate private companies' donations	Unskilled	Both
	Community-based Organisation				
Pastoral care (local churches)	Faith-based Organisation	Inconsistent	Congregations	Semi-skilled	Both

Some stakeholders serving rural populations had their infrastructure and offices established in urban areas or targeted other rural districts in central and western Uganda, which were

not included in this research as case study sites, thus broadening the conceptualisation of care services available in rural Uganda.

In discussing the concept of social care, this quote from a researcher in a private company is important in guiding our understanding of why stakeholders perceive social care services differently from the mainstream literature:

> The concept of social care for older people in rural areas is not yet well understood or developed. We have policies which talk about it, but the implementation of these policies into the real settings is lacking. Decision-makers lack competencies in social care, ageing or geriatrics. We just do it rudimentarily. We do not have people who can come up and advocate or have a better argument for caring for older people, yet without that, there is no way the political commitment will come in. (K4-C-P)

Similarly, the head of one older persons' association said:

> The care system is not so streamlined but all hope is not lost because we have leaders, many organisations coming out and some people studying gerontology like you. So, it will provide a better understanding of the situation of older people and we hope that a mechanism is in place to improve on the social care system. (K7-C-P)

In light of this lack of a comprehensive collective understanding of social care, the following findings indicate how stakeholders do perceive social care and the services they provide. Not surprisingly, they encompass some services that are not typically categorised as care services.

5.2.1 Community-based care services

Stakeholders identified only one FBO in central Uganda that provided ongoing community-based care services for older people in rural areas. One FBO manager noted the range of services provided by his organisation FBO, including direct care, as follows:

> There are those seniors who are bedridden and require social care services. Such seniors can no longer do anything for themselves. They can no longer even bathe themselves. Some reach an extent when they can't feed themselves, so for such a category, they really need home-based caregivers. (K03-C-FBO)

However, these services were not provided in isolation, and were compounded with other services that promoted holistic wellbeing of an individual. The same manager said:

> We focus on six strategic objectives looking at the health, spiritual part, food and income security. And then lessening the burden is about taking care of the grandchildren living with these older persons and of course awareness through seminars and meetings and lobby the government to acknowledge these older persons and fight for their rights. (K03-C-FBO)

The FBO manager noted that care services provided at home, such as support with ADLs and IADLs, were provided to people aged 80 years and above who were usually bedridden. In contrast, community-based services, such as pastoral care, medical care and outreach, as well as income-generating projects[6], were targeted towards people aged 64 years and above who participated actively in income generation and cultivated the land. These services were not typically care services but encompassed a holistic approach to addressing vulnerabilities faced by older people within the targeted communities, instead of personal care only. Provision of these other services can be explained by the limited public services provided to older people in rural Uganda by the government.

The organisations that provided home, community-based and residential care in rural areas and interfaced with the health care system expressed concerns about its ineffectiveness. All stakeholders noted its flaws and structural challenges, which were linked to shortfalls in public service provision. For instance, one manager said, *"The medicines they [older people] need for their chronic illnesses, especially, they cannot find them in these government health centres" (K03-C-FBO).* The shortage of medication could be associated with the government's prioritisation of infectious illnesses over non-communicable diseases. For example, one academic stakeholder noted, *"Our health system is more inclined to infectious diseases compared to non-communicable diseases, which are more prevalent in older persons" (K14-C-R).* If older people cannot access medical services, the care provided to them is inadequate and unresponsive to their care needs.

The same FBO could be seen to be filling this void as the health centre it built attends to older people's medical care and provides outreach programs targeted at older people in the community. The manager reported: *"We have a medical team and a doctor overseeing and ensuring that all our beneficiaries in our program receive the health care required. The medical team, at times, does medical outreaches and health education talks" (K03-C-FBO).* These programs are designed to reach older people in rural communities who cannot travel to the health centres, thus enhancing access to medical care by older people in their own communities. This health centre is also a meeting point for the older people receiving community-based care services provided by the FBO.

[6] Income generating activities are small informal businesses that are managed by groups of people within the same community to increase their household income. These could include agricultural production (crop and livestock) and small trade.

5.2.2 Residential care services

In Uganda there is limited allocation of residential care homes, which are viewed as a last resort. In the present study only two residential care homes were located in central Uganda, in urban Kampala and the rural Jinja district. At the time of this research, the national government had recently taken over the funding and management of the rural care home, which had been formerly run by the Jinja Catholic Diocese, taking responsibility for 30 older people and offering various services. A respondent from the central government noted that in the Jinja Home, *"Government mainly offers services of accommodation, food and primary medication for the elderly persons." (K09-C-CG).* The Nalukolongo residential home in Kampala district was officially opened in 1980 and was funded and run by an FBO affiliated with the Ugandan Catholic Church. At the time of the interview, the home was reported to be caring for 70 older people. As in Jinja district, the Nalukolongo home provided ongoing residential care services. The sister-in-charge said, *"We take responsibility for them [older people] and even have a cemetery for them in Mukono where we bury them" (K16-C-FBO).* These faith-based stakeholders reported they were attentive to older people's care needs and took on full responsibility for all their care needs, providing care until the recipients died. The responsibility to cover burial costs could be explained by the fact that this care home takes in older people who do not have any relatives in the community.

5.2.3 Home-based care services

With no government services or NGOs providing funded care services in rural Uganda, private companies have stepped in to fill the void. However, their services are provided only to those families who can afford to pay and they are not subsidised by the government. Interviews with stakeholders identified only two private companies in urban areas in central Uganda that provided care services to both rural and urban populations, but they were not in the study sites. Their range of home-based care services were described by one manager of a private company as follows:

> Majorly what we do is supervise the medication. We do laundry, supervise meals and move together to church, shopping places, entertainment places depending on the instructions we get or from the consent we have with the family members. (K1-C-P)

This revealed that private companies provided functional and social support to older people challenged in performing activities commonly described in OECD countries as activities of daily living (ADLs), like bathing, and instrumental activities of daily living (IADLs), like doing laundry, handling medication and transportation (Graf, 2008; Vlachantoni, Shaw,

Evandrou, & Falkingham, 2013). The manager of another private company noted: *"We give home care, physical therapy, occupational therapy, speech therapy to the older above 65 years. We help them shower, companionship, we transport them to hospital and follow up" (K15-C-P).* These care services also included the management or delivery of more complex treatments in the form of physical and psychological therapies.

As mentioned earlier, private companies provide care only to older people whose families could pay for the services, either in full or in instalments. One company manager noted, *"We do an assessment and talk to the family and let them know the situation of their relative and tell them how they are supposed to pay. We have payment plans if they cannot pay the full amount at once" (K15-C-P).* No participant reported engaging older people in the decision-making about their care. Rather, company managers emphasised the involvement of family members in making decisions, giving consent and paying for social care services. The financial responsibility of home-based care was shouldered by adult children, as one private company manager described:

> Their [older peoples'] elder children usually pay for the services or their siblings. Since the world is changing, and children are busy or going to other countries for greener pastures, parents end up having no one to care for them. Children usually pay; it is their responsibility. (K15-C-P)

This indicates that while private companies offered hands-on care, adult children were often forced to bear the financial responsibility of these services. Therefore, although care provision was seen to move towards market, profit-oriented providers, the responsibility for care was still individualised at a personal level and or family level, with no government intervention evident. So far, the care services mentioned were identified by stakeholders generally across rural areas of Uganda. In the following section, I focus specifically on the care services in the study sites in Buikwe and Apac districts.

5.2.4 Material support

In addition to their other services, FBOs and CBOs delivered material support to older people in both rural study sites in central and northern Uganda, including clothing, soap, food and bedding. A CBO manager in central Uganda said: *"We normally give dry food, maize flour, rice and other home necessities like soap, matchboxes, etc. And even the vulnerable children that they are staying with and the grandchildren, we take them books, pads etc" (K02-C-CBO).* This indicates that the provision of material support was provided to meet the basic needs not only of older people, but also of their dependants. The pastor

interviewed in Apac district said, *"I have visitation day. I inform church members about the day of the visit. We take them some things like salt, soap, sugar and even beans and any raw materials" (K20-N-FBO).* Besides the material support, FBO leaders also performed other acts of kindness. For example, *"We give them clothes and buy them some soap to wash their clothes and sometimes taking them to hospital when they are sick" (K19-N-FBO).*

5.2.5 Pastoral care

Stakeholders explained that pastoral care was carried out by numerous leaders of local churches in the rural study sites in Buikwe and Apac districts, through pastoral visits to older people's homes or to groups in the community. Pastoral care included spiritual support like praying for older people and their caregivers, offering advice and counsel. A pastor in Apac district said:

> In the church, as a pastor, I advise those who are taking care of them to do so in a good manner. I pray for them. I go to their homes, I hold a meeting, then children gather. I choose one of them who I know will take care of the older person or keep the things [material support] that we are going to give them. Then we advise the caregiver not to be drunkard, to take care of the older person. Sometimes, you find that the relatives select one person who can take care of the older one. (K20-N-FBO)

This highlighted further action taken by FBOs in ensuring that older people were being taken care of in their homes. Besides providing counselling, they offered other acts of kindness or compassion. As a leader from the Anglican church noted, *"If where they are sleeping is not good, we help them with renovating their house. If they have a garden, we help them weed their cassava. As a church, we organise ourselves, select one day and we help them" (K19-N-FBO).*

5.2.6 Financial support

All the stakeholders interviewed made reference to the financial support provided by the central government through the Social Assistance Grant for Empowerment (SAGE) program. This was delivered by local governments to a few targeted districts in northern, eastern and south-western Uganda, and hence was specific to the Apac district but was not provided in the Buikwe district. SAGE is financed jointly by the government and foreign donors. Although this financial support was previously categorised under social security in the NSPP, which was analysed in the previous chapter, stakeholders referred to it as a form of social care provided by the government. One central government stakeholder asserted: *"The moment an older person is catered for with a grant, which means that he/she can be*

in position of accommodating the psychosocial support which is offered by other government agencies e.g., OPM" (K08-C-CG). This indicates an assumption that social care needs were being met through the provision of these grants, which may or may not have been entirely the case. Another stakeholder in the central government explained that the *"government allocates money in this cash transfer program together with other partners like Irish Aid and DFID [UK Department for International Development] who are in a joint venture to ensure that old persons are supported" (K11-C-CG).* It was also established in the previous chapter that international aid actors provided approximately 68 per cent of these cash transfers distributed by the government. A parish chief revealed that *"each month they transfer UGX 25,000 [US $ 7, AUD$10]" (K10-N-LG).* This SAGE program was the only government financial support that benefited only a few older people, given that pension was not universal. The NSPP states that pension schemes cover only the civil servants through the Public Service Pension Scheme, employees in the formal sector via the National Social Security Fund and members of parliament by means of the Parliamentary Pensions Schemes (MGLSD, 2015a). Although this chapter cannot ascertain how the SAGE money was used, the subsequent chapters will expound on this as they explore the lived experiences of caregivers and older people.

5.2.7 Community development

Another support program that was referenced by stakeholders that may not traditionally be categorised as a social care service was the community development initiative funded by the central government and implemented by the local government in the rural study site in Apac district. Such initiatives are community-focused and not age-specific, such that rural older people benefit from them. One respondent from the MGLSD said:

> We have programs like Operation Wealth Creation which provides agricultural support services to communities, so old persons are part of communities. We have community development programs like NUSAF [Northern Uganda Social Action Fund], where old persons are considered a segment of the population and benefit. (K11-C-CG)

These economic empowerment schemes that target post-conflict communities were reported to be operating only in northern Uganda. NUSAF was associated with the LRA war that took place in northern Uganda and aimed for rehabilitation and development. A local government respondent stated:

> NUSAF is mainly in northern Uganda. It was to elevate the poor people who have suffered at the hands of the LRA war ... In the third phase, it is now NUSAF III, which has come up with a model that focuses on one community. The NUSAF can

> buy for you two bulls and an ox plough so that you can earn and buy the seedlings. (K18-N-LG)

This initiative highlights the government's efforts to address income insecurity in conflict-torn areas. Stakeholders perceived the agricultural resources provided to beneficiaries as offering a sustainable source of income. However, these initiatives were reported to be underfunded yet distributed among multiple vulnerable groups. Another local government respondent said, *"We normally integrate them [older people] in government projects like re-stocking [purchasing livestock] in NUSAF so in case government sends support, we usually select older persons, people with disability, youth, people with HIV/AIDS" (K17-N-LG).*

5.3 Rationale for providing care services to older people

The variety of reasons given by stakeholders for providing social care to older people reflected the element of stakeholder attentiveness to care in the EoC care phases. These included care for older people aged 60 years and above, who had a disability, were residing with grandchildren and/or lacked social networks or family members. Similar to the policies analysed in the previous chapter, stakeholders from FBOs, CBOs and central government considered older people's vulnerabilities, and assumed responsibility if no other option was available.

The only FBO providing home-based and community-based care services in central Uganda targeted those who were highly vulnerable for services. Aa a manager commented:

> All the seniors in our program who are benefiting must be 64 years and above. We then look at the vulnerability because we want to target the very needy ones in the communities. The senior has disabled children, or their children have passed on; we look at widows and widowers. They [older people] do not have a formal or stable income, so you find the entire household in total misery. You realise that older adults are not given priority, so most of them are abandoned because many concentrate on their nuclear families. Some are bedridden and it is really worse in rural areas where there are no relatives to come in. (K03-C-FBO)

The provision of material support by the CBO and religious leaders at local level was also determined on the basis of older people's health and disability status. As the manager of a CBO explained:

> Before we take on the person, we analyse the age bracket, and some of them [older people] want so much to join [while] they are still productive. Someone has to be incapacitated, but there are those [older people] who can still do some labour, farming and they feed their families (K2-C-CBO).

The association of disability with non-productivity and the subsequent need for material support among older people was evident. Consequently, older people who were still deemed as productive were not eligible for material support. The financial support provided by the government through the SAGE program also used age as a form of targeting. As a central government stakeholder noted, *"When they initiated this program, they started from people aged 65 years and above. As I talk now, the policy has changed, and they are going to start from 80 years and above" (K18-C-CG).*

Both the care homes providing residential care services also identified the need to target impoverished older people, such as those who were homeless, and specifically those without support, care or social networks. A sister-in-charge of the FBO care home reported:

> We look after older people who are needy, have no support, with no one to help from the streets or in the villages. They bring them here and we care for them. We have responsibility for them because they do not have any relatives. We do not discriminate because we have older people from Congo, Tanzania, Sudan, Rwanda, Burundi, Ugandans (K16-C-FBO).

Therefore, this FBO care home could be viewed as a place of last resort for older people who did not have families to turn to, an organisation that assumed the responsibility of caring for older people until the end of their lives.

Access to financial support from the central government was limited to Ugandan residents. Unlike the residential FBO that accepted older people from different countries, the government-based financial support was available only to selected citizens. A government stakeholder said, *"Old persons should access the program through the possession of a national ID, so in some instances, you find that they have lost the national IDs or did not register for the national ID, so you find that they were omitted" (K-11-C-CG).* Some older people who did not take the initiative of acquiring identification cards were thus self-excluded from such government financial support.

Household composition was another essential determinant for home and community-based care services and for material support from private and FBO care providers. Home-based services were provided inconsistently, especially when family members were present to take on caring responsibilities. A private care provider noted that *"whenever we come to school holidays, most of the people terminate the service as the students are able to take care of the older persons" (K1-C-P).* This indicated that care was provided according to the family's capacity to pay and the organisation's ability to provide care. Therefore,

stakeholders from private companies took on partial responsibilities on a short-term basis, in this case, centring around the school term cycle. The responsibility of school-going children for providing care for older people was also evident, as caring duties were reportedly resumed during their school holidays. Once the children returned to school, however, older people who had no adult children to pay for these services were left without support altogether. Taken together, the potential of these factors to influence the disruption of care was evident.

5.4 Competency and capacity of stakeholders in assuming responsibility

This section presents results relating to the ethics-of-care element of competency. As the following discussion demonstrates, the competency and capacity of stakeholders to assume responsibility was determined by their financial capacity, staff qualifications and resilience to structural challenges.

5.4.1 Stakeholder financial capacity

Stakeholder capacity and competency to provide care was determined by their access to funds. These were provided in different ways, including donations from local people and global actors. The ability to provide ongoing home and community-based care services by an FBO was enhanced by financial donations. As one manager stated: *"We run a sponsorship program for these older persons. The sponsors become friends to the seniors and agree to give monthly support. We have friends from Canada, Germany and Australia and even here in Uganda" (K03-C-FBO).* The monthly donations sourced from various countries benefited the most disadvantaged older people in the rural communities, an example of global actors indirectly assuming some care responsibility through financing care providers. A sister-in-charge of one care home said: *"This home is funded by the Catholic Church and is also dependent on the small offerings given by the well-wishers" (K16-C-FBO).* Another FBO providing material support reported received donations from well-wishers in the community and the congregation. A religious leader said: *"We organise ourselves, collect some money and then give it to the older person. We have a group of 23 people; it is called the born-again group. Every Sunday, we come with UGX 200 [US 8 cents] and collect it after service" (K19-N-FBO).* This reliance on small contributions made by the congregation could explain inconsistencies in support provision. It was evident that the provision of material resources was continuously disrupted. Inadequate finances hindered the fulfilment of caring responsibilities among most stakeholders. One FBO

manager said: *"They [older people] need care, so most of the challenges rotate around the fact that we don't have enough money to take care of their needs" (K03-C-FBO).* Another stakeholder from an FBO providing residential care services stated:

> Medical care is costly. Most of the people we have are sick, we try our best, but older people have some sort of illness every time. It is difficult to get pampers [adult nappies], which are very expensive. We have to pay for electricity and water bills, fetching firewood, all challenge us. (K16-C-FBO)

These limited financial resources restricted FBO care providers from assuming greater responsibility, thus leading to disruptions in care.

Budgetary constraints also appeared to limit the number of older people who could benefit from financial support. Earlier in this thesis, it was established that the government's capacity to provide financial support for older people was reliant on grants from Irish Aid and DFID. The financial support in the northern parts of Uganda was relatively limited. For example, a central government respondent said, *"The SAGE we are talking about is due to the donors coming in, we started around 2010, but we have not covered the whole country because of the challenges with the finance" (K08-C-CG).* The dependence on donor funding could explain why the government's responsibility extended only to a few older people in selected regions. In principle, one could argue that donors were taking on this responsibility through funds channelled through the government. Despite support from international donors, the aid was inconsistent, as a stakeholder from the central government confirmed:

> But we are getting this money from donors, who can limit the money they are giving you and you do not meet the population, which is there, as I talk now, not every older person is getting SAGE, the money that is meant for them. (K18-C-CG)

The international partners putting a cap on the funds directed towards the SAGE program indicated the program's vulnerability, as the funds were provided through aid.

The criteria for accessing SAGE program financial support from government have since been narrowed, and the government's financial capacity seems to contribute to changes in the age eligibility criterion which in turn determines the number of beneficiaries who receive financial support. A CDO said:

> When they initiated this program [SAGE], they started from people aged 65 years and above. As I talk now, the policy has changed, and they are going to start from 80 years and above. They have enrolled so many people, and the grants are not enough to reach the number of people enrolled. (K18-N-LG)

Consequently, stakeholders assumed responsibility and provided care only when they were funded and when they were financially constrained, care provision was disrupted.

Both the religious leaders who were providing pastoral care were dismayed by the work of the local councils (LCs), who provided no social care. The religious leader in northern Uganda noted, *"The LCs in this area do not care for older people. I have spent here five years … I have never seen anything the LCs have done for these people" (K19-N-FBO).* The LC respondents attributed their limited responsibility to two factors: lack of funds and being new to the office. One respondent noted:

> We have limited funds; the budget has UGX. 250,000 [approximately USD 67] a year, which is very little money to help out the elderly in the sub-county. So, you find it is hard for these lower leadership positions in the country to help out the elderly. (K12-C-LG)

Another local council chairperson said, *"I have just been elected to this position, so we haven't yet come up with any efforts to help these people. The former LC1 was not helping these people" (K13-C-LG).* These quotes highlight that stakeholders' responsibility was attached to their jobs. Hence any change in local leaders contributed towards care disruption as the incumbents had to develop strategies before assuming responsibility for older people's social care. There was no clear division between government responsibility, despite policies stipulating that central government decentralise or delegate social care responsibility to local governments.

5.4.2 The skill sets of those providing care

All stakeholders had varied skill levels and qualifications, which were essential factors in shaping their competency in caregiving, determining the types of care provided and influencing stakeholders to assume responsibility. None of the stakeholders interviewed held a specialised qualification in gerontology/ageing studies, aged care or geriatrics. This study indicated that the managers or founders of all organisations were skilled in, or had academic qualifications in, such different professions as social work, nursing, counselling, medicine, psychology, community leadership, project planning and development studies, as bachelor's degrees, diplomas or certificates. One respondent reported:

> We have social work and social administration, community leadership and management, project planning, development studies. Most of them [staff] have certificates in counselling to support their work. I think most of our staff have Bachelor's in social work and some have both, they had a diploma, and they upgraded. (K03-C-FBO)

This indicates a limitation in their perceived/assumed responsibility in their counselling, social work, managerial and administrative roles.

Highly qualified stakeholders from private companies, associations and central government working at the national level viewed research and advocacy as vital roles in promoting older people's social care. Informed by a human rights perspective, a manager from an association of organisations working with older people noted that the limited representation of older people's rights and violations prompted their engagement in advocacy: *"There are very few people who are concerned. That is why we do a lot of advocacy to raise awareness on issues of negligence, rights abuse and denial. For example, some older people are neglected and starved up to death" (K07-C-A).* The National Council of Older Persons (NCOP), which was established from district to local council levels, was viewed as a channel of advocacy. As one public servant noted, *"The other structures I told you about are political and are in place to ensure that the voices of elderly persons are heard in the district councils, parish councils and national councils, and that is another way government is providing social care services to elderly persons" (K11-C-CG).* These councils were perceived to take on the responsibility to amplify older persons' voices and ensure that policymakers and power holders heard them.

Most staff providing care, however, were semi-skilled, with very limited qualifications. Both stakeholders from private companies claimed that their caregivers were trained before placement, as a manager of a private company providing home-based care noted:

> We do not really need qualifications of the caregivers [staff offering care] because we want to create more employment opportunities for those who do not have a chance to compete in the world of the educated, so they have a chance to learn about caregiving. We teach them CPR, basic life skills, first aid. Teach caregivers how to overcome depression, counselling classes. I have a doctor who trains them for a week or so, then gives them the examination and a certificate. (K15-C-P)

As noted above, private care providers sought to promote formal employment and empower early school leavers by offering them training sessions and jobs. The previous quote indicated that skilled personnel offered non-formal training within the organisation to help people acquire organisation and job-specific skills. However, the duration of training varied, from just one week, as indicated above, to several months, as described by an FBO manager, *"We train the field assistants in home-based care for about three months so when they visit these seniors, they know what to do" (K03-C-FBO).* The training of semi-skilled personnel across all organisations followed the same pattern. Stakeholders also noted that

most of the training did not follow a specific curriculum. In cases where certificates were issued, they were not accredited; hence they are not recognised by the Ministry of Education and Sports. In relation to the reliance on non-formal training, it is important to note the lack of regulated, endorsed or accredited formal training in social care provision for older people in Uganda.

Unskilled care providers in most organisations were mainly volunteers. For example, unskilled attendants managed the government care home, as one gerontologist noted:

> They [staff] are about five, they have a warden and his wife, a cleaner and two cooks. The government has just taken over this place, and it is in preparation to get government employees on the payroll. The staff are basically volunteering. The church has managed this home, so the government has just taken over, and it is in preparation for putting a gerontologist, geriatrician and making it quite formal. (K09-C-CG)

In northern Uganda, unskilled representatives oversaw programs provided by public and faith-based organisations. A stakeholder said, *"We have representatives of these people at the sub-county level who witnessed whatever services reach their people" (K17-N-LG).* However, some volunteers also worked in CBOs and FBOs to support staff in the organisations and community outreach programs, especially for older people in their communities who could not access certain services. For instance, a CBO manager noted, *"I have, like, five volunteers, when we have some outreaches, they come to help because some do the HIV testing, capacity building, workshops and cleaning up elderly homes" (K02-C-CBO).* This indicated that volunteering was based on altruism, mostly to benefit older people and the CBO to meet their goals.

Inadequacies in care staff hindered stakeholders across all sectors in delivering social care services and fulfilling caring responsibilities. For example, stakeholders at the local government level were allocated heavy workloads in large operational areas that were viewed as cumbersome and affected performance and productivity. This challenge was also noted by the manager of a care home, who said, *"Even the work itself is challenging because it is tiresome, yet a voluntary and charitable work" (K16-C-FBO).* A private company director said the emigration of qualified personnel was another challenge: *"The system [of caring for dementia patients] died out when the doctor we were coordinating with left the country" (K01-C-P).* This discontinuity in social care services associated with highly educated professionals seeking better opportunities abroad affected the stakeholders' ability to provide efficient care services and positive outcomes.

All stakeholders in both northern and central Uganda noted limited capacity to access older people in rural areas, which was associated with poor access to transportation. For example, a private company director said, *"Some older people cannot board taxis, the roads are not good, boda bodas [motorcycles] are not professional" (K01-C-P).* Moreover, although some stakeholders indicated their resilience in accessing remote areas, they too found it challenging. One CBO manager noted, *"It's challenging to reach to where they [older people] are staying because some areas are very remote... [the] road is impassable, you have to park your car and then walk" (K02-C-CBO).* This demonstrates that the lack of accessible rural roads contributed to the exclusion of older people from care services, as both older people and stakeholders were constrained.

5.5 Anticipated care responsibilities for stakeholders

This chapter has up to this point identified the care services that various stakeholders provide, the reasons they assumed responsibility and for whom. It has also highlighted the varied competencies of stakeholders. In this section, I look at who stakeholders perceived should be responsible and for what. These findings fit with the last EoC phase of care of "caring with", and the principles of solidarity, trust and plurality. The findings reflect a divide between some stakeholders who expected NGOs and government to assume more care responsibility while others expected cultural leaders, families and communities to take on the role. These expectations also aligned with what stakeholders could do to meet the challenges impacting on social care service delivery. However, some of these expectations did not account for the incompetencies that some stakeholders experienced.

Given that individual cases, rather than groups within sectors, were analysed, there was a difference in perception of who should be responsible for care provision. Hence, the opinion of one interviewee could not be generalised to other people in the same sector. Some stakeholders (whose identifiers are included in the quotes below) from local government and private companies argued that NGOs should assume more responsibility for care. As they remarked:

> If we could get non-government organisations that target the elderly because we have seen many organisations working with the children, disabled and women, but for the elderly, we have not seen many organisations come up (K12-C-LG).

This highlights the view that since NGOs supported other vulnerable groups, they should also be responsible for the social care of older people by providing material and financial

support. Although both FBOs and NGOs in this study, were not-for-profit, it was evident that the FBO stakeholders did not perceive their organisations as NGOs. The difference was apparent in the basis for their establishment, namely, that the FBOs were founded on religious beliefs while the NGOs were founded by citizens. One of the religious leaders stated, *"The NGOs can also provide food and money because if you have money, it means that you have everything that you want. If you have money, you can buy sugar, salt, and even change diet" (K20-N-FBO).* Likewise, stakeholders from central and local government suggested that government need not take on responsibility, one of them stating:

> There is a need for partnership when serving the old persons, let it not be looked at as a concern for the government but civil society. NGOs and other bodies need to work together to look at it holistically and support the older persons (K11-CG central).

This notion of multi-stakeholder partnerships in the public domain to address older people's social care needs was consistent with the policy documents analysed in Chapter 4. However, despite this study finding that there was limited government responsibility for funding and social care services, some of the stakeholders still gave the government a ticket out of social care responsibility, a perspective that Tronto (2013) referred to as privileged irresponsibility.

Some local government stakeholders expected the central government to provide other social care services, increase the financial support for older people in northern Uganda and expand financial support for those in central Uganda. A local government stakeholder noted:

> Because the money they receive is very little and cannot afford to buy all those things. They should increase to at least 50,000# a month. And that money should come monthly and not wait for five months. The government should take over from caregivers. If the government can plan and build for them houses. Because some of these people do not have houses to sleep, some materials for sleeping like beds, mattresses, and bedsheet, they do not have. (K21-N-LG)

This highlights expectations that government should provide more practical support with accommodation for older people to relieve informal caregivers of some responsibility. The expectation of financial support could be explained by assumptions that older people made contributions to the nation when they were young. A central government respondent stated: *"The expectations or demands of older persons are too high, they expect a lot from government. Since they worked for the government when they were young, they feel that the government should pay back by giving money directly" (K08-C-CG).* These stakeholders perceived this provision of monetary support as an entitlement for older people.

Conversely, the lack of government support influenced some stakeholders in central Uganda to note:

> The government should develop a good system to take care of older adults. It is strange that our area is not getting the money, yet they tell us to register all the elderly persons within the village. The government should be the one to take care of these elderly persons because I believe that it has all the necessary resources. (K13-C-LG)

This perception that the government should provide money to older people in central Uganda and take on caring responsibility was based on the assumption that the government could take on this role. However, findings from the analysed policies and the central government stakeholders repeatedly revealed the government's financial incapacity.

Despite this, the private companies and local government stakeholders also expected the government to provide medical cards for older people and publicly funded geriatric care in each parish. One private company manager noted:

> If the government or well-wishers could come up and put up a geriatric facility with a clinic and care centre, they [older people and care staff] do not have to line up for a long time. Maybe a day-care centre. (K15-C-P)

Stakeholders from private companies, FBOs, local and central government agreed that the government should use existing resources and personnel by equipping village health teams (VHTs) to handle older people's needs. As a central government stakeholder noted:

> The VHTs are an opportunity that as they are providing health services, let them look at the elderly through an inclusive policy to make sure that older persons also benefit from the services. (K08-C-CG)

The VHTs were community volunteers under the Ministry of Health who carried out home visits, followed up of pregnant mothers and newborns, assisted in managing common illnesses and long-term treatment within the community, and practiced and promoted health education (Turinawe et al., 2015). Respondents viewed these teams as human resources that should also made available to meet older people's health and wellbeing needs within their communities. The link and causal pathways between health and social care, whereby improving the health care service access would improve care processes and social care outcomes was evident here.

Stakeholders from the FBOs, local and central government also expected the government to take initiatives to reduce poverty by providing retirement packages, creating income generation activities for caregivers, including older people in village saving groups, and

investing in modern agriculture. By providing this welfare support, older people would be able to meet their care needs. Various stakeholders noted:

> A package should be designed for people retiring from formal and informal work that includes free services and allowances (K08-C-CG). Piggery, ox plough can be given to those caring for them to cultivate and plant for them instead of leaving them without anything (K20-N-FBO). If we could use this land for farming and government improve farming, food will be enough. People will get jobs in the community, increase income, and definitely improve living standards (K18-N-LG). Another service that could improve their lifestyle is VSLAs (village savings and loans associations); they think it is only the active people who can do that. But when they [older people] are brought on board, teaching them how to save their money could improve their lifestyle. (K17-N-LG)

These statements indicate an association between welfare support and access to care services, while the local government and FBO stakeholders in particular highlighted the need to improve caregivers' incomes and formal and informal employment arrangements in order to strengthen the social care system in Uganda. These findings provide evidence of the need for protective or preventative measures to counter the risks and vulnerabilities emphasised in the NSPP. Stakeholders also noticed the existing resources like the land and village saving groups that could be used to support older people.

Stakeholders from the private companies and an international organisation considered the government and NGOs to be responsible for providing education and training to care workers and informal caregivers to solve the human resource challenges and proposed that social care be incorporated into the education curriculum. As a private company stakeholder noted: *"Maybe we involve this social care system in the education curriculum right from junior schools up to university level… We can get trained people in rural areas" (K01-C-P).* This revealed that stakeholders perceived designing traineeships would increase the competence of health personnel in geriatrics and improve social care provision. However, a stakeholder from an international organisation viewed informal caregivers' training as a responsibility of the NGOs, noting *"… the need for CSOs [civil society organisations] to provide knowledge and information to this family and caretaker and to get a program where these caretakers are trained for example according to districts" (K05-C-I).* The expectation of knowledge sharing and transfer to informal caregivers and their traineeship requirements were expected to cover various geographical locations and administrative units.

Besides the NGOs and central government, some local government stakeholders also expected youth, families, clan leaders and communities to participate in social care initiatives.

> The clan leaders should come in to ensure that the family members are not suffering. I know that there are certain rules and regulations in their clans that children have to care for their parents. The communities where our people stay in should also take up responsibility. (K10-N-LG)

The stakeholder perspective here seemed to place greater responsibility back on the families, cultural institutions and community, based on filial piety and culture. Other stakeholders assigned responsibility to the donors, academicians, and researcher. Two local government stakeholders in northern Uganda said that international donors should also share responsibility for social care. As one said, *"The donors should also come up and give their support to these people" (K10-N-LG).* This expectation could be explained by the involvement of foreign donors in providing financial support. One researcher called on academics and other researchers to produce more knowledge and information on social care and ageing, saying, *"Academic institutions, universities and research organisations are quite pertinent to improve our understanding of this phenomenon, to address the issue of social care for older people. If we do not include academicians, we are doing nothing" (K04-C-R).* The provision of research evidence about older people's care needs is regarded as a catalyst in promoting evidence-based practice and increasing responsibility among the families, communities, organisations and governments. It was evident that various stakeholders linked their perception of who should be responsible to the roles actors could play in improving the factors that influence care service provision and addressing challenges in social care service delivery in rural Uganda.

5.6 Discussion

This chapter set out to examine stakeholders' perspectives on responsibility for the social care of older people in rural Uganda. Vulnerability was a key indicator for stakeholders to assume responsibility towards the care needs of older people. However, the findings have also highlighted geographical and care inconsistencies in the social care services provided by stakeholders. These inconsistencies can be explained by underfinancing, limited skill sets and structural challenges that impacted on service provision, leading to care disruptions. This study also indicates that stakeholders held differing expectations of who should be responsible for social care services that were characterised by shifting

responsibility. They also expected government and NGOs to address the barriers in care service provision for older rural populations.

The justification for stakeholders from the public and voluntary sectors in particular to take responsibility for providing social care was influenced by their awareness of the vulnerabilities of rural older people in Uganda. Their motivation for addressing older people's care needs aligned with the findings from my analysis of the relevant policies, including issues of disability, chronic disease and poverty, the lack of informal caregivers and social networks, and age. Similar to gerontological research, older people's demographic and socio-economic characteristics, physical health and disability are presented as essential factors in determining their need for social care (Vlachantoni et al., 2013). These considerations are consistent with the arguments presented by care theorists who position vulnerability as a central concept in the political discourse of care ethics (Engster, 2019; Philip, Rogers, & Weller, 2012; Tronto, 2010). To illustrate this, FBOs often prioritised care for older people without extended families and social networks or skip-generation households (older people looking after grandchildren but with no adult children present) over other demographics. However, stakeholders from the private companies and FBOs withdrew support when family members were able to provide care. Concerningly, this study found that grandchildren were increasingly becoming caregivers for older people in rural Uganda. Hence, the CBOs and FBOs extended their responsibility to meet the needs of orphans and vulnerable children or grandchildren in the care of the older people by either directly or indirectly adopting holistic and family-centred approaches. Previous literature has also recognised the need to focus on grandchildren residing with older people (MGLSD, 2015a; Rutakumwa, Zalwango, Richards, & Seeley, 2015).

Some social care services provided by stakeholders are not traditionally viewed as social care in mainstream literature in the Global North. Although EoC scholars have noted that the connotations and practices of care in the global lobal South are ambivalent (Nguyen et al., 2017), they do not explain those points of ambivalence. This study has highlighted these differences in the conceptualisation of social care. These services include financial support (i.e., other than for care services), community development programs and material support. For example, the SAGE program was largely referred to as a form of financial support by the government, and community development initiatives through programs like NUSAF were directed only to Northern Uganda. These initiatives were provided to empower older

people affected by the historical LRA conflicts to increase household incomes. Such promotion of social care through community development interventions and community rehabilitation, which combines social care and income-generating activities, has been noted by some scholars in Uganda (Bilson et al., 2013). This perception could be explained by the conceptualisation of social care services in the National Social Protection Policy (NSPP) (MGLSD, 2015a) analysed in the previous chapter which, first, clusters social care and social security (where the SAGE program is situated) under social protection. Second, the definition, though it could be viewed as holistic, is rather too broad to include a range of services that protect, provide care to, support, and empower vulnerable people. This implies that the policy frameworks have a great influence on how various organisational stakeholders perceive the social care services for which they assume responsibility.

Irrespective of the different conceptualisations of care services, the social care system also comprises care services referenced in mainstream literature. The institutionalisation of social care regarding care homes is a relatively new phenomenon. This study found that the Uganda government had assumed responsibility for one care home only recently and did not provide home and community-based services. The Nalukolongo care home cited in previous research by Najjumba-Mulindwa (2003) was still operational while the Nkokonjeru Providence Home, identified in the literature to be operating in the study site of Buikwe district, had shifted its focus to orphans and vulnerable children (OVCs). FBOs provided home and community-based care and a residential care home in central Uganda, and pastoral care in both central and northern Uganda. However, with limited coverage by the government, private companies stepped forward to provide some care services for both rural and urban populations.

In relation to attentiveness as an element of EoC, the relationships of stakeholders with care receivers in various institutions influenced the uptake of responsibility. It was evident that the government targeted its citizens, most FBOs targeted their religious congregation and community members and private companies based their responsibility on a client-provider relationship, the continuity of which required paying for services. According to Tronto (2010), care institutions that consider care as a commodity rather than a process are viewed as providing bad care, thus raising questions about the effectiveness of care provision that is left to the market (Tronto, 2013). In this study, private companies seemed to be involved only when families could shoulder financial responsibility. Private companies provided home-based care according to market principles. However, they also relied heavily on

demand and supply mechanisms to deliver only services that could be paid for (Baart, 2016), mainly by adult children. The lack of regulation in care provision sets private companies in a powerful position as price-setters and controllers, which disempowers care consumers who have to negotiate, decline or walk away from services they need but cannot pay for. Moreover, affording marketised care services can be problematic for older rural residents who work mostly in the informal sector, which is characterised by limited incomes. Essentially, children have taken on the responsibility of financing private care. The mention by one private company of adult children who reside overseas paying for home-based care services highlights the impacts of the global care chain, where people from low-income countries go to rich nations for employment (Nguyen et al., 2017). In such cases, care is disrupted as older people are left without family caregivers yet have no public safety net to rely on.

The caregiving capacity or competence of a stakeholder directly influenced the extent of assumed responsibility towards the population, most of which was targeted. In rural Uganda, the element of caregiving was challenged by the financial and human resource incapacity of stakeholders who took on responsibility for social care services. Therefore, care was largely underfunded, which resulted in care disruption. Care funded by well-wishers and congregations in support of FBOs was inconsistent. Similar to previous studies, this study showed that the donation of material support by private corporate companies to support CBOs could be viewed as part of corporate social responsibility (Pype, 2016), but such donations were infrequent. Moreover, the government offered piecemeal food packages, agricultural supplies and ongoing financial support only in northern rural Uganda. The influence of the international political economy through the engagement of foreign donors and organisations indicates influence over some stakeholders' total budgets, such as those of FBOs and central government, which in turn has a large impact on how services are distributed in rural Uganda. For example, the funding from DFID and Irish Aid to sponsor the SAGE program influenced the day-to-day governance of programs that used targeting to establish the beneficiaries reached by the central government and the scope of activities and programs. As a result, some service providers in rural areas, like the CBOs, often discontinued care, and the government-targeted smaller groups of older people (due to budget limitations) led to geographical inequities. Therefore, older people requiring support in rural areas where stakeholders providing care did not operate missed out.

The nature of responsibility that was characterised by standardisation and limited choice of care directly impacted the responsiveness of care. The financial support received from the government was standardised to all beneficiaries and did not consider specific individual needs or the household composition of older people in rural communities. The FBOs and CBOs provided material aid based on the contributions they received, rather than first asking older people how they wanted their needs to be met. This meant that older people had no say in the kind of care services provided to them. If I may expound on this, an example of material aid from CBOs and FBOs, like posho[7], beans and soap might not have been pressing care needs of the older recipients. By not consulting older people about their care needs, these stakeholders claimed to provide care, yet could be viewed as unresponsive to rural older people's care needs. This shows an incomplete consideration of the heterogeneous differences and circumstances that need to be incorporated into funding decisions. Tronto (2010) suggested that caring institutions need to consider older people's sensibilities and real needs.

The elements of solidarity and plurality were influenced by the responsibility held by stakeholders across different sectors. In caring institutions, the element of solidarity and plurality was expected as part of the care phases proposed (Tronto, 2013). However, this research revealed that the stakeholders, including the government and other service providers, held conflicting views regarding social care responsibility for older people. While some from the FBOs and public and private sectors argued that NGOs should have an increased role in care responsibility, government stakeholders called for a multi-stakeholder approach that excluded government from care responsibilities. Gerontologists have criticised such variations in perception for creating contested spaces that impact rural ageing (Skinner & Winterton, 2018), although Tronto (2010) noted that bringing these conflicting views to light was a step towards solving them and shaping better caring institutions. It is under such conditions that care continues to be contested and largely disrupted. Despite these conflicting views regarding care responsibility in rural Uganda, all stakeholders proposed that the government should address the key factors impacting social care services delivery and causing disruptions in care provision. These challenges included the malfunctioning healthcare system, education and workforce training and low incomes. However, some local government and association stakeholders also called for donors, academics, and research engagement to improve social care. No stakeholder in this study

[7] Posho is a food made from maize flour. It is also referred to as ugali in East Africa and sadza in Southern Africa.

explicitly suggested individual responsibility on the part of older people for their own care. This could be attributed to the more substantial reliance on families and informal social networks based on cultural values and that older people requiring care have a limited capacity to meet their care needs.

5.7 Conclusion

This chapter offers significant insights into the stakeholders' perspectives towards social care responsibility and the current social care system for older people in rural Uganda. Seven models of care were identified in this study, including home and community-based care, residential, and material, and financial support in the form of cash transfers and community development. All these care services were inconsistent, limited in scope, unregulated and underfunded, leaving untargeted rural communities excluded from access to social care services. The analysis of these findings through both a critical and ethics-of-care lens associated with the transformative paradigm indicate that taking on responsibility was influenced by attentiveness and competency in stakeholder caregiving. Furthermore, responsibility influenced elements of caregiving, responsiveness and solidarity and care disruption. The findings indicate that these services were provided to vulnerable older people, highlighting the attention to care based on the vulnerability framework and relations, consistent with the EoC theory and the findings from the policy analysis. Furthermore, they also recognise how a variety of factors and moral orientations influenced stakeholders' assumption of responsibility. Despite the formulation of policies at a national level that incorporated social care, this study demonstrates significant limitations in the ability of stakeholders to engage in caregiving, because they were underfinanced, untrained and faced structural challenges leading to care disruptions in social care provision in rural areas of Uganda. Stakeholders held conflicting expectations of who should be responsible for providing social care services for older rural populations, indicating a long distance from solidarity among them. Consequently, older people in rural areas were generally forced to rely on family and social networks for social care and support, which is evident in the micro-level ecological framework. In the next chapter, the experiences of the caregivers in social care provision for older people in rural Uganda are explored.

CHAPTER SIX: VIEWING SOCIAL CARE RESPONSIBILITY THROUGH A CAREGIVER LENS

"There are only four kinds of people in the world - those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers." (Rosalynn Carter)

6.1 Introduction

As demonstrated in chapters Four and Five of this thesis, informal caregivers play an essential role in shaping Uganda's social care system. From an ecological perspective, informal carers are situated in the microsystem, which comprises family, neighbours, extended relations and kin (Keating et al., 2020; Keating & Phillips, 2008). This thesis has so far established the conceptualisation of social care responsibility in national policies and explored responsibility allocation and expectations between different stakeholders in rural Uganda. The previous chapter shed some light on the sort of care services provided to rural older people in the context of limited and inconsistent care provision, and the lack of special consideration for rural areas in both northern and central Uganda, which resulted in most of the caregiving responsibility being devolved to informal caregivers. However, global knowledge on rural caregiver experiences and care practices in developing countries and more specifically, in Uganda, is limited. Therefore, it is important that this chapter focuses on exploring informal caregivers' experiences of responsibility in rural communities and the daily care practices for which they are responsible. Hence, this chapter examines the third research question: what are caregivers' lived experiences in providing social care to older people in rural areas?

To answer the above question, two ethnic groups in rural Uganda — the Luo in the northern region (Akokoro sub-county, Apac district) and the Baganda[8] in the central region (Ngogwe sub-county, Buikwe district) — were selected to consider the cultural and geographical diversity between the two groups. Forty caregivers participated in focus group discussions (FGD) and were asked questions about how they came to assume their caring responsibilities, the care activities and challenges they experiences in caregiving and their

[8] Baganda (plural), Muganda (singular), Luganda (language spoken by Baganda).

coping strategies and expectations. Most carers in both regions were married. The younger caregivers (aged between 18 and 60 years) accounted for 75% of the participants, compared to the 25% of participants aged 61 years and above. Most of the care dyads were characterised by middle-aged carers who were grandchildren (23%), children (23%) or daughters-in-law (18%) of their care recipients, while the older caregivers were mostly spouses (15%). There were multiple carers who attended to more than two care recipients who were either spouses, parents, siblings, or neighbours. Other carers included siblings, hired help[9] or distant relatives. As discussed in the subsequent sections, the caregiver/older person kin relationship was an important consideration for carers in deciding to care for older people.

The findings in this chapter are presented in five sections to reflect the key elements of the EoC framework (Tronto, 2013): responsibility, attentiveness, caregiving, responsiveness and solidarity. The first section presents the activities performed by caregivers who assume responsibility, identifying certain gendered and ethnic differences. The second section demonstrates the attentiveness of carers by exploring their reasons for assuming responsibility. The third section demonstrates the challenges that contributed to a negative caregiving experience across both the Luo and Baganda caregivers resulting in care disruptions, and the coping strategies devised by carers to solve challenges. The fourth section highlights the perceptions about the responsiveness of care provided by informal caregivers. The fifth section reveals caregivers' expectations of the government to implement various strategies to improve social care provision for older people in rural areas.

6.2 Care responsibilities among informal caregivers

Similar to the findings from the policy analysis and stakeholder perspectives described in the previous two chapters, the findings here reveal that the family caregivers viewed themselves as having primary responsibility for care. All caregivers charted the various activities they performed and these were coded into 14 activities (see Table 6.1). Taking into account previous research (Graf, 2008; Pashmdarfard & Azad, 2020; Vlachantoni et al., 2013; Won et al., 2002), these activities were further grouped according to the scales commonly used to assess functional status and care needs in OECD countries, namely the Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs).

[9] These are domestic servants commonly known as house girls, paid to complete domestic chores.

However, some activities performed daily by caregivers in the context of this research differed from those traditionally included in OECD definitions, including digging, tending to animals, fetching water and collecting firewood. Other activities identified include emotional support, which encompassed counselling, giving advice and disclose bad or good news to older people. Companionship involved co-residing with older people in their dwellings at night to support them and visiting or greeting older people. In northern Uganda, resolving conflicts and ensuring the security of older people is regarded as a key component of providing care that may not be observed in other countries, reflecting the concerns people still have about security due to the LRA conflicts (Bird, Higgins, & McKay, 2010). Other forms of support consisted one-off care activities, such as giving walking sticks and a body massage.

The findings also demonstrate that there were both ethnic and gendered differences relating to activities performed by carers. The key activities performed by male caregivers in both regions included farming and tending to animals (20%), and IADLs like transportation to a hospital (15%) and shopping (11%). Across both areas, none of the men assisted older care recipients in ADLs like toileting and feeding, with only 6% indicating that they helped with personal hygiene. Also in both regions, however, women were mainly responsible for fetching water and firewood (17%) and ADLs that included personal hygiene (17%), toileting (12%) and feeding (14%). Women also engaged in the less common IADLs of laundry (9%), using a telephone (4%), home cleaning and maintenance (8%) which are home tasks, compared to men in both study sites. Hence, women were more likely to perform tasks associated with ADLs, care that is mostly performed in the private sphere, while the men more commonly took on responsibilities for IADLs, which entailed care in the public sphere like interacting with health workers in hospital settings, shopping, farming and tending to animals. Both men and women provided emotional support; however, women engaged more in counselling (14%), while men provided more companionship (21%). The other forms of support (11%) provided by men in northern Uganda met pressing demands from older care recipients, which included resolving conflicts, ensuring older people's security, providing walking sticks and giving a body massage. These findings indicate that female participants were more likely to assist with ADLs while male participants regularly assisted with IADLs across both study sites. Prevalent cultural beliefs or customs could explain the cross-cultural, gendered differences in roles and societal expectations held by both the Baganda and Luo in Central and Northern Uganda.

Table 6. 1 Care activities across region and gender ranked from most to least performed

	Apac (Northern)			Buikwe (Central)			Overall	
Care activities	**Female**	**Male**	**Total**	**Female**	**Male**	**Total**	**Female**	**Male**
ADLs								
Personal hygiene	17%	6%	11%	11%	0%	6%	13%	3%
Toileting	12%	0%	5%	0%	0%	0%	4%	0%
Feeding	14%	0%	6%	13%	0%	7%	13%	0%
IADLs								
Shopping	0%	13%	7%	0%	10%	4%	0%	11%
Farming	2%	13%	8%	19%	26%	22%	13%	20%
Administering medication	0%	17%	9%	14%	0%	8%	9%	8%
Transportation	12%	15%	14%	0%	15%	6%	4%	15%
Laundry	7%	0%	3%	9%	3%	7%	9%	2%
Home maintenance and cleaning	0%	8%	4%	7%	0%	4%	5%	3%
Using telephone	0%	0%	0%	4%	0%	2%	2%	0%
Handling finances	0%	2%	1%	0%	0%	0%	0%	1%
Fetching water and firewood	12%	2%	6%	19%	21%	20%	17%	12%
Emotional support								
Counselling	14%	11%	13%	0%	5%	2%	5%	8%
Companionship	5%	2%	3%	5%	21%	12%	5%	12%
Other	5%	11%	8%	0%	0%	0%	2%	5%
Total	100%	100%	100%	100%	100%	100%	100%	100%

In this study, men were still expected to engage in labour work (farming) outside the home and hence possessed the means of transport, while women mostly undertook domestic chores or in gardens next to the homes. In Chapter Two, I noted that the social/relational and historical structures continuously placed caring responsibilities and expectations on girls during childhood, but taught the boys skills, behaviour patterns and responsibilities related to protection and production. These cultural and social structures subsequently influenced how responsibilities were assumed by men and women.

There were also reversed gendered roles in terms of the types of care provided in the two ethnic groups. For example, the Baganda women in central Uganda administered medication, maintained and cleaned the house, while among the Luo people in northern Uganda, the men performed these same tasks. This variation in roles could be explained by the differences in built environment structures. In northern Uganda, the maintenance of older people's huts required grass thatching the roof and smearing of cow dung on the walls.

In central Uganda, where the housing standard was superior, some houses were cemented or covered with mud and required only sweeping or mopping. Another interesting gendered variation related to how modes of transportation shaped caring responsibility and practices. It was evident that none of the women in central Uganda transported older people to the hospital. This could be explained by the presence of motorcycles in central Uganda which were driven only by men, unlike in northern Uganda where bicycles were the main transportation mode and used by both men and women.

Climate and weather conditions also influenced economic and caring activities. Caregivers assisting older people with farming were significantly lower in northern Uganda (8%) compared to central Uganda (22%). This difference could be explained by the wet and dry climate with two rainy seasons in central Uganda, making farming less difficult and able to be managed by women. However, the semi-arid climate, famine and drought affected the northern region, as mentioned by stakeholders in the previous chapter and confirmed by FGD participants in northern Uganda. One female caregiver said, *"The major problem I am facing is that there had been a prolonged drought, so feeding is very hard" (LB-FGD2-Northern-granddaughter).* These variations in weather between geographical locations indicate how environmental factors impact on care practices and shape caregivers' experiences in rural Uganda.

6.3 Reasons for assuming responsibility for caregiving

The findings demonstrate that caregivers from both regions had similar justifications for assuming responsibility for caregiving. These reasons are situated in the first care phase of attentiveness presented by (Tronto, 1993; Tronto, 2013). In this study, informal caregiver's attentiveness to care needs was categorised into the broad reasons of vulnerability and intergenerational solidarity.

6.3.1 Vulnerability experienced by older people

The findings indicate that participation in caregiving was associated with the limitations experienced by older care recipients in their ADLs due to increasing frailty, illness and age. For example, a male caregiver commented, *"Yes, even me, mine is weak; that's why I always dig for her; she has no strength to dig anymore" (OF-FGD1-Northern-neighbour).* Most carers described performing IADLs as daily routines that older people could no longer engage in. A male Luo caregiver to his mother commented, *"I realised that they have many problems, my mother is very old and weak, she is unable to do work on her own, hence I*

could not sit and watch her suffer" (BM-FGD1-Northern-son). Illnesses and crises that older people faced also led family members (and others) to provide care for them. For example, a daughter-in-law described:

> Her legs got sick, and she could not walk for long distances. She could not go through hilly areas to reach the streams, nor to the forest to fetch firewood and animal grass feeds are far away, so you carry them [firewood and animal feeds] and bring them close to her. (NA-FGD3-Central-daughter-in-law)

A Muganda male caregiver to a sibling in central Uganda commented:

> She can no longer help herself; she is frail, not able to walk for long. It worsened when she got that accident when a cow knocked her. So, I decided to care for her even more and making it a lasting tradition of visiting her daily and helping. (WG-FGD4-Central-brother)

Consequently, older people who experienced stressful events, such as physical illnesses, disabilities and decreased mobility prompted carers to assume certain responsibilities.

6.3.2 Intergenerational solidarity

The findings show strong evidence of intergenerational solidarity shaping caregivers' rationale for providing care to older people in rural Uganda. Intergenerational solidarity is *"A model which measures and defines the set of behaviours, attitudes, values and structural arrangements that bind generations"* (Bengtson, 2001; Hodgkin, 2014, p. 55). While Bengtson (2001) conceptualises solidarity across six dimensions, in this study four aspects of solidarity were evident in caregivers' experiences shaping their decisions to provide care. In the next sub-section, I demonstrate how these features of solidarity shaped caregiving experiences and perceived/assumed responsibility.

6.3.2.1 Structural solidarity

Structural solidarity concerns proximity of caregivers to older care recipients, which is seen to either constrain or promote interaction and taking on responsibility. Caregivers who were neighbours mentioned providing care mostly in situations where the next of kin or relatives to the older person was not living nearby. Some carers perceived neighbours as more helpful to them than siblings and other family relations. A female caregiver to multiple care recipients including a mother, aunt, two sisters and a neighbour explained, *"Only the neighbours (provide) support with food. The grandchild can come only once a year. The neighbour who decides to help has to bear the burden" (AG-FGD3-Central-multiple recipients).* This demonstrated that having relations was not conclusive in securing care as care from the grandchildren in this case was disrupted and inconsistent. However, the

concept of presence associated with proximity of relations, either relative or non-relatives and friends, is important in determining how people in the community assume responsibility.

In another example, a male caregiver in central Uganda made reference to a cultural proverb linking proximity and responsibility when he voiced, "'*Omulirwano gwokya bbiri' [the danger or problems at your neighbour's house could also affect you], you find that we send them [older people] some food or firewood" (WG-FGD4-Central-brother).* The proverb cited by this participant emphasised communal support and a cultural belief that if a neighbour in need is not supported, their challenges will affect other people in the neighbourhood. The proximity of the relatives and social networks to the care recipient was also seen to promote caregiving culture. A carer to a grandmother stated, *"I am the only grandchild nearby. When she is sick, and her condition worsens, I make a phone call to my mother" (NS-FGD3-Central-grandchild).* Consequently, the geographical closeness of carers to care recipients was also associated with the assumption of responsibility.

6.3.2.2 Normative solidarity

Normative solidarity was evident through a strong cultural belief associated with the sense of obligation. Adult children and older care recipients expressed normative solidarity through sharing caregiving responsibilities with young grandchildren. In this study, five of nine participants in the male FGD in central Uganda affirmed being involved in such decisions that placed responsibility on children aged between seven and 16 years. A Muganda male respondent caring for his mother explained:

> My mum requested me to send my children to live with her to care for her. They assist with small house chores that neither my mother nor myself could do. They live with her, go to school, and come back to her place. I only help sometimes when they are not there. On Saturday, when they do not go to school, they have to do everything. I take care of the feeding issues if they are not there. (DA-FGD3-Central-son)

This indicates that caregiving undertaken by these young caregivers was performed through a sense of duty and respect to their parents and grandparents, and not necessarily their own choice. The previous chapter noted the reliance on school-aged children to provide caregiving as an alternative to private services. However, even the presence of adult children living near the older people did not warrant direct caregiving by them. These adult children devolved hands-on responsibility to young children to care for their grandparents. While this experience could be interpreted as privileged irresponsibility whereby adult

children (particularly men) are exempted from caring responsibilities, there is strong evidence of consensual solidarity in intergenerational relationships. The desire for intergenerational residency/living arrangements was evident, associated with the longing for older people to have caregivers in proximity.

The findings also demonstrate that the caregiving process was shaped by longstanding norms, taboos and cultural expectations regarding who should engage in a specific task and how it should be undertaken. Scholars have noted that based on cultural beliefs, it is taboo for children to see their parents unclothed (Kyazike, 2016). Daughters-in-law professed taking on the responsibility to support their spouses to care for their parents by performing tasks that children were forbidden to directly undertake. For example, a female caring for her mother-in-law noted, *"I care for my mother-in-law, in a way, I help my husband because he cannot care for his mother in some aspect, like bathing her" (NB-FGD3-Central-daughter-in-law).* However, some participants discussed challenging these cultural norms. For example, one female caregiver in central Uganda caring for her father said:

> You cannot let your parent die because no one can take care of him [due to cultural prohibitions]. I brought him [father] close to my marital home, and my husband built him a small house close by. I do everything for him, bathe and feed him. He is my father; he also took care of me. Even if there is "buko" [palsy], I cannot let him die just because the culture prohibits that. But for me, as a born-again, no cultural rituals should be performed on him or me when he dies, the blood of Jesus washes me. At first, he used to refuse, but I encouraged him that I was his only hope and caregiver. But now he got used to it. (PC-FGD3-Central-daughter)

The participants perceived that not adhering to the cultural norms resulted in negative consequences which they tried to avoid. In this case, a woman caring for her father reveals a concern that seeing his nakedness could result in a medical condition called palsy that involves paralysis and involuntary tremors, and consequently, certain rituals would need to be performed during the burial. However, despite these fears, the absence of other relatives propelled her to be the only caregiver for her father's personal hygiene needs. While other participants saw this decision as conflicting with traditional norms, this carer perceived that her beliefs in Christianity would resolve the conflict as she continued caring for her father. This example shows how traditional norms that shape caregiving were challenged and disrupted by Christian beliefs. Christianity is widespread in Uganda and emphasises the moral obligation to care for everyone in the community without identifying the scope and focus, as seen in cultural rituals around care and relationships (Wardell, 2018). Hence, spirituality, too, shapes the process of assuming responsibility in the caregiving experience. Although both cultural and Christian beliefs promote care, the areas of divergency are

evident in the view of self, rituals and care practices. While Ugandans have cultural identities alongside religious ones, it is evident from the above quote that PC seemed to struggle with finding a comprise between her cultural and religious identities, the identity of being a daughter from a tribe in Buganda required to follow her forefathers' doctrines and the Christian identity of being born again who belonged to a global fellowship of Christ believers. This struggle with care practices was acknowledged in a Uganda Christian care community where Christians identified themselves as "being in the world but not of the world" (Wardell, 2018). Therefore, refusing to follow the cultural traditions can be viewed as rejecting to conform to the standards of this world.

6.3.2.3 Consensual solidarity

Consensual solidarity was shaped through an agreement between older people and their adult children to engage young grandchildren in direct care work for their grandparents. The caregiving culture, its virtues and values passed on across generations over time seemed to influence decisions and choices related to caregiving in this present age. When asked why they provided care, participants revealed that consensual solidarity prevailed through the beliefs and care practices imparted from grandparents to parents and grandchildren. An older male caring for a sibling explained it this way:

> When we were young and growing, we used to see and copied from our parents how they took care of our grandparents which I believe our children will do the same to us because they are also copying from us, seeing how we are taking care of our elders. (BB-FGD1-Northern-brother)

Moreover, carers also expected to receive care from younger generations when they grow older. Participants further indicated that taking responsibility for caring for their relatives was an obligation they were expected to fulfil, and which they expected of themselves. For example, a respondent caring for his mother in central Uganda explained, "*She is my mother. I am supposed to look after her. There is no one else who will come and look after her. It is my responsibility; I cannot just leave her without care."* Therefore, providing care is based on similarities in the values and attitudes about intergenerational solidarity highlighting expectations of filial obligations.

6.3.2.4 Functional solidarity

Functional solidarity shapes the exchange of financial support, gifts of money, advice, older people moving in with carers; hence participants viewed the caregiving process as a rewarding experience. The majority of caregivers viewed their responsibility for care as

being beneficial and a rewarding experience. A caregiver to his mother expressed this notion of reciprocity, noting:

> These are our parents, they gave birth to us and raised us in this village. Some are our sisters, aunts, they have raised us, as years have gone by, it is now our turn to look after them when they can no longer support themselves. (KB-FGD4-Central-son)

Besides providing care based on reciprocity, carers reported that stronger bonds were generated with their care recipients; additionally, they in some cases received financial rewards and advice. The benefits of caregiving were also noted beyond the family boundaries, as community members praised carers. A male carer said:

> [I] have received love and favour from within the community. Everyone in the community praises me for what I am doing, and I feel good about it because I have received blessings already due to those positive tongues talked about me (OF-FGD1-Northern-neighbour).

Caregivers thus received praise and recognition in the community due to their care of older people as they fulfilled cultural and societal expectations. A Luo carer to her grandmother noted, *"I am caring for her to get appreciation from the community because she will be looking healthy and clean" (LT-FGD2-Northern-granddaughter).* The extrinsic rewards associated with appreciation and recognition from the community appeared to motivate carers.

Some Luo caregivers also mentioned receiving financial and material rewards from older care recipients after assuming caring responsibilities. A carer said, *"from the time I started taking care of my father, he paid my school fees, gave me an easy life" (OM-FGD1-Northern-multiple recipients).* Another carer acknowledged they received properties from the care recipient. He noted, *"I have been given plots of land because of being a caregiver. Secondly, I was given cows, so that I could marry, let me say I used it for paying bride price" (BM-FGD1-Northern-son).* This demonstrates that care recipients appreciated their caregivers or felt obligated to offer a financial reward. In another discussion, a caregiver also mentioned receiving daily necessities as a benefit of their caring role: *"the good thing I have got from caring for her, is that when am lacking anything, she gives me if she has, like foodstuff, soap, salt, sugar" (SY-FGD2-Northern-daughter-in-law),* which indicates the interdependencies between caregivers and care recipients.

Caregivers also reported receiving advice, spiritual guidance, knowledge of historical events, counselling and problem-solving strategies from their engagement with older care

recipients. These experiences highlight the positive outcomes of intergenerational solidarity. A participant said, *"we are caring for them because we want their advice and blessings that can help us in the future" (MK-FGD1-Northern-grandson).* Similarly, a Muganda female caregiver of multiple recipients asserted:

> I am thankful that I can experience fellowship with them and talk about God. And they also offer me spiritual guidance; they know historical trends and tell me through stories. When they are in conversation, they speak only good about me, making me happy knowing that they are thankful (AG-FGD3-Central-multiple care recipients).

This finding reinforced the policy findings in the policy chapter that older people were encouraged to engage in intergenerational interactions because they possessed knowledge that could be transferred to younger generations. Furthermore, carers gained more knowledge about caregiving, as mentioned by a respondent, *"it has widened my knowledge on how to take care of any older people."* Older care recipients gave advice and counselling to younger female carers about marriage and avoiding early pregnancies. A female participant mentioned how she was *"offer[ed] guidance and counselling not to be swayed by men, to be patient. She cannot let you go astray" (CZ-FGD3-Central-granddaughter).* Similarly, another Luo female caregiver from the northern region mentioned in relation to her grandmother how *"her loving advice makes me love my husband and family very much since she gave me blessings to stay in a marriage."* These benefits stated by carers indicate that carers mutually benefited from performing caregiving roles, highlighting some of the positive aspects of caregiving.

6.4 Challenges experienced by caregivers

Carers discussed various negative aspects of the caregiving experience (an element of the care phase) and the coping strategies they adopted to minimise care disruptions and any impact on their competency. Some carers dealt with challenging care recipients and roles, financial constraints and structural challenges associated with the poor housing occupied by care recipients, poor roads and inadequate hospital personnel. It was important to note that in northern Uganda, carers were also confronted by drought and famine. Despite these challenges, the findings indicate that carers in both regions were resilient in finding solutions and coping mechanisms to ensure that older people continued to receive care.

6.4.2 Challenging care recipients

Some carers noted the difficulty in handling aggressive care recipients, as a female caregiver to her husband commented, *"sometimes they become aggressive with us, the*

caregivers, so you should know how to handle them" (AS-FGD2-Northern-spouse). Some care recipients were uncooperative when medicines were being administered to them, while attending hospital, and during feeding. Another female caregiver explained, *"Another problem that I find with older people is that they don't want to take medicines. Like mine, you have to talk to her politely or humbly as if you are talking to a child - then finally she will take the medications" (AF-FGD2-Northern-daughter-in-law).* Participants highlighted a range of strategies they adopted, including persuasion, removing themselves from the room, maintaining neutral feelings, and providing emotional support to the care recipient. A Luo female caring for her mother-in-law said:

> When you get to know that she has refused to take medication, give her some time to relax and come back to her after counselling her or talking politely as if you are talking to a child. And you as the caregiver should not be emotional and aggressive towards these older people. Try to apply all the skills to ensure that she accepts taking the medicines and telling her that it is the medicines that will help cure her (AF-FGD2-Northern-daughter-in-law).

This often meant that caregivers were required to undertake complex negotiations to ensure that older people adhered to their medication regimes, resulting in care disruptions. Other carers reflected on the problematic behaviours exhibited by some older people when going to hospital. A male carer stated: *"There are times when these older people refuse to be taken to the hospital, they prefer death. Like mine keeps saying she is tired of living and she has over-burdened me a lot, so she would rather die" (OM-FGD1-Northern-multiple care recipients).*

In explaining to other caregivers in the focus group about management strategies, one female caregiver noted:

> In this situation, if she refuses to be taken to the hospital, you the caregiver can go to the hospital and explain to the doctor the problems she is experiencing, a doctor will prescribe drugs then you will come home and give them to her to take (ON-FGD2-northern-granddaughter).

In exploring these challenges further, other participants said that some of their care recipients refused food:

> Like mine is blind, sometimes she does not want to eat unless I force her, the reason being, she thinks that she will be disturbing me to take her out to relieve herself. Also, sometimes she becomes emotional and refuses to eat the food, I have to beg her slowly until she accepts to eat (DK-FGD2-Northern-daughter-in-law).

This indicates that some older people perceived themselves as a burden to their carers, making it difficult for the caregivers to provide support and presenting challenges, such as having to implore care recipients to eat to ensure their dietary needs were met. Therefore,

caregivers provided considerable care depending on the care recipient's attitudes and extent of care disruption.

6.4.3 Complex roles

Participants also described several burdensome tasks associated with their roles as carers. For example, a female carer noted that older people with urinary and faecal incontinence were difficult to manage:

> Older people fall sick a lot. When they get a cough, it is severe, and if it is the legs, they delay standing up and end up urinating on themselves before reaching the toilet, so you end up having to wash a lot like you are caring for a baby (AG-FGD3-Central-multiple care recipients).

Illness and impaired mobility contributed to functional incontinence where an older person could not reach the toilet in time. In addition, one respondent stated, *"Another problem I am facing is that they defecate and urinate in the house, so it's very hard to go anywhere and leave them alone or with the kids" (LB-FGD2-Northern-granddaughter).* Carers of older people who were incontinent experienced increased frequency in performing tasks like laundry and personal hygiene, bathing the older person, thus restricting the caregiver's social activity and creating negative caregiving experiences. To cope with these challenges, strategies were devised, as one female carer suggested:

> I have to carry and put her on the plastic chair which has a hole in the middle, then guide her to relieve herself while the waste falls in the bucket that has been put under the plastic chair. After she has finished, the caregiver can remove it and pour it into the toilet (AF-FGD2-Northern-daughter-in-law).

The need to lift and carry the care recipient due to limited mobility put a severe physical strain on this carer. The lack of such products as incontinence pads to handle this distressing condition highlighted the complexity of caregiving when assisting with personal hygiene and toileting. Despite these confronting responsibilities, carers were resilient as they improvised with the available resources to manage their care tasks.

6.4.4 Structural challenges

In this study, carers provided care in precarious environments and were challenged by the vulnerabilities associated with living in a rural developing nation. Carers mentioned providing care in very difficult circumstances due to the structural challenges of inadequate health care, housing, transportation, food and water, security and extreme poverty in both study sites and famine and drought in northern Uganda, all of which ultimately disrupted care. The following provides an example of these vulnerabilities:

> Fetching water for them is hard because the borehole is very far, takes you four kilometres to reach the borehole especially when you need clean water for drinking unless you fetch water from the lake, that is when you may not travel a very long distance (OR-FGD1-Northern-son).

Carers linked their personal experiences with poor infrastructure, criticising the government's failure to take responsibility for ensuring basic services and proper funding of services.

Participants adopted various water management and purification tactics to cope with the lack of, and inaccessibility to, clean water due to geographical distance. A male participant caring for his mother noted, *"You may fetch that dirty water and bring it home, but you have to boil and sieve it again, let it cool and then you can pour it into the water pot for drinking or use it for cooking" (BM-FGD1-Northern-son).* Other carers made decisions about the type of water used in different tasks. A male caring for his parent explained, *"We fetch borehole water for drinking while lake water can be used to cook, wash, and bathe, but water has to be used sparingly, so no wasting" (JE-FGD1-Northern-son).* Other carers indicated that sometimes there was no choice in this regard. As a male carer of his grandmother mentioned: *"We use it like that even if it's not clean because there is no other option" (BO-FGD1-Northern-grandson).* The lack of basic amenities like safe water has negative implications for the care of older people in rural Uganda.

The challenges associated with negotiating poor infrastructure related to roads, transport and the health care system during the caregiving process were vividly presented. A female caregiver noted, *"The problem we are getting is that if she gets sick, it's very difficult to take her to the hospital since the roads are in a bad state and getting transport is also hard" (AF-FGD2-Northern-daughter-in-law).* The challenges were compounded when carers took the older people to the hospital and did not receive adequate services. Another female carer said, *"If I take my grandmother to the hospital, nurses don't give her good services. As if she is not important and is not treated kindly like others" (LB-FGD2-Northern-granddaughter).* Participants said they adopted various approaches to deal with poor roads, such as borrowing various forms of transport from neighbours. As a male carer to a grandmother said, *"We always borrow a bicycle or motorbike from neighbours, then I just add fuel in the motorcycle" (MK-FGD1-Northern-grandson).* Another male carer to his grandmother commented, *"I have to carry my patient on my back to cross over bad spots on the road since the road is bad; I do this to avoid my patient adding more problems/injuries" (OD-FGD1-Northern-grandson).* To avoid the inadequacies of

treatment at hospitals or health centres, many caregivers opted for clinics.[10] One female caregiver to her grandmother explained, *"When we have not received treatment, or they may tell us that the drugs are finished, we will take them to the clinic" (LB-FGD2-Northern-granddaughter).* Some carers took on diagnostic roles meant for medical doctors, as a male carer to multiple recipients described, *"If the illness is not a very serious case I may just go and buy medications and bring to her at home" (OM-FGD1-Northern-multiple care recipients).*

Other challenges included the significant demands on carers physically and emotionally, in particular, issues of powerlessness due to circumstances and environmental contexts beyond their control that caused disruption in care. For instance, poor weather conditions resulted in challenges in finding food for older people. A female carer noted, *"Sometimes we dig, but the sunshine affects us badly, causing famine for us" (CC-FGD2-Northern-daughter-in-law).* Carers mostly resorted to feeding older people according to the available food, which impacted on the recipients' nutrition. Moreover, some carers noted having other activities to perform and so could not commit themselves to farming. One female caregiver noted, *"We could think about planting nutritious foods for them. But we are often constrained by other work activities we engage in, yet the older person cannot look after the garden by herself" (AG-FGD3-Central-multiple care recipients).* Similarly, participants drew attention to the housing conditions of older care recipients, which limited carers in performing ADLs like personal hygiene and toileting. Some houses did not have proper toilet structures, as a female caregiver noted, *"the problem we are facing is that there is no proper toilet and bathing shelter" (AS-FGD2-Northern-spouse).* Moreover, some older people lived in poor housing. A male carer to his mother noted, *"We don't have proper shelter for them. It becomes so serious during the rainy season because of the roof leaks" (BM-FGD1-Northern-son).* To solve this issue, another Luo male caregiver to a sibling shared, *"I request neighbours to collect for me spear grass and use it for repairing the spots on the roof that leak because if not, she will cry for you till morning and you the caregiver can never fall asleep" (BB-FGD1-Northern-sibling).* Participants seemed to use their social capital in the community and deployed collective strategies in solving housing problems. Despite attempts to solve this challenge, caregivers in northern Uganda were often unable to resource grass to thatch these roofs, creating insecurity for older people.

[10] Clinics focus on outpatients and are privately managed.

6.4.5 Sexual abuse of older people

Older people living in the poorer areas of Luo live in insecure housing. Participants highlighted that this leaves some older women vulnerable to sexual assault and carers feeling helpless to prevent it. The following two quotes from a female caregiver capture this extreme vulnerability: *"The government should put up permanent rooms, even if one room, each because there is no grass, and we are witnessing these older women being raped by young boys who are drug addicts because the houses in which they sleep are frail" (ON-FGD2-Northern-granddaughter)."These boys after raping the older ladies they run away, and as you know these ladies are weak and cannot make an alarm, cannot even recognise the rapist. The case is never solved" (LB-FGD2-Northern-granddaughter).* The caregivers drew attention to the lack of government intervention in protecting these older women, highlighting that the perpetrators were not arrested for acts of sexual assault. Even older people not living in intergenerational living arrangements are assaulted, exposing gaps in the legal system.

6.4.6 Financial constraints

Financial constraints severely impacted the effectiveness of caregivers in getting treatment for, feeding and transporting older care recipients to the hospital. A female carer reported:

> Caring for some is challenging because of the lack of money. They [older people] may not get the necessary treatment when they are sick. Their diseases are not easily treated nor get adequate treatment. The situation we are currently in hinders our capacity to give them good food as we would have desired to feed them (AG-FGD3-Central-multiple care recipients).

A male carer noted, *"We have low incomes. You may want to care for them better but find that you also do not have the money to solve their problems" (WF-FGD4-Central-son).* This seemed to be more prevalent among northern Ugandan participants, as the government had imposed limitations on their sources of income. A male carer to his grandmother asserted:

> There were certain resources that we used to depend on, but these days they have lost value, like charcoal burning, which used to help us a lot. Still, these days, the Ugandan law does not permit this, and if you are found cutting trees for charcoal burning, they arrest you, which was one way we used to get money for treating these people (BO-FGD1-Northern-grandson).

Besides charcoal burning, fishing was another source of income; however, this was also problematic, as a male carer to his mother noted:

> Another source of income used to be fishing but now they stopped us and it is the soldiers guarding the lake. When you are found fishing, they beat you to death, I

> bear witness, go there right now you will find dead bodies floating on water. This has brought the fear of being killed and yet fishing used to earn us a lot (BM-FGD1-Northern-son).

Moreover, as described in previous chapters, cash transfers issued by government through the SAGE program were inconsistent and care therefore disrupted, as a male carer to his grandmother explained:

> The reason as to why it is a challenge to take care of these people is because the SAGE money delays up to six months, yet to us, we also do not have money that can help solve their problems. If this money was enough to support them, then taking care of them would be easy. (BO-FGD1-Northern-grandson)

This lack of financial capacity to meet older people's needs took a heavy toll on caregivers emotionally. A female carer to her father noted, *"If you do not have anything to give to the older person, you are also disheartened" (PC-FGD3-Central-daughter).*

Consequently, when questioned on how they coped with financial limitations, carers noted various strategies. A male carer to his grandfather said, *"You need to pick some beans or maize cones and sell them, then use the money for taking them to the hospital" (MKB-FGD1-Central-grandson).* While some carers reported borrowing money from neighbours, others sold off some animals and land when trips to the hospital were required for "serious illness". A male carer to his father in northern Uganda said, *"If the condition is so hard and serious, you can sell a plot of land and use the money for taking the patient to the hospital. You can go to Aduku H/CIV /Lira referral or Kampala at Mulago hospital"* (OR-FGD1-Northern-son). The decision to sell care recipients' properties to raise money to meet the transportation costs to hospitals in different geographic locations and user fees at the hospital was based on the caregiver's subjective perception of which illnesses were serious. Similarly, a male carer to his mother noted, *"If it is not serious, you may sell goats or chicken. But if it is extremely complicated you will sell 5-10 cows, then you use it for taking her to the hospital" (BM-FGD1-Northern-son).*

In the absence of assets to sell, the financial responsibility rested on the family caregivers. In central Uganda, a Muganda female carer to multiple recipients reported, *"I have to sacrifice the little [money] so that my father can also get something to eat."* Similarly, another male carer to his mother said, *"I always go and dig people's gardens and get paid so that will be the money I can use for taking her to the hospital" (JE-FGD1-Northern-son).* The adoption of various coping mechanisms portrays caregivers as active problem solvers who took the initiative and made continued affirmative choices to fulfil their

responsibilities by addressing instances of care disruption. However, the coping strategies were not sufficient to meet older people's care needs, thus impacting the element of responsiveness. The depletion of financial resources of either the caregiver or older care recipient was very evident in the caregiving process.

6.4.7 Limited formal support

Besides taking on daily caring responsibilities to their own relatives, the caregiving role extended to other older people as part of carers' roles in the church. There were examples in the data of solidarity between FBOs and community members to support older people, as evidenced in the following quote:

> As Catholics, we had some older people we assisted, bought for them some soap, harvest cassava, and gave them food, but some older people used to annoy us and sell them and buy alcohol, so people lost morale. You can buy a tablet of soap, half a kilogram of posho [maize/ cornmeal] and sugar. There is no particular program we follow. Only when we are able to support, only being thoughtful and charitable. (AG-FGD3-Central-multiple recipients)

This showed that the responses of some older people to the shared care resources provided by the FBOs and community members limited this commitment and contributed to inconsistencies in support and hence care disruption. In other instances, where support was purely from FBOs, participants emphasised that material support was disorganised and irregular. In the male focus group, respondents discussed care provided for Muslim groups. For example, a respondent commented, *"Uganda Muslim supreme council sent clothes, sugar, especially during fasting, they give us posho. They give us, the 'Imams', a cow to share with our friends" (MD-FGD4-Central-son).* Another carer clarified that this support was received only during religious fasts, adding, *"Those usually come only during fasting" (KB-FGD4-Central-son).* Consequently, this material support was inconsistently provided and dependent on available resources.

In Northern Uganda, the central government's provision of cash transfers was viewed as the most significant secondary support for older people that eased the informal caregiving burden. When asked about other actors that assisted caregivers, a female caregiver noted in relation to the Social Assistance Grant for Empowerment [SAGE]: *"They help us in giving them [older people] money to make their lives easy by changing their diet, making them clean [buying soap] and happy. There is no other organisation" (AF-FGD2-N-daughter-in-law).* However, the support received from the government (cash transfers) in northern Uganda and faith-based groups (material support) in central Uganda did not provide support

with ADLs, IADLs or emotional support to older people. This indicates that these tasks were left to informal caregivers, who were often left with no alternative but to meet older people's care needs. In central Uganda, a female caregiver to a neighbour said, *"The central government has not assisted older people in any way" (AG-FGD3-Central-multiple recipients).* This quote validates the findings presented by stakeholders in the previous chapter about geographical inconsistencies and the care disruptions emerging from shifting responsibility and incompetencies among stakeholders.

6.5 Responsibility and responsiveness to care by older people

Across the data, there were several examples of carers feeling that the care they were providing was not always appreciated, resulting in heightened risks of carer burnout. In relation to the care phase of responsiveness (Tronto, 2013), care providers reported that some care recipients were unappreciative of their efforts and assistance. This was expressed by one carer as follows: *"They are the most ungrateful people on this earth. You have to find out what she likes or does not like patiently" (CZ-FGD3-central-granddaughter).* Another respondent said, *"My husband is old, and he is so unappreciative. If you do not give him food in time, he will refuse to eat it and rejects it" (FB-FGD3-central-spouse).* This responsive behaviour can be seen to shape the caregiving experience where caregivers become more attentive to the time parameters while performing caregiving tasks to ensure that older people do not refuse care. According to a Muganda male caregiver to a neighbour in the central region, *"They [older people] have unending problems. You could be having your own problems, but their hope is to solve their problems when they come to you. And yet you are unable to solve them, and they term it as disobedience" (SL-FGD4-central-neighbour).* Some caregivers thus perceived a lack of consideration by care recipients of their individual needs. These statements also show the caregiver vulnerabilities and pressures associated with the disparity between caregiving tasks and recipient expectations.

Discussion across all focus groups associated the vulnerability and dependency of older people to that of children. This was directly linked with cognitive decline, and increased difficulties in feeding, bathing and toileting. One female carer said, *"You should continue struggling with her just the way you can take care of a child" (LB-FGD2-Northern-granddaughter).* Several participants used the expression *"treat them like children"* as a coping mechanism to manage the physical and functional decline. For instance, one carer noted, *"My mother has really grown old. She is in 'reserve years', she cannot do anything,*

and can no longer move. She is just there, so I have to care" (MD-FGD4-central-son). In these contexts, disruption to care was evident, with carers highlighting heightened carer tasks that left them frustrated and challenged in their day-to-day caregiving. At the same time, these coping strategies illuminated the moral quality of patience that caregivers exercised towards older people.

6.6 Caregiver expectations of social care responsibility

In relation to the element of solidarity (Tronto, 2013), people and entities that assume responsibility are expected to continue providing care that results in trust and solidarity in care recipients. Collectively, the caregivers shared the belief that the government had abandoned them and the older people they were caring for. They had several suggestions about where government could step in and take greater responsibility. Similar to the findings from other stakeholders, caregivers recommended that government should provide public goods as a strategy for improving social care provision. However, unlike some stakeholders who expected NGOs to take up responsibility while exempting the government from responsibility, caregivers in both rural regions expected government to provide and increase financial support. These expectations were clearly associated with the increasing inadequacy of their coping strategies to mitigate the negative effects of the limited resources available to them in fulfilling their responsibilities.

6.6.2 Addressing structural challenges

To mitigate the issue of famine and drought, caregivers suggested the introduction of modernised farming procedures. A female carer noted:

> The resource we have is land all right, but I wish the government could introduce to us animal traction or re-stocking. We the caregivers, together with older people, would benefit from this system hence improving on social care because much as there is plenty of land, we lack modern methods of farming like irrigation, and that is why our crops do not yield to the expectation. I wish we had modern garden tools and specific cows that can produce milk, because this would improve our lives and older people's lives (AF-FGD2-Northern-daughter-in-law).

In relation to water shortages, caregivers suggested water harvesting as a possible solution that required government intervention. While one female carer said, *"The government should provide clean water for drinking by drilling more boreholes" (DK-FGD2-Northern-daughter-in-law),* another female carer said, *"Water for those older people, building water tanks can help, and they can help themselves if they are alone" (AG-FDG3-Central-multiple care recipients).*

Regarding inaccessibility to hospitals, caregivers in both study sites raised the proposition of running medical camps in the rural communities, as a female carer noted:

> For the hospital, I suggest that outreach should be conducted in the community where the older people can receive all the necessary services instead of going to the hospital and coming back without any assistance rendered to them after spending their time for almost one full day. I wish they would train some medical people who could strictly be monitoring the older people since the VHTs that we have are specialised only in children. The health workers should be trained on how important older people are, and they have to take everyone equally (LB-FGD2-Northern-granddaughter).

The view was that outreach and medical camps could reduce medical costs and reduce the long journeys between health centres and homes. Participants also called for equal treatment of older people in the health care system, which would improve the experiences of both caregivers and older people in hospitals.

6.6.3 Caregiver projects and support

Participants reported the establishment of caregiver income-generating projects in both regions as viable initiatives that could address financial constraints and improve the incomes of both carers and older people. A male carer said, *"The government should open for us projects that can help us facilitate our older ones" (OD-FGD1-Northern-grandson).* Another male carer to his mother in northern Uganda said:

> They can open up poultry projects or goat keeping that will help facilitate the older people's needs. If the project materialises, what is picked and sold can be used to pay medical bills, buy food, clothes etc. for the older people (BM-FGD1-Northern-son).

Participants suggested income-generating activities that could directly support carers in rural communities, especially those that revolved around agriculture and trading. They recommended that government could provide the start-up kits for these businesses.

6.6.4 Increased formal support

Participants requested an increase in formal support in northern Uganda and its provision in central Uganda to solve the challenge of limited informal and formal support. As a female carer commented:

> We take care of older ones and know what can be enough since the money takes like three months without coming, it should be doubled. Each older person should be getting UGX 50,000, such that if it delays up to three months, the expected amount to be received is UGX 150,000. This has more weight in the sense that one can buy goats, cows and chicken, and can help to buy beef or fish for them to eat as a diet because their body needs this (AF-FGD2-Northern-granddaughter).

Participants perceived the current cash transfer contributions to be relatively low, hence they argued for the government to reconsider the amount given to older people in northern Uganda. In central Uganda, a female carer to a paternal aunt challenged this expectation by stating, *"The government promises us, but only chooses other places. I wonder what is wrong with this place; it is never favoured. We elected poorly" (NF-FGD3-Central-Niece).* To some participants, the government's inaction in meeting these needs was political and created geographical inequities in aged care provision. Moreover, as a female carer to her father noted, *"Government can identify the number of older people [and] can give us food support for the older people and provide each older person with a wheelchair that can help them move on their own to relieve themselves" (PC-FGD3-Central-daughter).* These participants expected that government would contribute material support like food and wheelchairs to older people, based on the perception that these items would ease the financial pressure experienced by carers and promote older people's independence with increased mobility.

6.6.5 Expectations bestowed on the researcher

Some caregivers had expectations that the researcher would play an important role in ensuring that their challenges were solved. For example, a female caregiver to a paternal aunt said, *"Just as you have called us, you are more knowledgeable and can decide for us what we can do to help us and support our older people" (NF-FGD3-Central-Niece).* This quote indicated a perception of the researcher as an influential person who could advocate for their needs to be heard. Similarly, in northern Uganda, participants expected the research team to instruct older people about maintaining personal hygiene. A female caregiver commented:

> Also, older people should be trained in maintaining their hygiene, as you have come like this. There was a need to gather them together, and you advise them to try to keep their body clean rather than giving up in maintaining personal hygiene so early when they are still able to bathe, wash, cook (DK-FGD2-Northern-daughter-in-law).

This demonstrated some limited agency of caregivers in solving these challenges and reliance on experts was evident. However, this proposed training was suggested for the older people themselves rather than them, the family caregivers, which indicated their desire for older people to be more self-reliant in performing ADLs.

6.7 Discussion

The investigation in this chapter of caregivers' lived experiences among the Luo in rural northern Uganda and the Baganda in rural central Uganda has contributed to our understanding of the complexities surrounding caregivers assuming responsibility and their expectations of who should be responsible. The findings provide a vivid illustration of caregiving tasks that extend beyond western classifications of ADLs and IADLs to more physical and demanding tasks associated with farming and tending to animals and fetching wood and water. Thus, caregivers in rural Uganda face more compelling pressures that ultimately take a physical toll, as illustrated in mostly male caregivers physically carrying their older people to health care services in precarious circumstances. The task of meal preparation, usually undertaken by women, requires carers to engage in physically draining tasks like collecting firewood and fetching water, often walking more than five kilometres. This picture is in stark contrast to the western context, where activities around nutritional needs of care recipients are met by shopping in a supermarket and cooking/meal preparation may be supported by using a microwave to warm ready-made meals (Hestevik, Molin, Debesay, Bergland, & Bye, 2020). This study, therefore, highlights the inadequacies of definitions of IADLs and ADLs when applied to caregiving in developing nations and the application of EoC to consider the precarious circumstances in which caregiving takes place.

Between the Luo and Baganda ethnic groups, responsibility was greatly influenced by cultural aspects of caregiving, highlighting the gendered roles in performing care tasks. The gendered roles were evident across both regions, as women primarily assisted with such ADLs as feeding, toileting and personal hygiene, and such IADLs as laundry, home cleaning and maintenance. Moreover, some carers who undertook demanding caregiving roles (personal hygiene, toileting and feeding) experienced caregiver burnout. Applying an EoC perspective to analyse caring masculinities validated that men care, and that caring masculinity can possibly disrupt hegemonic views of masculinity. Men in both ethnic groups mostly performed IADLs like transportation to a hospital, shopping, and farming. According to Tronto, men are often relieved of household chores due to their perceived role in protection and production. Similarly, care theorists have noted that men's responsibility is often expressed by *caring about* someone, while women take on the responsibilities of *caring for* someone (Rummery & Fine, 2012). In applying EoC theory to this cultural context there was evidence of highly gendered roles, seemingly untransferable, particularly

transportation, as women do not ride motorcycles, a factor of production predominantly possessed by men rather than women.

The cultural context further added to gender dualisms with examples presented of privileged irresponsibility. A Muganda scholar has noted that this privileged position is assigned to boys at birth, who are preordained to inherit political and social authority, while girls are looked at as material properties (Kiyimba, 2005). The engagement of young caregivers (aged 7-16 years) established interdependencies with their grandparents and obedience to their fathers, limiting these carers' choices and autonomy. Previous research shows that children and young carers across the Middle East and sub-Saharan Africa engaged in specific caring roles determined by their local contexts (Leu & Becker, 2017). However, these school-aged children endured their caregiving in conditions of extreme poverty, inadequate housing, food insecurity and having to walk long distances to fetch water and firewood to strengthen family solidarity.

Investigating why informal caregivers take on this responsibility contributes to our understanding of how the attentiveness (the first element of EoC) of informal caregivers to the care needs of older people in rural Uganda shapes responsibility (the second element of EoC) in the private sphere. The findings provide strong evidence of vulnerability and intergenerational solidarity as normative assumptions around who should provide care. The care processes were heightened when dealing with increased dependence and vulnerability due to frailty, incontinence, illness and cognitive decline into “children” (Hockey & James, 1995). Some carers discussed using techniques employed with children. This notion is evident in Luganda, a language in central Uganda where a saying, *“bw’okula odda buto"* (as people tend to grow older, they start acting childishly), is commonly used in daily conversations. This demonstrates how socio-linguistic cultural representations impact people’s views of older people (Twigg & Martin, 2014). Notions of responsibility can be viewed through the lens of intergenerational solidarity theory, reinforced by cultural norms, reciprocity, Obuntu principles and societal expectations. The element of proximity was important, as most support in ADLs required a carer to live close by or in shared housing arrangements. Care theorists say that care is contextual, and humans exhibit caring behaviours towards those around them (Tronto, 2017). Informal caregivers in this study were mostly children, spouses, grandchildren and daughters-in-law. This finding agrees with the notion that responsibility is self-evident in relationships that are perceived as valuable (Collins, 2015) and that the caregiving experience is shaped by caregiver-care

recipient relationships and family dynamics, as well as social, economic, environmental and historical factors (Keating & Phillips, 2008). Care theorists acknowledge that these situational factors influence some people to feel more obligated to take on care responsibilities than others (Engster, 2007).

Examining the challenges carers face in taking on responsibility enriches our understanding of the complexity of informal caregiving practices and the competency (the third element of EoC) of informal caregivers in a rural area of a low-income country in sub-Saharan Africa. The uptake and continuity of responsibility and caregiving was constrained by poor socio-economic and environmental contexts and a lack of public services that resulted in in care disruptions. Some caregiving processes took place in insecure physical environments (Menec et al., 2015). Moreover, the health conditions and environmental factors that significantly affected urinary incontinence (Davis, Wyman, Gubitosa, & Pretty, 2020), though identified in this study, seemed to remain unresolved. The care environment in the study locations was problematic for both caregivers and care recipients. For example, the illustrations of insecure housing described in this chapter contributed to incidences of sexual assault on older women.

Findings from the current study illustrate how the element of responsibility influenced continuous attentiveness of carers who yet demonstrated resilience in addressing disruptions and limitations experienced in care provision. Resilience theory in critical gerontology and social work promotes resilience through coping strategies in difficult situations (Wild et al., 2013) and using community capital (Sapountzaki, 2007, 2012). In the present study, however, there were instances where coping strategies negatively affected caregiving and responsiveness to older people's care needs in rural communities, for example, the purchasing of unprescribed medications for older people by carers to cope with care recipients who refused or found it difficult to take medication or go to hospital. In some cultures, there is a reluctance on the part of families to discuss their family members' illnesses, preferring instead for fate to take its course and reduce confrontation with a poor prognosis of illness or with the likelihood of death (Surbone & Baider, 2013). This potentially poses a threat to older people's health and the continued existence of undiagnosed health conditions among rural older people. Similarly, among some carers, the inaction in improving the water quality before consumption and water shortage put older people at risk of non-communicable diseases, threatening their health further (Mushavi et al., 2020).

Regarding competence, the financial incapacity of informal caregivers often disrupted care provision, influencing the extent to which they could assume or continue in their care responsibilities. While Erhard (2019) noted that the financial capacity of care recipients and caregivers shapes daily caregiving experiences in family care provision, the cases of financial inability were extreme in this study, delaying care provision. The examples provided of selling off properties, land and animals prompted care disruptions as finances had to be acquired before care could be continued. Moreover, this appeared to exacerbate poverty as financial capital was depleted, resulting in unresponsiveness to care needs. In the absence of or limitations in financial assistance from the government, caregivers had to provide both hands-on care and financial assistance. In situations where carers took on casual work to obtain money to meet caring demands, some older rural people were left without adequate care, particularly older people who relied on carers who were providing care to multiple recipients, as the closest kin were prioritised.

The responsibility taken on by informal caregivers can be seen to shape their perceptions towards the element of solidarity. It was evident that improving care for older people at the micro level required structural solutions to improve the welfare of carers. Caregivers in both central and northern Uganda expected the government to take on primary responsibility for social care. This expectation indicated that informal caregivers had an understanding that the government was a key actor in social care provision, but not in relation to collaboration. Caring with solidarity, trust and plurality are essential in the care phases (Tronto, 2013). However, this is unlikely in Uganda given that the policy and practice approaches already discussed in previous chapters ultimately result in care being devolved to families. That said, the expectations presented by caregivers indicate their preferences in how care should be provided for rural older people and the possible ways that government can assist caregivers in fulfilling their responsibilities despite shortages in public resources and disruptions in care.

6.8 Conclusion

This chapter demonstrates that applying the ethics of care to a rural developing country context with a weak welfare system that places primary responsibility on families means that care disruptions and a variety of cultural and gendered care practices that are not commonly evident in developed countries have to be considered. This study has shown that intergenerational solidarity influences the attentiveness of caregivers and families, and

consequently its role in taking on responsibility and shaping the caregiving process is still strong. The cultural aspects of caregiving greatly influenced who took on responsibility in performing various caring tasks. The culture of responsibility towards older relatives seemed to further solidarity between FBOs and carers in supporting older people in the community, some of whom provided care to multiple care recipients. However, caregivers experience socio-economic and environmental constraints that cause disruptions in the provision of IADLs and interruption of timing of care, as carers are constrained in providing that care. Hence care disruptions impacted on responsibility, particularly in situations that required change in informal caregivers in rural Uganda. Although the caregivers in rural areas were resilient in solving and coping with various challenges and disruptions in care, their strategies also had negative implications for older people in these communities. It is evident that informal caregivers expect government to take on more responsibility in caring for older people, provide public resources and meet caregivers' needs to improve the social care system. In the next chapter, older people's perceptions of responsibilities and responsiveness to care provided in both formal and informal settings are explored through older people's experiences in receiving care.

CHAPTER SEVEN: SOCIAL CARE RESPONSIBILITY THROUGH AN OLDER PERSON'S LENS

> *A society that does not value its older people denies its roots and endangers its future. Let us strive to enhance their capacity to support themselves for as long as possible and, when they cannot do so anymore, to care for them. (*Nelson Mandela)

7.1 Introduction

The previous three chapters highlighted Uganda's ineffectual policy direction in relation to social care for older people, characterised by limited government funding and inequitable distribution of government programs. Consequently, stakeholders from FBOs and private organisations assumed responsibility, but only inconsistently. Moreover, with limited financing capacities and skill sets among stakeholders, responsibility for care fell largely on families. The previous chapters also identified numerous issues that exacerbated older people's vulnerability in rural settings, including inadequate health care, housing, transportation, food and water, security, sexual violence, extreme poverty in both study sites and famine and drought in northern Uganda. These issues simultaneously foster and disrupt care responsibilities among informal caregivers.

From an ecological perspective, the exploration of the individual level is important because macro-level changes are considered to impact an individual's ability to acquire informal care and enhance our understanding of why the number of older people requiring care will increase in the future (van Groenou & De Boer, 2016). Moreover, older people are viewed as human beings that hold a range of subjective perceptions about the experiences of the care they receive (Estes, 2019). These experiences are often ritualised and embedded in intermediate physical and social environments (Meiers & Tomlinson, 2003). Therefore, the perspectives of older people about who is rand who should be responsible for social care are embedded and shaped by their lived care experiences. This chapter addresses research question four: *What are the lived experiences of older people in receiving social care in rural Uganda.* Tronto's (2013) ethics-of-care phases were used as the analytical tool to explore the experiences and expectations of responsibility in this study.

To answer this research question, the research assistant and I interviewed 19 older people, including 10 in northern Uganda and nine in central Uganda. 15 participants were women, while four respondents were male. 14 participants had completed no formal education, while five participants had completed primary level education. 15 participants were widowed, and only two participants were married. 17 participants co-resided with other family relations, most of whom were grandchildren. Six participants were Bagishu, who had migrated from Mbale district in Eastern Uganda, which demonstrated that rural-to-rural migration contributed to the cross-cultural diversity of the study sites.

7.2 Care recipients' experiences of responsibility

7.2.1 Individual responsibility for care

Several examples in the findings highlighted that older people could take on varying degrees of responsibility for their own care. Most older participants continued to undertake self-care like bathing and toileting, as they thought it inappropriate for some caregivers to support them with these activities. For instance, one participant, Kalema, disengaged from meal preparation, a strenuous task that required fetching water and firewood and digging. He noted, *"I still must bathe myself. I cannot tell this lady to help me. She only helps me with feeding and communicating with my grandchildren" (Kalema-male-83years-central).* Some older people also adjusted by engaging in activities periodically to assist their caregivers in raising some income and minimising a sedentary lifestyle. For example, Apiyo noted, *"I also dig a little with her [daughter-in-law]. I do not like every single work to be done for me. I do not just sit and wait, but I also dig people's gardens to raise money. Digging helps to exercise my muscles" (Apiyo-female-70years-northern).*

However, participants identified a number of macro-level factors that disrupted their ability to care for themselves. Participants said the lack of public services disrupted their ability to maintain their independence. For example, the poor road transportation system negatively impacted rural older people's access to the hospital. Awor noted, *"There is always [a] transport problem when trying to seek medical help. Unless you hire a motorbike you will not get access to the hospital" (Awor-female-80years-northern).* Furthermore, the poor transport system constrained affordability, availability and access to safe water, resulting in delayed fulfilment of care activities. Ojara noted:

> Roads need to be reconstructed because they are very bad, even currently there is no water, we have only one borehole. This affects our daily activities, making us fail to perform them. Water is limited. For the case of water, we spend long hours

> and at times, we sleep at the borehole, so it affects my daily activities, for example, delays in cooking and washing. (Ojara-male-78years-northern)

Besides the poor transportation system, the health care system was equally concerning for older people in rural areas. Unfortunately, all respondents who had untreated illnesses declared they had had an unsatisfactory interface with the health care system. For example, Namusisi, who had pain in the legs, arms and back and cough, stated, *"It has lasted about ten years now when am in pain. I have been getting medicine but not noticed any change" (Namusisi-female-64years-central).* Respondents indicate using coping strategies to manage the symptoms. Elem, who had a swollen throat, explained:

> I was referred to the main hospital, but they gave some treatment of drugs and injections and my throat reduced in swelling. But it is still very painful from the inside because it has wounds. This problem needs medical treatment. There is no money, but my son keeps buying medications from the clinic. (Elem-female-68years-northern)

This quote indicates that some participants had a limited understanding of their diseases and limited financial capacity to access comprehensive medical treatment.

Also due to the poor health care system, this analysis revealed increased helplessness on the part of some participants. Watuwa remarked, *"Based on the fact that I am sick, I am thinking of dying. No, there is nothing I have liked about ageing. My life got ruined after I fell, and my legs got injured" (Watuwa-male-89years-central).* Watuwa did not see any purpose in life as death was approaching. Some participants also said that the care provided was insufficient to deal with more challenging medical care needs. For example, Kalema said:

> I have toothaches on one side, four teeth on another, almost all of them. I feel pain in my body. But when someone gives support and some food, they cannot solve these internal problems, and you remain in pain because of the illnesses. It has been 10 years since the condition of hands shaking started, I cannot hold anything, although I may look strong (Kalema-male-83years-central).

Participants had come to terms with their challenging life conditions, holding the view that the care experience could not solve their illness and some were expecting to die soon. These participants felt hopeless about their self-care, the care processes, and their heightened need for care due to their progressive illnesses over which they had no control.

Participants further revealed that environmental factors related to drought and famine had inhibited them from assuming responsibility for their feeding due to limited access to food

and water and increasing poverty. Aryemo commented, *"I find many limitations due to prolonged drought this year that has caused famine for people in the community. I have nothing to cook for my children; it's a struggle to get what to eat in this community" (Aryemo-female-63years-northern).* Furthermore, due to prolonged dry spells and arid weather conditions, older people had difficulty in obtaining safe water for consumption. Adong said, *"Water is a problem because it is far. During the dry season, it is worse since many water sources get dried up. You get a long queue of jerricans without minding of elders" (Adong-female-78years-northern).* Coupled with water scarcity was the long distances that older people and their carers had to travel in search of water.

Besides the drought and famine, the government's restrictions relating to fishing activities in Apac district negatively impacted community livelihoods and older people even further. Aryemo noted:

> They [the government] have stopped people from fishing. When they find anybody fishing, they arrest and torture you badly. The government stopped people from fishing because of poor methods they were using as in catching young and matured fish leaving the lake with almost nothing, they will resume with time. Still, we do not know when that can happen. This has brought many financial problems because a third of the population depended on fishing. (Aryemo-female-63years-northern)

Participants revealed that without an alternative source of income, the fishing ban increased financial insecurities for older people. The combination of environmental factors and government directives affecting fishing activities resulted in food insecurity and starvation in northern Uganda. Despite many older people attempting to dig, some participants noted challenges in meeting their dietary needs. Some older people had only two meals a day and went to sleet hungry. As Awor noted, *"There are hunger and famine. It's not easy to afford daily meals, and for me, I eat only twice a day" (Awor-female-80years-northern).* Alum added, *"Feeding is the most difficult thing to get in life and I am not able to afford three meals a day, like now that I have eaten; I have to wait till another meal is got" (Alum-female-70years-northern).* The socio-economic status of older people was noted as a limitation to their ability to take responsibility for their own care.

7.2.1.1 Care responsibility towards grandchildren

Despite the challenges of inadequate care, as discussed above, older people also had responsibilities to care for grandchildren, neighbours and spouses in both the study sites in rural Uganda. Participants discussed taking on these obligations in exceptional

circumstances due to a skip-generation (where older people's children died of HIV/AIDS in central Uganda or were killed in the LRA conflicts in northern Uganda). For example, Nandutu, who had lost nine of her 12 children, said she had the sole responsibility for six orphaned grandchildren:

> Most of my children have died. I am here just taking care of the grandchildren and paying their school fees, and feed them. I had many children, but they would get ill for a very short time and die. I must raise these grandchildren; my arms and legs can become paralysed, and I have a backache. The grandchildren cry for money for school fees, yet my remaining children also have their children to look after. It is about being strong. When I leave this world, they will fend for themselves. (Nandutu-female-72years-central)

Indeed, 10 of the 19 older people had to take on the care of grandchildren due to their own adult children's death. Some of these participants had little ability to care for themselves, implying that their care was continually disrupted. For instance, Bilal said, *"I am very weak such that sometimes when I start doing my work, I get too tired, sometimes I feel a little paralysed, that makes me very weak and unable to cook for my grandchildren"* (Bilal-female-82years-northern). Moreover, older people often deprived themselves of basic necessities such as food to undertake the role of carer. For example, Layet revealed:

> At times grandchildren cry so much and ask for food but I am unable to provide for them. If I meet someone and they give me what to cook, I prepare for the grandchildren. I have issues of hunger; many times, I even sleep hungry. I have no one to help me. (Layet-female-68years-northern)

The participants' stories indicated the choice that older people had to make between fulfilling their individual responsibility and the responsibility towards grandchildren when spending their scarce resources. Decisions were characterised by self-sacrifice and some had compromised their own health. For instance, Namusisi, who cared for nine young grandchildren, stated that she habitually sacrificed her medication to ensure her grandchildren got food: *"I can use the little money I have which would have been for medication, I hire a causal worker to dig" (Namusisi-female-64years-central).* Despite these dire situations, respondents expressed gratitude for having their grandchildren and did not see them as burdens. Namusisi noted, *"I am proud because I got grandchildren, and I am still around and able to see and be with them. In this era, how can't someone be proud of having grandchildren?" (Namusisi-female-64years-central).* While older people's role in caring for grandchildren was noted in policies and affirmed by stakeholders and caregivers, this examination underscored the demanding conditions in which this care was undertaken, to the extent that older people often sacrificed their own care needs when undertaking care in interdependent relationships.

7.2.2 Family responsibility

In the absence of an efficient social care structure and in the face of the challenges older people experienced in caring for themselves, older people relied on family to provide care. They noted that the majority of care responsibility fell on children, spouses, and children-in-law, as identified by caregivers in the previous chapter. For example, some married participants mentioned receiving spousal care. Namimbi said,

> I face hardships in washing, collecting water, firewood and in case I am sickly, I can't take the goats for grazing. My daughter-in-law helps me with some of my work like fetching water, chopping firewood and tending animals that are supposed to be taken for grazing. (Namimbi-female-69years-central)

As Alum noted, *"My spouse takes care of me every day, for example, giving me food to eat, washing my clothes and bathing water"* (Alum-female-70years-northern). Participants acknowledged receiving assistance with personal hygiene, toileting, feeding, shopping, farming, administering medication, transportation to hospitals, laundry, home maintenance, cleaning, handling finances, fetching water and firewood, counselling and companionship from caregivers, as stated in the previous chapter.

Older people noted that family members took responsibility when their health and functionality deteriorated to the point that they could no longer do essential tasks. Sixteen (16) of the 19 participants said they had health issues and that their health status and physiological changes were essential in determining the extent of care that they needed and who would be responsible for that. Participants reported that for them, old age was characterised by illnesses, physical impairments or falls, or frailty that engendered feelings of worry about their ability to care for themselves and this self-reporting of poor health was seen as a major factor in shaping responsibility. Furthermore, it underscored the age-related illnesses and management of non-communicable diseases (NCDs) as symptomatic issues associated with functional abilities. Watuwa, who was bedridden at the time of the interview, noted, *"These children [daughter and son-in-law] take care of me, they buy me the medications I need" (Watuwa-male-89years-central).* Those who were severely ill required assistance with daily living activities like mobility, eating, bathing, grooming and toileting.

Participants expressed fear that the responsibility was inconveniencing their caregivers. For example, Awor said:

> What I do not like in getting older is that I cannot manage to do certain things as I used to do, now I feel sick all the time, and whenever I go to the hospital, they just tell me growing older is associated with body ache, so I feel bad about it. I cannot manage to dig now, other things like cooking, washing, are being done for me. I feel I am bothering people. (Awor-female-80years-northern)

Even though older people living in rural areas were living in precarious circumstances, they felt dependent on their carers for whatever could be provided and whenever that could be provided. For example, Namataka said, "*Our children or grandchildren can also bring sugar, mostly my brother's children. They bring when they see the need or think that I have used up what they brought. We try to manage*" (Namataka-female-70years-central). Similarly, Bilal noted, *"I always get those services whenever my caregiver sees that I need them" (Bilal-female-82years-northern).* Hence the carers decided what type of care was provided, highlighting some power issues around care decision-making. Even in situations of neglect in their care experience, older participants often expressed gratitude and a reluctance to engage in conflicts. Kalema said, *"I cannot complain, when I receive some help, I thank God for that" (Kalema-male-83years-central).* Watuwa also stated, *"There is nothing I can really do, what they give me is what I go with"* (Watuwa-male-89years-central). The older people considered the socio-economic contexts of their family members, hence some had unformed expectations. For example, Namusisi said, *"Bringing for me sugar if he [son] can afford; he is not that well off, he earns little. He is also home and does not have a job" (Namusisi-female-64years-central).* Taking into consideration the circumstances of their caregivers was important for older people when defining their care experience. Overall, older people adjusted their expectations, adapted to change and accepted their situation.

7.2.2.1 Normative expectations of responsibility

The analysis revealed that older people had expectations based on the cultural and historical contexts of who should care for them. The traditional norms around gendered roles in care provision were a vital component of care responsibility and arrangements and included rules about who provided care or not and the type of care relatives could provide. Namusisi, a Muganda, gave examples of cultural rules around care: *"'Kizibwe' [the son of your uncle] cannot look after you. Also, my son-in-law cannot look after me. It is prohibited to touch him. But he can send me support or materialistic things by sending his wife (my daughter)" (Namusisi-female-64years-central).* Adherence to the cultural values and norms of caring remained vital for several older people and it shaped the arrangements and forms of care

provided by different relations. For example, Kalema, a Muganda man, stated, *"I still must bathe myself. I cannot tell this lady [neighbour] to help me. She only helps me with feeding and communicating with my grandchildren" (Kalema-male-83years-central).* Older people preferred culturally sensitive and appropriate care from their carers and they often refrained from making care demands outside these established relations and gendered boundaries.

Older people without filial relations in society participated in ceremonies of 'blood brotherhood' that joined non-blood relatives to become a family. Blood brotherhood was acquired by exchanging blood samples between two consenting adult men to establish relations, reciprocity and trust. However, Namataka, a Mugishu, noted, *"They used to have blood brothers (battanga omukago), but now, those relations do not exist"* (Namataka-female-70years-central). This fading practice of forming relations with non-kin is an example of how social networks and relationships within which care can be required and provided in central Uganda are diminishing, especially for older people with few or no filial relations in their society. This could explain why a female caregiver from the previous chapter resorted to bathing her own father, despite this being regarded as a taboo.

7.2.2.2 Expectations about the care environment

Most older participants and caregivers resided in their immediate dwellings. 17 participants co-resided with family members, including grandchildren, characterising intergenerational and multi-generational living arrangements. However, some older people expected that informal caregivers who took on responsibility would provide care in the recipient's home, some of which were hazardous for older people. Most older people in northern Uganda resided in rural homesteads and lived mainly in huts with grass-thatched roofs, mud walls smeared in cow dung and an earth floor. By contrast, in central Uganda, houses were mostly made with brick walls, a cement or earth floor and iron sheeted roofs. Older people with well-built physical structures said that their home environment promoted a sense of independence, personal control and care.

As highlighted in previous chapters, housing structures for rural older people were poor. For instance, they had pit latrines, making it difficult for older people with mobility issues. In situations where older people were living in these precarious environments but with no adult children, they preferred to stay in their homes but asked grandchildren to live with them. For example, Kalema, who lived alone, and was cared for by a neighbour, explained:

> You can see the house fell apart and it is leaking. I am alone. My grandchildren brought bricks, indicating that they would build, but they have never come back. I

> cannot perform most activities. I cannot build it because I do not get money to get builders. Although my grandchildren wanted to take me to Kampala for treatment, I cannot go when my house is in this situation. It needs to be repaired. I requested for a grandchild from the town to take care of me, but no one accepts. I do not have a good shelter, so they do not have anywhere to stay. The weeds around my house are overgrown, and it is becoming a bush. (Kalema-male-83years-central)

At the time of the interview, Kalema viewed his neighbour's house as a place of care, where he could feel welcome and comfortable sharing meals and communicating with distant family relations. When it rained during the interview, we sought shelter in the neighbour's house, where the interview was completed.

In rural areas, family members residing in the same neighbourhood as the older person were more likely to be responsible for providing consistent care than those in distant locations. For instance, Nafuna said, *"My son brings me food, soup and sugar. I have other children who are far away, who only come occasionally. But he is close and knows all my needs, so he helps when he can" (Nafuna-female-63years-central).* Besides any proximity *within* rural areas, the distance between rural and urban areas of carers and older care recipients was an important indicator of responsibility for older people, as well as the type and frequency of care received. Some older people revealed that relatives who had moved to urban areas attempted to provide care in several ways. Some carers travelled from distant areas to the rural communities to care for older people. Ntege stated, *"My feet are paralysed, so my daughter and granddaughter came from Kampala to look after me" (Ntege-male-89years-central).* Other participants in central Uganda revealed that some family caregivers in urban areas sent material and financial support through taxi drivers to show their commitment to responsibility and to ensure that older people in rural regions received care. Namimbi said, *"Those who are far can send me some necessities by loading them on a taxi, then they assign someone the responsibility of making sure that they get to me" (Namimbi-female-69years-central).* Consistent with the findings from the previous chapter, the geographical distances between older people and carers shaped the type of care provided and determined the continuity of care. Distant relatives provided mostly material and financial support, while those geographically closer to older people provided daily care. It was evident that the human-constructed physical environment and geographical locations shaped care provision in rural areas.

However, in some instances, older people in precarious situations moved into the responsible caregiver's home. Some participants had been displaced from their homes and

were dealing with severe health conditions. For example, Watuwa, who was residing with his daughter and son-in-law at the time of the interview, said:

> After burying my grandchild, my son told me not to go back to Mbale, so I came. My son-in-law gave me a piece of land, and I started bricklaying because I was a bricklayer, but one day when I got home, I slid, fell, and landed on my head. When I reached here [daughter's house], I badly fell again. My daughter helps me out even when I want to sit down at night or raise my feet. We sleep in the same house. (Watuwa-male-89years-central)

Having had multiple traumatic falls, Watuwa influenced his need for care as he faced disability and challenges in mobility, thus requiring him to reside with the primary carer. This indicated how frailty, migration, family relations and living environments influenced responsibility and experiences in the care process. While all older care recipients in this study resided in rural Uganda, only four respondents had lived in the same rural space since birth. Although migration meant increased family care for some recipients, it disrupted social networks and narrowed the pool of both family and community care resources. Yet some homes of both carers and older people were not suitable, putting residents at great risk of injury from a fall.

To some older people, the neighbourhoods in which they received their care were unsafe, increasing their risk of sexual abuse. For example, Adong in northern Uganda reported:

> Some people over drink, and when they become drunk, they start disturbing people's peace, so my suggestion is that when I cry for help, the government should come to my rescue. For example, it happened to me where someone followed me up to my home and disrespected me. (P12-female-78years-northern)

Before Adong experienced challenges with her hands that prevented her from completing housework and cooking, she noted,

> They [family members] used to leave me at home while others go to the garden, I do general house cores like cooking, fetching water so that we eat in time. Now, there is no food to eat unless you go to Ayago market[11]. (P12-female-78years-northern)

Adong's lived experience indicated that besides being in an insecure neighbourhood, her isolation was another risk factor that increased the incidence of sexual abuse.

7.2.2.3 Inadequacy of family care

All respondents spoke of being appreciative of the care they received; however, some felt abandoned when children or relatives who had previously provided care moved to distant

[11] The distance between Ayago market and Apoi village is approximately 13.5km.

urban areas. For instance, Watuwa, who was bedridden, commented, *"The two children in Kampala and one in Mbale really abandoned me. They only came once, but they no longer visit me" (Watuwa-male-89years-central).* While some older people were emotionally distressed about their distant children's lack of concern, others attributed this to the difficult circumstances their adult children faced. For example, Namusisi perceived that the inability of her children living in urban areas to send care was because they did not have anything to offer. As she noted, *"In most cases, they fear to come if they have not brought some material items with them. Their conditions are not that good. My husband Hajji used to assist us, but when he died, our conditions worsened" (Namusisi-female-64years-central).*

Some participants expressed dissatisfaction over the timing of medication, nutritional care and completion of care activities. It was revealed that these expectations stemmed from their own experiences of providing care to older family members. Thus, past experiences were used as a yardstick to evaluate their current care experiences, Auma, a Langi, noted:

> Our grandparents used to eat pasted food like "bojo, akeo, alaju", smoked wild meat, not fried ones like these days, they used to eat other foods like greens, "agili-gili" which makes people strong, not like our beef, chicken, eggs, only soft foods which make the body weak. There is no proper food for me to eat. (Auma-female-92years-northern)

Additionally, Adong, a Langi, commented:

> Those days elders were supported through counselling and giving them food following the right time to eat. If it was medicine, they were given at the right time, but today our caretakers give us food and medicine at any time they feel like. (Adong-female-78-northern)

These older people highlighted the change in their nutrition and associated the current foods they consumed with poor health compared to their previous generations. Namimbi, a Mugishu, added,

> In the past, we would pick fresh fruits, e.g., passion fruits, since they were being grown in the compound, but nowadays, it is very hard to find them. People have now resorted to Cheers[12] and Quencher[13]. (Namimbi-female-69years-central)

Similar to findings from the previous chapters, care disruptions were evident when school-aged caregivers were absent. For example, Nafuna had to wait for a grandchild to return from school to collect water, as she revealed, *"But if she [grandchild] is in school, I try to*

[12] A kind of cordial juice
[13] This too is another brand of a cordial juice

get for myself, but it is hard. I get very little which I can manage until they come back from school." (Nafuna-female-63years-central)

7.2.2.4 Responsibility and conflict with caregivers

Conflict issues between responsible caregivers and elder care surfaced in the interviews when participants were asked about recommendations to improve their care. Ntege reported having conflicts that arose due to finances. He said, *"Conflicts do happen because from time to time, you can't fail to disagree with someone about something, especially with my children or grandchildren. It was about financial matters" (Ntege-male-89years-central).* Some participants were concerned about the level of resentment they faced, given their declining health status. For example, Awor said:

> Caregivers should not be rude to older people, even if you are doing everything possible for me but you are harassing me a lot, it gives me a hard time, and my life will not be easy. You will have killed me already indirectly as you know, we older people, our brains are tired, and reason like children. (Awor-female-80year-northern)

Some participants revealed experiences of mistreatment and requested that their carers provide more compassion. For others there was a recognition that carers, balancing multiple tasks, were burnt out. Elem noted, *"I would advise them [older people] to stay calm even if their daughters-in-law refuse to feed them, wash for them clothes and beddings, since they don't have much energy to do a lot by themselves" (Elem-female-68years-northern).*

7.2.3 Community responsibility

Friends and neighbours often provided secondary sources of care. Kalema described:

> My neighbour sometimes gives me a cooked meal. If I am sick or need anything, she calls my grandchildren. She [neighbour] has their [grandchildren] phone numbers. If they need to talk to me, they contact that neighbour, and I converse with them. (Kalema-male-83years-central)

This highlights how friends and neighbours also source support from younger generations in assisting older people with communication tools. Nafuna, a widow, also revealed receiving care from a friend, *"Mr. John can give me some money, buys for me some food, even on special days of the years, he can offer me something nice" (Nafuna-female-63years-central).*

Older people also revealed examples of social exchange and reciprocity with neighbours. Nafuna said, *"Some things, like soap, can last you some months. But when you receive*

these things, you must send some to the neighbour. So, the one who looks after me can know, and he sends some" (Nafuna-female-63years-central). Elem also stated:

> I would dig for them [older friends]. Whenever I could get money, I share it with them in cash and part of the money was spent on buying sugar, soap, clothes etc. But when they passed on, I was left alone, now I am also growing older, yet I have no one to take care of me. (Elem-female-68years-northern)

However, it was also noted that reliance on friends and neighbours was not sustainable, with many participants noting community support in their immediate location was limited, unreliable and inconsistent, resulting in care disruptions. Although Awor stayed with eight grandchildren, she acknowledged receiving irregular care from neighbours. She noted its inadequacy this way, "*Neighbours give me assistance, but once in a while, they are not reliable, which is why I could not count on them" (Awor-female-80years-northern).* Indeed, several participants in both northern and central Uganda indicated not receiving any care from friends or neighbours. For example, Namimbi commented, *"Besides my daughter-in-law, no one in the community helps me out"* (Namimbi-female-69years-central). Nambuya said something very similar, *"Besides the people I stay with, other people don't help me, each has their own home and family to take care of" (P8-female-67years-central).* Despite close proximity and cultural expectations identified in Chapter Six, some older people were not guaranteed support. This was connected with the increased nuclearisation of support, where carers provide care only to their family members and neighbours viewed as secondary carers, highlighting care hierarchies (LaPierre & Keating, 2013).

With little help from the neighbours in the community, some families in central Uganda who could afford to do so resorted to hiring domestic workers to fill the gap in provision of ADLs and IADLs. This shift to employ domestic workers or house help in rural areas was an emerging strategy to assist older people with daily activities. The domestic help often resided in the house with the older person and was paid for by children or relatives living in the cities. As Ntege noted*, "The children and grandchildren would look after these old people, not like these days where they decide to get a maid"* (Ntege-male-89years-central). This was all dependent on affordability and raised issues of inequity in care provision.

7.2.4 Government responsibility

The theme of insufficient government responsibility has been consistently raised in this thesis. From the viewpoint of the older people themselves, there was a common feeling of

abandonment. Older care recipients had expectations that responsibility should go beyond the family and neighbours to include government. The analysis from the policy documents discussed in Chapter Five, particularly the NSPP of 2015, referred to the SAGE program as a cash transfer (social security) that was different from social care services. However, older care recipients equated this cash transfer to social care from the government. Government financial support through SAGE, which was considered a form of care, was provided in northern Uganda, but not to central Uganda, indicating geographical inequalities. Five participants in northern Uganda said they received financial support from the government, which was therefore viewed as a key player in their overall welfare assistance. Adong said, *"My grandchildren are the ones with full responsibility of caring for me. Beyond my grandchildren, there is no one, not even people in the community. Apart from the government through SAGE, that I can say [I] am also a beneficiary" (Adong-female-78years-northern).* Ojara viewed the advent of government interventions, such as financial support, as beneficial, noting, *"It [the care] is not like ours these days. In those days, the older people were not cared for. Because they used not to receive money for older people and there was no concern from the government" (Ojara-male-78-northern).* These participants mentioned that their care experience and their lives had improved because this financial support was used for important tasks that met their basic needs, as an emergency fund, paying school fees for grandchildren and hiring causal farmworkers. Awor noted:

> I used it for emergencies. Last month I picked part of it and paid school fees for some grandchild of mine who is attending tailoring lessons. Then I used the balance to buy necessities like smearing oil, soap, clothes, sugar, etc. (Awor-female-80years-northern)

While expressing their gratitude towards Uganda's government, some respondents in northern Uganda commented that government support was insufficient and inconsistent. For example, Aryemo said,

> I thank the government for coming up with this SAGE program because it is helpful, but the money is little. Secondly, it takes longer to come, like the most recent time they got the money, it had taken four to five months without coming. (P19-female-63years-northern)

Participants also mentioned the ineffectiveness and inefficiency in the SAGE program implementation, where disruptions in payment could take approximately five months. In Chapter Five it was revealed that stakeholders from the central and local government admitted this inadequacy, and that all overdue amounts were eventually paid to older beneficiaries. It was evident that the money received was relatively little yet desperately needed. Besides these inadequacies, some older people also revealed being deprived when

their government financial support was discontinued. Apiyo, a widow, said, *"Another problem is that I do not get SAGE money since my card got burnt and they stopped giving me. This money used to help me a lot in buying things like salt, hire people to dig in my garden" (Apiyo-female-70years-northern).* Moreover, older people also experienced barriers to accessing financial support as they had to walk long journeys or had their money stolen. For example, Alum stated:

> I have to walk on foot, which is another big challenge for me. To make it worse, at times, our money is grabbed away from us. Thieves have so far snatched for three people in my presence, and two people have been killed. (Alum-female-70years-northern)

The other five participants in northern Uganda indicated that they had received no care support from the government. Bilal revealed her unpleasant experience when she noted, *"When I went to register with SAGE, I was sent away, they told me [I] am left with two more years to qualify. This was a problem because I cannot afford to buy necessities at my house" (Bilal-female-82years-northern).* In central Uganda, older people revealed that their care experiences included no support from the government. This applied particularly to those who had relocated from areas where this was provided. Nafuna commented, *"The government promised us but has never come up to provide us with anything like money. But I see in Mbale where I came from, they were given" (Nafuna-female-63years-central).* Moreover, none of the FBOs, NGOs or private companies identified in previous chapters operated in the study sites. This section thus demonstrates the inequities experienced across rural areas in Uganda in accessing social care for older people.

7.3 Social care responsibility expectations in future

The ideal social care system revealed by participants included two important presumed responsibilities: the government providing financial assistance and children providing intimate care. 10 participants looked to the government to take a strong role in providing financial assistance by extending the SAGE program and improving their overall living conditions. For example, Elem commented:

> I see that the government should be the first to see that we receive appropriate care service in all ways. The ideal future care services that we need are that the SAGE program should continue and care for every older person's needs, not only a few to benefit. (Elem-female-68years-northern)

Moreover, participants also anticipated increases in these cash handouts, as Auma noted:

> The government should reduce the age for receiving the money to 55 years in the future and increase the amount from 25,000/= to 50,000/= and should be given monthly, not missing some months, to reduce our suffering since basic needs are

> very expensive. They should provide us with foodstuffs in the future, since most of us cannot manage to dig now. Even I have no clothes to wear; they should provide us with clothes and shelter for sleeping. (Auma-female-92years-northern)

Similar to the findings from stakeholders and caregivers, participants voiced their expectation of government to address structural challenges through the provision of public infrastructure. These included better roads to ease their travel to a hospital, building houses for older people and financing business initiatives for both carers and older people. Bilal remarked, *"There should be the reconstruction of roads since our roads are extremely bad. That affects our business and becomes very hard to go to the hospital in time of sickness" (Bilal-female-82years-northern).*

There was also an expectation that the government set up projects that would provide them with additional income. For example, Aryemo said:

> We need projects because giving ready things has no value since you have to wait until they are brought for you. Still, if projects are opened here with us, then the government only keeps checking or monitoring and correcting parts that are not handled well would be far better than just waiting for things to be given. (Aryemo-female-63years-northern)

Elem stated that the government should set up income projects for caregivers:

> Caregivers should also be supported with some project that will help raise money that will sustain them and the older people they take care of. The government should open the project of rearing animals, especially for older people or even seeds that yield faster. (Elem-female-68years-northern)

Some participants argued for a multi-system approach to care, entailing a collective responsibility between government, NGOs and children in caring for older people in rural Uganda. As Awor stated, *"The government should take the lead to help us. Children should help the government in the provision of social care services to me" (Awor-female-80years-northern).* Adong noted, *"The children, NGOs and government should work hand-in-hand to oversee the wellbeing of elders"* (Adong-female-78years-northern).

Three respondents expected this researcher to take on responsibility for ensuring aged care provision of services to older people in rural Uganda. Similar to suggestions presented by caregivers in central Uganda, older people anticipated that the researcher would advocate for their rights. Aryemo said, *"To visitors like you, when you go back, channel our voices to different NGOs and government to drill for us more boreholes, open projects for us and construct better roads for us" (Aryemo-female-63years-northern).* The expectation that I could advocate for older people could be explained by the earlier misconceptions that I was

with the government or perhaps an outsider who had greater resources to express their concerns to various actors. The limitations in decision-making about their care among some older people were also an issue, as Nandutu said, *"Just like you have come, you could just think about what to give the older people depending on what you can manage" (P2-female-72years-central)*. Participants further drew attention to the unique individual characteristics of older people and their experiences, implying that they could not all be treated in the same way. Ntege noted, *"It's hard to plan for different older people because they all go through different circumstances" (P7-male-89years-central).* This was an acknowledgement of the heterogeneity and diversity of care experiences of older people in rural areas and the need to consider their individual circumstances when formulating solutions to improve their social care.

7.4 Discussion

This chapter has examined how the care experiences of older people living in rural Uganda contribute to our understanding of care responsibility. It has revealed the precarious circumstances in which older people live, the real inequities in how they receive financial support and their access to care. The collective stories highlight significant disruptions in care.

The presence or absence of responsible actors shaped the element of responsibility and care experiences. Similar to the findings presented in chapters Four, Five and Six, family members, both nuclear and extended, were primarily responsible for older people's care in rural Uganda. When this care was inadequate due to family members being absent or migrating to urban areas, friends and neighbours were expected to fill the void. In doing so, care was positively disrupted to enable continuity in care provision. Applying these findings in the present study to the hierarchy of care model (LaPierre & Keating, 2013) and the 'hierarchical compensation model' of Cantor (1989), older people preferred spouses, then female family caregivers, followed by sons and family members, to provide hands-on care. While gendered tasks towards caring are noted in rural Uganda (Mugisha et al., 2015), in this study, compromises to cultural norms were accommodated in dire situations where no other caregiver was present. There were also differing viewpoints regarding the role of friends and neighbours in the provision of care. Although most participants mentioned the lack of care support from friends and neighbours, some older people living alone received care from neighbours, thus relying on "friend-focused" social networks (Djundeva et al., 2019).

Similar to previous chapters in this thesis, the element of attentiveness was manifested through the concept of vulnerability, which was a significant determinant in shaping care responsibility and the care experience. The facets of vulnerability manifested in three pathways: the vulnerability of older people and the precarious situations in which they live, the vulnerability of caregivers shaped within responsibility, and the vulnerable care environments evident in the caregiving process. In relation to EoC, vulnerabilities were compounded to include need, harm, loss, domination and unwanted conditions (Engster, 2019). Extremely ill older people required personal care, including support in mobility, eating, bathing, grooming and toileting, which often felt like a burden to family caregivers. As noted by previous studies in Uganda, the participants' self-reported health noted NCDs and dementia (Musisi & Jacobson, 2015; Wandera et al., 2015), yet these conditions remained largely undiagnosed and untreated. Faced with increasing functional decline, older people expected their family members to assume responsibility.

The situation in rural Uganda was dire and the present study revealed examples of insecurity in living arrangements and in some cases sexual assault. Living in a rural community did not guarantee security and support for older people, implying that responsibility assumed in vulnerable care environments affected both carers and older people. Care theorists argue that good responsible caregivers create an environment where an individual's vulnerability, harms, threats or undesirable needs are minimised, can be addressed or easily avoided (Engster, 2019; Gilligan, 2011; Tronto, 2013). However, this was not the case due to the context of the care environment. The homes of rural older people were characterised by one or more components of unsecured housing structures, dilapidated housing structures, pit latrines, a poor land tenure system and land wrangles. Most older people preferred to have care in their own homes. However, some carers did not take on responsibility due to the poor care environment, while other carers assumed responsibility only when the care recipient moved into the carer's home. In developed nations, the heterogeneity of older people in rural areas and their care experiences show the complexities in the care environments of older people (Petersen & Minnery, 2013; Skinner & Winterton, 2018). This present study revealed much more vivid and compelling evidence of how inequities shape care experiences and responsibility.

Unresponsiveness in older people impacted on carers' responsibility as it characterised another aspect of vulnerability manifesting as strife. Conflicts between older people and

their family carers resulting in examples of neglect and arguments pertaining to financial issues. Furthermore, some of the older people were non-responsive to the care, especially in taking medication and meals or refusing to go to hospital, and some were aggressive to their caretakers. Vosman et al., (2020) question the extent to which the element of vulnerability can be accommodated in circumstances of aggressive behaviour, saying these manifestations in care practices demonstrate the ambiguity of vulnerability. In the present study, the vivid illustrations of vulnerability demonstrate that greater attention needs to be placed on the dual aspects of care needs and the needs of carers. What was striking about the issues of conflict was older peoples' proposition of an ethical principle of tolerance which encompasses peace and respect for and by those who assumed responsibility. The EoC theory also encompasses principles of respect and trust at the phase of "caring with" (Tronto, 2013). Coupled with the principle of tolerance, this study illustrated how the caring with respect, trust and solidarity is essential in resolving conflicts between caring relationships at the responsibility/caregiving/care-receiving stages of the care phases.

With limited family and community support, older people looked to the government for financial assistance; however, this support was equally inadequate. The circumstances around limited financial and human resources identified in the previous chapters explain the inconsistencies in financial provision and geographical disparities between northern and central Uganda and they show non-adherence to the principles of universality, fairness, equity and equality stipulated in the analysed national policies at individual and regional levels. The financial challenges faced by government resulted in delay in cash deliveries, discontinued support, omission and total exclusion of older people in central Uganda. The application of EoC needs to consider the cultural values attached to care provision in rural developing countries of sub-Saharan Africa and the limited capacities of actors to assume and continue care provision that result in care disruptions.

The limited solidarities outside the family impacted on responsibility. In the present study, there were examples of increasing marketisation of care where non-kin domestic workers were employed to assist older people with daily activities. This finding was consistent with research that has highlighted demographic changes and increased reliance on domestic helpers to care for older people identified in Ghana (Coe, 2017). What this raises is large inequities in access to care, particularly for older people and families that cannot afford to pay domestic workers. In these study sites, older people noted the absence of NGO, FBO and CBO support. It was rather surprising that none of the older people interviewed

referenced support from the local FBOs/ churches identified in Chapter Five. However, this could be explained by the inconsistent and limited coverage of FBOs.

Consequently, care disruptions were evident associated with vulnerabilities, low socio-economic status, lack of basic needs and public services for older people impacted on their own responsibility, resulting in unmet care needs (unresponsiveness). Older people also noted vulnerabilities associated with natural disasters that caused famine and drought resulted in poor access to safe water and food. As highlighted by stakeholders and caregivers, limitations in specialised geriatric health workers, poor transportation to hospitals and medication shortages at health centres in rural areas impacted older people. Care theorists have argued that responsibility should progress to caregiving that is responsive to people's care needs (Tronto, 1993; Tronto, 2013). The application of EoC theory to rural areas of developing countries like Uganda, where basic amenities like accessible toilets, sufficient food and clean water are lacking in these study populations, needs careful consideration. Applying EoC needs to consider the extent to which care can be termed as responsive or good care in the context of vast limitations in the public service and the challenges experienced by stakeholders and informal carers with no clear guidelines. In the present study, older people and their carers strove to limit the gaps in care provision, providing care in difficult circumstances.

Social care responsibility was seen to shape solidarity from two distinct positions suggested by older people: the family primarily responsible for hands-on care, and the government responsible for financial assistance and development of basic infrastructure. A study of intergenerational solidarity by Timonen et al., (2013) drew distinctions between public solidarities (support from government in the provision of care) and private solidarities (support from family in the provision of care). In the present study there was clear support for a greater role of government in the provision of financial support. Participants' expectation of government taking more responsibility revealed the desperation of older people to have their financial care needs met. Older people expected the government to be more responsible for financial support by continuing cash transfers and offering an increment from UGX 25,000 ($10) to UGX 50,000 ($20). They also requested for permanent houses for older people living in poor housing structures, finance income-generating projects for older people and caregivers and addressing the structural challenges of poor water, roads and health centres. The literature on aged care responsibility calls for collaborative efforts between systems (Jolkkonen, 2019; Powell, 2007). The application of

the term “responsiveness” is problematic in a state where people have idealised expectations, allocating responsibilities to entities that have limited capacity and resources, all of which result in continued care disruptions which in turn result in unmet social care needs of rural older people.

7.5 Conclusion

Exploring the lived experiences of older people in receiving care in this chapter has added to our knowledge about care responsibilities for older people in rural Uganda, specifically who is responsible or who should be responsible. It has demonstrated how care disruptions impact responsibility and that responsibility is then impacted and impacts other elements. It has revealed that social care provided by the family and government remains inconsistent, inadequate and untimely, and is provided in unsupportive care environments and changing cultural contexts. Though older people strive to maintain their independence, responsibility, autonomy and decision-making within the care processes and relationships, they often lose them. While this study is not generalisable, it highlights how the care provided to older people is shaped by the responsibility assumed and by the care provided within micro and macro environments. Additionally, this study details the heterogeneity of rural older people, their diverse care, life experiences and perspectives that shape care at individual levels and how their considerations are essential in addressing older people’s social care problem in rural Uganda. The cultural values, dire circumstances, care disruptions and expectations identified in this chapter pose questions about the application of the EoC theory to rural developing contexts where tolerance is identified as a key ethical principle which might not necessarily result or align with the element of responsiveness. The next chapter offers a summative discussion of the key study findings and models the social care system for rural older people in Uganda.

CHAPTER EIGHT: INTEGRATED CRITICAL DISCUSSION AND CONCLUSION

Learn from yesterday, live for today, hope for tomorrow. The important thing is not to stop questioning. (Albert Einstein)

8.1 Introduction

This study has analysed Ugandan national policies and explored the views of stakeholders, caregivers and older people to critically interrogate the state of social care for older people in rural Uganda. It has also investigated the construct of responsibility and expectations held by various actors. In this chapter, I present a summary of key findings, followed by an integrated discussion of findings guided by the key theories and approaches underpinning this study — ethics of care theory (Barnes et al., 2016; Engster, 2019; Herron & Skinner, 2013; Kaufman-Osborn et al., 2018; Sevenhuijsen, 2000; Sevenhuijsen, 2018; Tronto, 2014, 2015a, 2015b) and critical rural gerontology (Baars, et al., 2016; Burholt & Scharf, 2019; Estes, 2018; Skinner et al., 2020; Skinner & Winterton, 2018; Wild et al., 2013). This enabled a thorough examination of how and why different actors assumed or devolved aged care responsibility in rural communities in Uganda, and how interactions between actors at different levels of context empowered or disempowered rural older people and different rural communities. This chapter then presents the significance and implications of these findings for policy, practice and future research and outlines a series of recommendations. The chapter closes with a discussion of the strengths and limitations of this study.

8.2 Summary of research findings

The following section summarises the key findings from each stage associated with actors at each level (macro and micro) of the ecological framework, as shown in Table 8.1. The ecological exchanges relating to responsibility for social care of older people in rural settings identified in this study appeared to be unidirectional. The conceptualisation of care and construct of social care responsibility at the policy (macro) level influenced the perceptions about responsibility, allocations and expectations at subsidiary levels in various ways.

Table 8. 1 Summary of research findings

Research questions	Key findings
1. *How is social care provision for older people conceptualised within Ugandan policy, and what are the implications for older people in rural Uganda?*	There were various conceptualisations of social care in policies
	• Social care was viewed as a social protection strategy alongside social security, where minimal funding was provided to targeted groups. • Social care was conceptualised within vulnerability and human rights approaches championed by regional and international organisations and legal frameworks. • Social care was framed within neoliberalist ideologies towards poverty eradication as a service for the most vulnerable groups to enhance active participation of older people.
	There were ambiguities in allocation of aged care responsibility
	• The ideology of familialism predominated in policy documents, based on arguments that families provide better care and that it is culturally responsive. • State responsibility for financial assistance was directed towards the most vulnerable older people but decentralised fiscal responsibilities to local governments which were financially constrained. • A multi-stakeholder approach in social care provision was promoted amid unclear allocation of responsibilities among actors, hence the vast responsibility rested on families.
	There were systemic challenges associated with competence in policy development that influenced responsibility for older people's social care and presented risks of care disruptions.
	• Lack of an exclusive policy framework, guidelines and standards of social care for older people. • Transnational organisations had a degree of power in the policy process, which fostered dependence on foreign partners. • The coordination mechanism was an enabling factor yet it enhanced power imbalances that promoted social injustice in the implementation process. • Policy implementation processes were affected by the lack of expertise in the field of ageing.

2. *What are the perspectives of stakeholders on responsibility for the social care of older people in rural Uganda?*	The irregular responsibility resulted in fragmented and inconsistent caregiving in social care services in rural Uganda.
	• There were limited social care services for older people in rural Uganda. The government provided very limited care services (one residential facility). • Stakeholders from central and local government perceived financial support and community development initiatives as social care services that were delivered only sporadically in Apac district through donor funding. • Material support was infrequently delivered by the FBOs and CBOs and pastoral care was provided only selectively by FBOs in the study sites of Buikwe and Apac districts.
	Stakeholder responsibility for social care provision was contingent on competency resulting in care disruptions.
	• Stakeholder responsibility was influenced by attentiveness to individual and socio-demographic characteristics of older people, which encompassed age, income, social networks, dependents and availability of informal caregivers, the health status and disability of older people. • The ability to assume responsibility was associated with stakeholders' capacities to provide social care services, including financial ability and qualification of staff. • The insufficiencies in resources and professional staff, coupled with structural challenges (like poverty, poor roads and the inadequate health care system) inhibited service providers from providing social care and taking on responsibility. • The solutions in managing limited resources led to geographical inequities in social care provision.
	Stakeholders had diverse expectations relating to responsibility for social care provision that impacted on solidarity and plurality.
	• Stakeholders held diverse conceptions and expectations of who should be responsible for providing social care services for older rural populations. • All stakeholders agreed that the government must solve structural challenges regarding the flawed healthcare system, poverty, education and workforce training, food security and housing. • Stakeholders from the government called for a multi-stakeholder approach in aged care responsibility. • Respondents visualised an ideal social care system that involved addressing existing challenges, utilising available resources and engaging other stakeholders in social care provision.

3. What are the lived experiences of caregivers in providing social care to older people in rural areas?	Informal rural caregivers were responsible for significant levels of assistance with ADLs and IADLs
	• Caregivers assisted older people with ADLs (personal hygiene, toileting, feeding), IADLs (shopping, administration of medication, transportation, laundry, home maintenance, handling finances) and non-market activities (digging, fetching firewood and water) and emotional support (counselling and companionship). • Informal caregivers were largely children, spouses, grandchildren, and daughters-in-law.
	Assumption of responsibility influenced attentiveness to vulnerability and intergenerational solidarity
	• Family caregivers engaged in care responsibility for older relatives with chronic illness and increased frailty. • Caregiving culture was embedded in cultural beliefs, values, gendered care roles and expectations of intergenerational support and solidarity, which influenced caregivers' choices and decisions to assume responsibility. • Benefits of caregiving were evident through functional solidarity like community recognition, financial and materialistic rewards, stronger bonds with care recipients, financial rewards, advice and knowledge. These provided positive caregiving experiences, which enhanced continued care provision.
	Responsible informal rural caregivers faced environmental, personal, and financial challenges, resulting in care disruptions.
	• Carers were responsible for care recipients with multiple acute and chronic needs, faced financial constraints and demanding roles. The challenges were significantly associated with poverty, unsafe water, poor housing and roads and a malfunctioning health care system that continuously interrupted the timing and type of care provided. • Changes in the natural environment, causing drought and famine impacted negatively on the caregiving experience. • Carers in rural areas were resilient in resolving difficulties, yet often adopted coping strategies that were more likely to increase vulnerability or harm older people in rural Uganda.
	Informal rural caregivers expected the government to assume greater responsibility in the social care of older people to create more pathways of plurality.
	• Caregivers had mixed views about responsibility allocation; most of them expected the government to assume the main responsibility for providing care. • Despite positive coping strategies, carers expected the government to provide basic and public goods, provide caregivers with income-generating projects, and increase formal and material support.

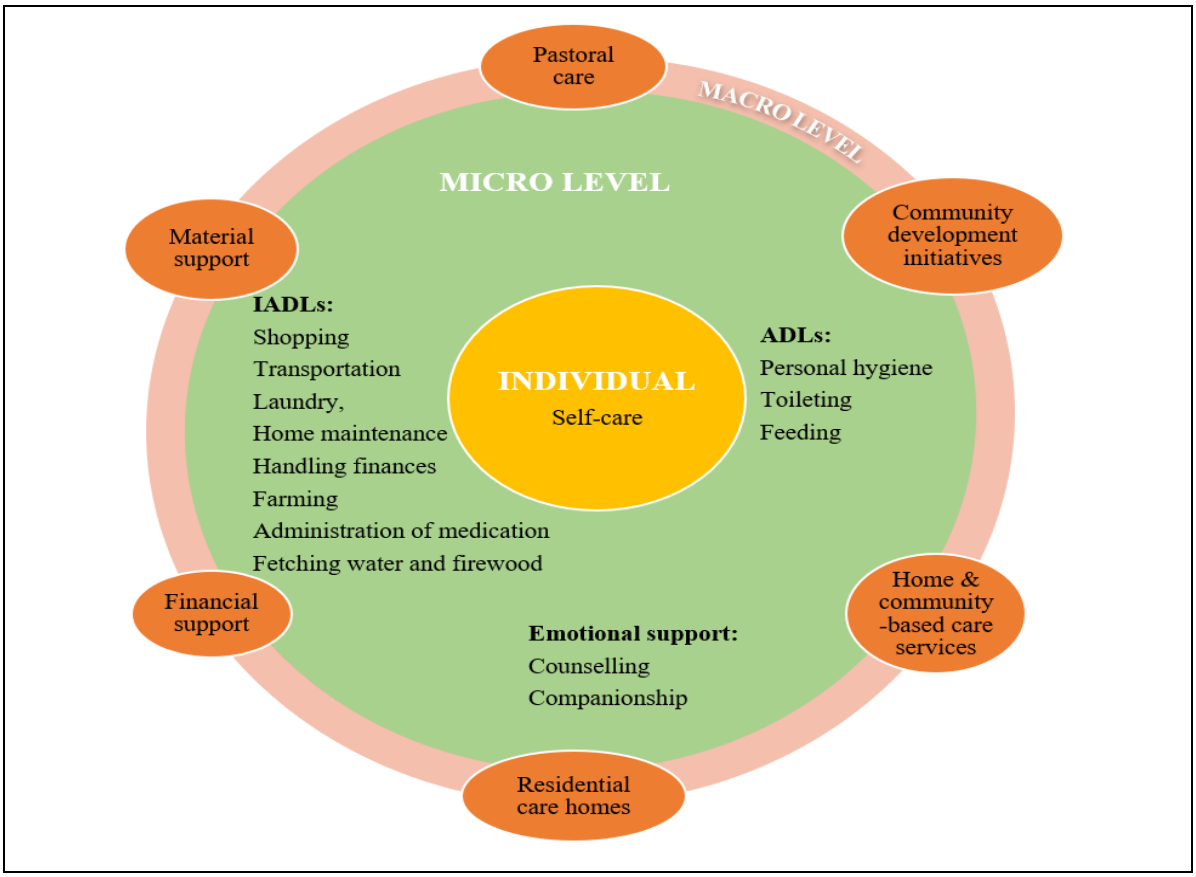
4. What are the lived experiences of older people receiving social care in rural Uganda?	Rural older people perceived attentiveness to their social, economic and individual characteristics of extreme vulnerability to prompt care providers to assume responsibility for their care.
	• Care recipients' health status, relations, and social networks, living arrangements and proximity of carers (geographical distance and location), socio-cultural factors and shift in norms, life events and place of care were important determinants of needing care among older people. • The carer-care recipient relationship, care provided, cultural context, past generational care experiences, and care spaces were important determinants in shaping older people's care experience and responsibility.
	Rural older people felt that the responsibility assumed by formal and informal care providers resulted in insufficient and unresponsive care.
	• Older people perceived care services from informal caregivers (family members, community members, friends and neighbours) and government was limited, unreliable and inconsistent. • Older people did not identify any FBOs, private companies or CBOs as care providers in the study areas.
	Rural older people faced significant challenges that reduced their competencies in providing care and resulted in care disruptions.
	• Older people experienced various challenges, including caring for grandchildren, verbal, physical and sexual abuse that violated their human rights, highlighting the heterogeneity of older people's experiences and problems. • Geographical differences in the challenges faced by older people that negatively influenced their care experience were based on natural disasters like drought and famine in northern but not central Uganda. • Challenges commonly faced in both rural sites were structural factors like poor road transportation system, poor access to safe water, lack of income source and poor health care system, all of which contributed to negative care experiences. • Caregivers could discontinue care, disruptions due to migration, the caregiver moving to the city, transitioning to a new carer or death of the carer.
	Older people felt that governments had a greater role to play in taking responsibility for rural social care.
	• Government should address structural challenges like poor roads to ease transport to the hospital, building houses for older people and financing business initiatives for both carers and older people. • Researcher should take on responsibility to enhance aged care provision for older people in rural Uganda through advocacy.

8.3 Integration of findings

This study responded directly to the WHO's call to examine care systems in African countries, in preparation for establishing long-term care systems (WHO, 2017). It used an ecological framework to examine the actual, assumed and perceived responsibilities for the social care of older people in rural Uganda. The integration of the key findings in Table 8.1 provides a comprehensive understanding of social care in rural Uganda from the perspective of older people, caregivers, service providers, civil servants and national policies. This thesis makes a significant contribution to the literature, in that, to date, there have been no in-depth studies interrogating social care for older people in rural Uganda and in developing countries in sub-Saharan Africa.

From the perspective of developing countries, scholars have often explored social care provision for older people in combination with childcare (Dhemba & Dhemba, 2015), or have examined care policies (Van der Geest, 2016) in developing countries of Africa like Zimbabwe, Lesotho, Ghana. In Uganda, studies have mostly focused on older people with HIV/AIDS (Mugisha et al., 2015) or their caregivers (Ssengonzi, 2007; Ssengonzi., 2009). As detailed in Figure 8.1, this research has produced an ecological view of the social care system for older people in rural Uganda that is characterised by miniscule macro level due to the provision of inconsistent, inadequate and under-resourced social care and support services.

Figure 8.1 Summary of the social care system developed from the study findings



8.3.1 Who is primarily responsible for care, and what do they provide?

In the present study, an analysis of policy documents and findings from stakeholders, caregivers and older people revealed that families remain primarily responsible for providing social care to older people in rural Uganda. Like contemporary ageing research in both low-income countries (LIC) and high-income countries (HIC), informal caregivers play a significant role in assisting older people with IADLs and ADLs (Vlachantoni et al., 2013). However, this analysis revealed that farming and fetching firewood and water were additional care activities performed by rural caregivers in Uganda, in addition to other ADLs and IADLs. This suggests that a broader classification of IADLs in rural developing nations is required. Other activities included emotional support, non-professional counselling and companionship.

This analysis echoes findings from previous studies which have presented familialism as the dominant ideology driving policy and practice across sub-Saharan African countries and Asian countries (Aboderin, 2017a; Coe, 2017; Dhemba & Dhemba, 2015; Van der Geest, 2002, 2016; Zhao et al., 2017), and in conservative welfare regimes of Europe (Esping-Andersen, 2016). In this current study, sensitivity to older relatives' care needs,

cultural appropriateness in terms of care provision, the lack of formal social care services and other informal caregivers to take on responsibility are presented as arguments for allocating care to informal family caregivers. Some care theorists argue that families are best suited to care for their loved ones because they are attentive to care needs and respond respectfully (Goodin, 1995). Others also view family care as naturally occurring and based on the care recipient's relationship with the caregiver (Tronto, 2013), with family caregivers close relatives i.e., children, spouses, children-in-law, to the older people. Feminist care theorists have continually noted that care responsibility for older people is a profoundly gendered women's task (Gilligan, 2013; Sevenhuijsen et al., 2003; Tronto, 2015b). This study reinforces the gendered role of men in assuming care responsibilities associated with the factors of production, like transporting older people to hospitals and shopping. These gendered roles were evident among female family caregivers but also to an extent differed in both cultures (the Langi and Baganda), based on their different environmental contexts. While women in both cultures performed mostly tasks associated with hands-on care of ADLS, the variation in IADLs were evident, hence the gendered roles were not necessarily uniform.

The findings highlight that the social care system for older people in rural Uganda is largely fragmented; services are limited and provided inconsistently in rural geographies. In Uganda, the term "social care" is broad, encompassing elements of social protection. Hence it is important to note that when participants in the study were discussing financial assistance, they were referring to a broader social protection approach. Thus, most of the care services presented in this study differ from mainstream western literature about systems of care for older people. Taking this broader approach and within a limited policy framework, the state has assumed limited responsibility for social care for older people. The analysis of stakeholders' views indicates that the government provided community development initiatives and financial support in the northern part of Uganda through NUSAF III programs in partnership with development partners like Irish Aid and DFID. However, these programs were not implemented in central Uganda, thus contributing to geographic inequalities. When it came to the funding of hands-on care, there were only two care homes, one run by the government and another by an FBO. There were home and community-based care services located in central Uganda but these were funded FBOs, not government, and there were none in the study sites. Private companies providing home and community-based care services were physically located in urban areas despite their stating that older people in rural areas could also access their social care services. Material support

and pastoral care were provided by CBOs and FBOs respectively in both study sites, though often inconsistently. In the absence of any other actors assuming responsibility, older people in rural areas were expected to meet their own social care needs.

8.3.2 Who should be responsible?

Some stakeholders, caregivers and older people expected the government to increase social care provision in rural Uganda. Across each stage of the study, the predominant view was that government should provide more public infrastructure through construction and restoration of the health care system, transport and agricultural systems, and provide safe water, food security and housing for older people in rural areas. This was seen as necessary to address the basic needs of older people in rural Uganda. Caregivers and older people held expectations of government financing income-generating activities instead of being dependent on the limited government financial support. In other words, they hoped that they could be more empowered to use the resources available in their communities. In developed countries, care theorists agree that supporting caregivers fosters their ability to provide direct care to care recipients, thus ensuring that their capabilities are not compromised (Engster, 2004). In the present study, this was even more critical given the older care recipients' dire circumstances and the types of tasks carers undertook. Other stakeholders from the public sector called for collective responsibility for social care provision.

8.4 Critical discussion of findings

To understand why social care remains inconsistent and fragmented in rural Uganda, despite actors taking on responsibility, I present my arguments in relation to the phases and moral dimensions of care, namely, the elements of attentiveness, responsibility, competence, responsiveness and plurality (Tronto, 1998, 2014). Based on the integration of the findings across all ecological levels, I draw out five major arguments:

1. The various moral orientations held by actors limited the extent of attentiveness to, and responsibility for, the social care of older people in rural Uganda.
2. Ambiguities in pluralistic responsibility allocation led to fragmented care provision for older people in rural Uganda.
3. Various (in)competencies in caregiving influenced the extent of assumed responsibility for, and the type and quality of care provided to older people in rural Uganda.

4. Irresponsiveness to care needs was associated with inattentiveness towards basic needs and public services, the limited responsibility uptake and inability of actors, the negative attitudes of older people towards receiving care and care disruptions.
5. Care disruptions impacted the extent to which actors assumed responsibility and engaged in caregiving, contributing to inconsistent care provision.

8.4.1 Ambiguities in pluralistic responsibility allocation

Care theorists expect that responsibility is either assigned, assumed, deflected or implicitly expected (van Nistelrooij & Visse, 2019). This study found that the ambiguities in responsibility allocation in the analysed policy documents at the macro level impacted on how responsibility was assumed by stakeholders and informal caregivers at the micro level. This ambiguity was evident in the provision of inconsistent information, limited consideration of the socio-economic context of families and the financial capacity of actors and a lack of task allocation in social care delivery to stakeholders. Despite central government indicating a commitment to social care services to all older people in need of care, it delegated responsibility for financial and hands-on care delivery to local government, which was under-resourced and ill-equipped to provide care services. The government responsibility was evident only when and where international donors provided funding, which impacted on social care responsibility and care provision within rural Uganda. In relation to this, some care theorists argue that if the national government falls short, the responsibility should be transferred to the international community (Engster, 2007). Yet some scholars have noted that global power inequalities present ethical risks related to caring about from a distance, whereby countries in the Global South expect "salvation" from the Global North (McEwan & Goodman, 2010). They contend that this leads to dependence on foreign donors at the international level, largely dictating how resources are distributed (Lie, 2015; Manyire & Asingwire, 1998; Park, 2019). When it comes to hands-on care services, again a review of the policy documents highlighted that this responsibility was transferred to FBOs and private companies. The national government's limited financial assistance to older people in rural areas resulted in further inequities in care provision. The policy ambiguities had further implications for social care service delivery where FBO and private company stakeholders had limited scales of operation, most of which did not cover rural areas, as revealed by the findings in the selected study sites. At the same time, there were no clear guidelines as to when these actors should take on responsibility, resulting in more demand for care and less uptake of responsibility. Goodin (1995) contended that allocating task responsibilities should ensure

service provision and accountability and he used the scenario below to illustrate this standpoint.

> It is usually better to assign one doctor the particular care of each patient in a hospital rather than assigning all doctors equal responsibility for all patients. If we were to assign all doctors the care of all patients, the likely result would be confusion, inefficiency and less attentive care for all. (Goodin, 1995)

In more recent work, Goodin (2018) presented a form of responsibility called *constitutive responsibility* where he argued that each individual constitutes part of the whole and therefore holds responsibility of at least that fragment for the whole.

The non-allocation of responsibility to meet care as a basic right means that stakeholders have to determine who the deserving and undeserving vulnerable older people in rural Uganda are. Consequently, and due to the limited uptake of responsibility by other actors, the primary responsibility social care falls back on families, at the micro level. The assumption that governments in low-income countries should shoulder the social care responsibility to implement global agendas has resulted in limited progress in achieving the MIPAA (Sidorenko & Zaidi, 2018). This implies that the social care system for older people is not sustainable. As clearly noted above, the responsibility falls on families and older people in rural areas, yet in most cases, without any government agencies and organisation actors assuming responsibility, the care needs of older people in rural Uganda remain unmet. I therefore argue that the manner in which responsibilities are perceived, and assigned, unassigned or deflected is due to the various moral orientations of actors.

8.4.2 Various moral orientations in attention to care

This study identified that actors at different levels of the ecological system had a variety of motives for attending to older people's care needs, which consequently limited their perceptions and allocation of responsibility. Conflicting notions of moral motives towards social care were evident in the policy documents. For example, attentiveness to older people's social care needs was based on: (i) political motives, particularly a social protection approach, with the expectation of empowering so called 'passive, dependent, and unproductive' older people in society and promoting economic and social participation, (ii) legal justifications based on universal human rights and (iii) the obligation to international commitments made in the MIPAA and support from transnational organisations. At the macro level, policies were derived from principles of universality, equity and equality; however, they were not actualised when it came to funding. Instead,

what did come through were the ideologies of individualism and familialism. At the practice level, the stakeholders also held a range of ideological positions and principles in relation to responsibility for social care. For instance, the FBOs were funded by international sponsors who brought their agendas and were influenced by the ideology of communitarianism, taking the major responsibility for the social care of older people. Thus, they held moral values associated with assisting the needy, fronting charitable works, religious beliefs around "the good Samaritan" and compassion. Here decisions were based on selectivism and vulnerability-based targeting of the most vulnerable older people, resulting in care disruptions and inequalities.

In Uganda, the emergence of private companies has seen hands-on care delivered according to a market model. Unlike western governments, they were not funded by the government, but operated on a fee-for-service approach. They provided care based on principles of profitability whereby families (mostly adult children) paid for the care services. Families and older people who could not meet these costs were thus not able to access hands-on care services.

At the micro level, it was evident that the ideology of familialism, the expectation that families are ultimately responsible for care, was most prevalent. Family caregivers, especially spouses, children, children-in-law, siblings and grandchildren, were attentive to the care needs of their relatives. Yet, this was also influenced by personal and cultural ethics, and the motives towards care were shaped culturally and individually, based on intergenerational solidarity, reciprocity, altruism, normative expectations, benefits of caregiving and moral obligation. For those families that could afford to pay, domestic workers were employed when family members moved to urban areas to get paid work. Although intergenerational solidarity was still strong and cultural expectations towards care were highly regarded, families alone were not sufficient to guarantee care to older people in rural areas.

When it came to neighbours and friends, there was some evidence that community members assumed responsibility. However, there was also an overlap in moral positioning manifested by the Obuntu principle. Here, the consideration of the 'self in others,' was evident. I can refer to a proverb quoted by a caregiver, "omulirwano gwokya bbiri, nga gwagalana" [the danger or problems at your neighbour's house could also affect you]. The

cultural/societal obligations towards members in need were evident in one of the cultures, hence the notion of cultural relativism was still present.

8.4.3 Varied (in)abilities in caregiving

The policy documents highlighted limited personnel specialising in geriatric issues. At the practice level there were a number of concerns in relation to workforce issues, with home-based care service providers hiring unskilled personnel and engaging them in unaccredited training. Indeed, the government's one and only care home employed untrained staff who performed hands-on care activities. However, the church-run care home had staff qualified in social work and community development to carry out managerial and administrative roles. This study confirmed previous research in South Africa that found that an unregulated social care system that lacked standards of practice, ethics and professional conduct guidelines impacted negatively on client handling and led to abuse of clients (Lloyd-Sherlock, 2019), particularly in rural areas.

Within the microenvironment, informal caregivers engaged mostly in daily care tasks that required no form of expertise. However, at this micro level, informal caregivers were not skilled enough to attend to the complex social care needs of older people. Therefore, families provided basic care were taking on only the care activities that required less specialised care training and were less attentive to specialised care needs. This implies that older people in rural Uganda who required specialised care did not access it and some stakeholders that claimed to provide care did not participate in caregiving at all.

8.4.4 Irresponsiveness to care needs

In this study, irresponsiveness to care needs is associated with the inattentiveness, limited responsibility uptake, rationed care and inability of some actors to address the care needs of older people in rural Uganda. Due to the inadequate provision of family care, limited community support and inconsistent care from FBOs and government, older people viewed the care process as unresponsive to their needs. Care theorists have argued that responsiveness of care requires caregivers and care recipients to remain attentive to the potential for neglect or abuse that could arise with vulnerability (Tronto, 1993). However, at the micro level, caregivers revealed that despite being attentive, some older people were unresponsive, as some refused to take food or medication, resulting in needs being unmet. At the same time, some older people noted that care was not provided in time to meet their expectations and care needs. Consequently, some older people manifested negative

responsive behaviours, becoming aggressive and abusive to their caregivers. This conflict is noted in caring relationships to expose the vulnerabilities of caregivers. Care for grandchildren could also explain why the care provided was unresponsive to older people's care needs. Most older people sacrificed their basic needs or medication to take care of their grandchildren. Moreover, targeting the Orphan and Vulnerable Children (OVC) in older people's care without addressing the older people's own issues could yield fewer outcomes, raising more questions about who should be responsible and how care should be achieved in the context of the heterogeneity of older people's care needs and experiences in rural areas.

At the infrastructure level, little to no consideration was given to older people's health care services, food security and income There was a high degree of perceived government failings in attending to the poor housing conditions and other facilities of older people living in rural Uganda. In other instances, the financial care provided did not meet care recipients' expectations. For example, although some older people received financial support, they and their caregivers indicated a need for more sustainable income sources like income-generating activities and increments in financial support from the government; in other words, the form of care provided was not responsive to their needs Therefore, without responsiveness, the social care system was grossly inadequate for rural older people.

8.4.5 Care disruptions

The issues around the element of responsibility, such as various moral orientations, ambiguities in responsibility, varying capacities in caregiving and irresponsiveness to care need, were all prompted by care disruptions. This study revealed that care disruption could be grouped as minor or major. The minor disruptions were evident in daily routines where the timing of medication or food was regular or in some cases not, in other caregivers needing to step in to provide care, or in recipients needing to transition from an informal care arrangement to a formal one. These disruptions could be a minor setback in the care process, manifested over a short period of time, and require mainly some adjustment.

The major disruptions entailed a discontinuation of care brought about by the cessation of a care arrangement, migration of caregivers, structural challenges of natural disasters like famine and drought, leading to food insecurity and inability to access medical care, and extreme poverty. These major disruptions resulted in rural older people having no person or organisation to assist them, leaving them in precarious environments.

After I had completed the fieldwork for the present study, the New Vision newspaper reported a care disruption in which the SAGE program's coverage had been reduced to include only people aged 80 years and above in 71 districts (Ssejjoba, 2020). This political decision was reportedly based on the assumption that the program would cover more geographical and administrative districts but clearly discriminated against older people between 65 and 79 years of age (Ssejjoba, 2020). Yet, according to the WHO (2018), in 2015, the life expectancy at birth for Uganda was 62.3 years; 60.3 for males and 64.3 years for females. This meant that many older people's financial support was disrupted, further disempowering older people in rural Uganda and offers a more recent example of how the government was devolving responsibility towards its older citizens. The cessation of this inconsistent support was an example of care disruption that needed to be planned for, as it could increase the vulnerability of some older people who were no longer eligible. For people aged 80 years and above, a transition or dualism of care across both spheres required adjustments and a major care disruption such as this called for a broader response in both policy and practice.

This study also recognised that some older people may not have experienced disruption but exited the social care process when their vulnerabilities reduced, when they gained independence or when they recovered from an illness. Care disruptions were associated not only with negative outcomes but may also contribute to better access to care and responsibility uptake by carers, either in formal or informal care.

At the practice level, stakeholders' ability to provide adequate services was sometimes challenged by limited resources, leading to inconsistent provision or termination of care. In other cases, the FBOs formal care was terminated where an older person's extended kin were identified to take on the responsibility or could no longer afford the private care services. Due to challenges, conflicts, tensions and constraints in financing and expertise experienced at each systemic level, limited responsibility was taken for older people in rural communities. At the micro level, care disruptions involved older people going through multiple care transitions between informal and formal care and care environments. The latter was particularly evident after migration — either of the older person (from one rural area to another) or a carer (from a rural area to the city) or the death of a caregiver. However, stakeholders and informal caregivers manifested resilience and adopted coping strategies to ensure continuity in care provision, identifying which strategies were unsustainable and

which had negative implications for older people. This research has highlighted that despite the actors' enthusiasm to provide care to older people within the boundaries of their moral orientations, they were constrained in managing the challenges and assuming responsibility.

8.5 Significance of the study

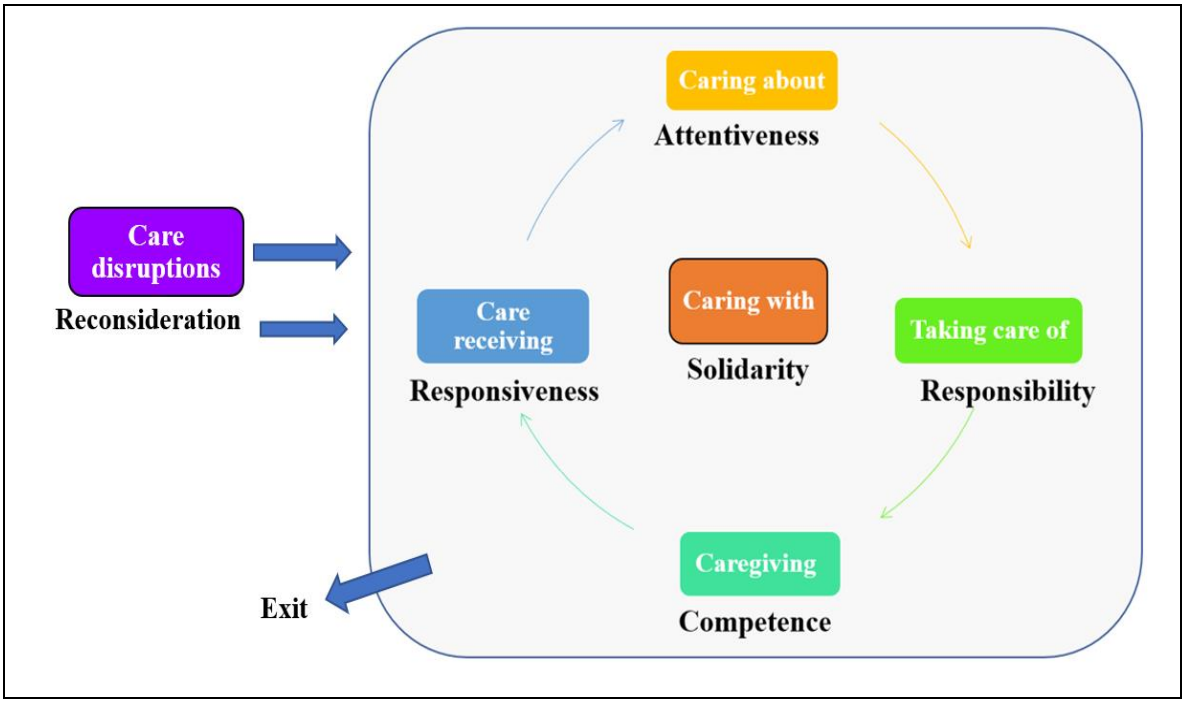
My research directly supports the World Health Organization's call to develop long-term care systems in developing African countries (WHO, 2017). The WHO called on researchers and governments to identify the current situations, initiatives, experiences, practices, policies and care models, and financing approaches that were beneficial in the development and implementation of long-term care systems (WHO, 2017). This examination and critique of the current social care system in rural Uganda offers essential information to further research and design long-term social care systems for rural older people in developing nations. Moreover, exploring the challenges in responsibility allocation has revealed valuable information about care disruptions across subsequent stages of care. These care disruptions further explain why responsibility perceptions and allocations manifest in an ambiguous manner and why the social care system is fragmented.

8.5.1 Contribution to the ethics of care theory

This study applied the EoC theory, which is rarely applied in developing countries, to understand responsibility for social care of older people in rural Uganda. Exploring the element of responsibility has contributed to understanding how other elements impact, and are equally impacted by, responsibility. Furthermore, exploring the element of responsibility has emphasised the care disruptions that occur during the care cycle in a developing country's rural context. Unlike in developed countries, where care provided by the government or other stakeholders is consistent, care provision in rural Uganda is limited and inconsistent. A key contribution to EoC theory emanates from exploring the challenges around irresponsibility, inequities and the inconsistency of care, revealing care disruptions across the macro (public) and micro (private) spheres of care. While the literature indicates that the care cycle encompasses attentiveness, responsibility, responsiveness and solidarity, this study argues that the application of EoC in developing country contexts needs to consider care disruptions that happen during the care process at both macro and micro levels. Tronto (2010) has previously acknowledged that conflict, power relations, inconsistencies, competing purposes and divergent ideas about good care could affect care

processes. Throughout the thesis, these issues were evident in the element of responsibility, leading to care disruption, a stage that can be positioned in the care cycle, as illustrated in Figure 8.2.

Figure 8.2 Positioning care disruption in the cycle phases of the care process



This study has identified various challenges, points of exit or changes in the care provided within this cyclical nature of the phases of care. Care disruptions could be considered in the care process, leading to termination of services, a call to attentiveness when the cycle starts all over again or when the need arises to address the challenges as they manifest in the care process.

Positioning the element of reconsideration against other elements in the phase of care is essential to understanding why I propose its inclusion. In the very nature of promoting solidarity and trust at the stage of *caring with*, where the care recipient is given a voice in the allocation of care responsibilities, the disruption of care is inevitable. Here, care recipients are able to choose responsible entities, which can change from time to time. Solidarity requires honesty from stakeholders regarding their ability or inability to take on responsibilities. However, with stakeholders in this study working in isolation and having limited coverage of rural areas, there was a lack of collaboration among stakeholders from government, FBOs and informal caregivers. Hence, reconsideration requires stakeholders to question and assess their resources and take responsibility for social care services they

can meet while being transparent and honest about the social care services they cannot meet. Consequently, trusting relationships across institutions and informal caregivers and older care recipients should be promoted.

Tronto (2015a, p. 6) noted, "When care is responded to, through care-receiving, and new needs are identified, we return to the first phase and begin again." However, this study identified that care was continually disrupted, and new care needs were presented. For example, most older people indicated worsening health, which caused a decline in their functioning abilities, despite caregivers taking them to a hospital or offering them traditional medicine. This meant that self-care was disrupted and provided care was unresponsive, requiring family members to be more attentive to finding alternative strategies to address care needs. Where care needs were not reconsidered, older people were often left struggling. Moreover, the study identified that some older people did not communicate when care was unresponsive, as they mentioned being tolerant of what was provided by caregivers. Tolerance or patience requires being accommodative when disruptions happen in the care process. This calls for self-discipline in handling situations such as delays in care provision. However, in cases of aggressive behaviour, neglect and abuse, both older people and caregivers should not have to tolerate this. Tolerance should also entail being open-minded and accepting when a disruption in care occurs or must occur and voicing it is essential to handling the phase of care disruption positively. For example, caregivers were patient with care recipients who refused to respond to the care when given food or being taken to the hospital, or with older people who were aggressive towards them. Further, caregivers and older people tolerated the unjust conditions in which they provided care and the challenges in the rural Ugandan context of poor roads and unsafe water, as well as other structural challenges. In northern Uganda, the drought and famine were also tolerated, to the extent that both caregivers and recipients devised coping strategies, showing their resilience. However, resilience and tolerance are not sustainable without safety nets for older people and their caregivers.

Regarding competence, care providers at both the macro and micro levels who were financially under-resourced to meet the care needs of older rural people continually contributed to the evidence of care disruptions. The inability to fund care services and provide basic needs like food, water and secure housing resulted in poor care provision and unresponsive care. Moreover, the presence of unskilled personnel in social care provision challenged the extent to which specialised care needs were met. Consequently, older people

in rural areas were continually excluded, or provided with inconsistent care that was mostly determined by the funders or care providers. For example, the FBOs decided to whom to provide material support such as sugar, soap and salt, and the frequency of this support, some of which was provided only during festive seasons or whenever they had got material assistance to distribute. Due to limited government funding, recipients of financial support could go five months without receiving any money.

The need to reconsider responsibility is further evident in the transitioning of care between informal and formal care providers; as some care providers assume responsibility, others could withdraw their commitment. As witnessed in this study, some formal care providers discontinued care once an informal caregiver was identified. Further, responsibility also shifted between informal caregivers. When responsibility is reconsidered, it is important to ascertain who then is responsible at any given time. Without such evaluation, some older people in this study were left without care at all, were neglected and/or were excluded from some services. Therefore, as the government of Uganda plans to change the target years of beneficiaries from 65/60 years to 80 years, it should reconsider who will be responsible for providing that financial support to those excluded (aged 60/65-79 years), and whether the stakeholders it proposes will have the financial and resource capacity to fulfil that responsibility. The care disruptions described in this study imply that rural older people will be disempowered and marginalised. This raises questions of who should address the care disruptions that occur at the macro and the micro levels.

This shows that decision-making associated with care and responsibility is never finished but requires a continuous cyclical phase of care. When care is disrupted, the cycle needs to be re-evaluated. Consideration of care disruptions in the ethics of care is important to understanding care practices and ethical issues at play in the context of a developing country, which experiences very different levels of vulnerability compared to developed regions, hence elevates our understanding of the precarity of care for rural older people.

8.5.2 Critical Rural Gerontology

This current study contributes to the CRG literature by employing a critical lens to look at the claims and debates of ethics of care in the rural context of a low-income country. Rural gerontologists have noted the need to expand CRG to developing country contexts to examine long-term systems (Skinner et al., 2020). The application of CRG and CHE has

elaborated the intersectionality between the macro and micro environments and the rural contexts in these countries.

Similar to previous research in rural gerontology, issues of geographical isolation, low socio-economic status, limited access to health and care facilities, a limited workforce and inadequate government funding (Walsh & Skinner, 2019a) are evident in the case study rural communities in this research. However, Uganda's rural disadvantage is particularly severe, given the reliance on subsistence farming, extreme poverty and a lack of safety nets. In northern Uganda, semi-arid weather conditions resulted in disasters like famine and drought that affected the carers' ability to provide basic needs, especially food, to older care recipients. This study has highlighted categories of strenuous care activities like fetching water and firewood and digging in rural developing countries that would not otherwise be considered in rural developed countries.

Keating et al. (2020) remarked that macro contexts generate opportunities or limitations in the lives of older people. In this study, the macro context largely constrained care provision in rural Uganda. Rural caregivers were continuously challenged in their caring roles by the state's inadequacy and ineffectiveness in providing public good, evidenced by poor roads, unsafe water and non-functional health centres. Therefore, and despite their resilience, the coping strategies of some caregivers in rural areas posed further threats to the lives and wellbeing of older people than otherwise. The rural inequalities in accessing social care were more pronounced due to the lack of clear guidelines around responsibility allocation of various actors and the lack of social care policy. Rural inequalities were further produced by the channelling of some financial aid or initiatives to some rural areas (in northern Uganda) as opposed to other rural settings (like central Uganda, as established in this study), which were excluded from the internationally donor-funded initiatives of FBOs and central government. It is clear that the poorly structured macro environment contributed to the disempowerment of older people in the micro environments.

This research has further captured the diverse lived experiences of older people in rural Uganda, which, according to critical rural gerontologists, offers a greater representation of older people in the Global South (Keating et al., 2020). The voices of discontent, the silenced voices in deciding the course of care received, voices of gratitude for the little they received, the plea of older people to have their social care needs met—these voices indicated that standardisation of financial assistance leads to further disenfranchisement of rural older

people. The perspectives of stakeholders, caregivers and older people are essential in guiding more sensitive policies that do not treat older people as one homogenous group with the same care needs, but rather both similar and diverse care needs that vary according to their geographical contexts and individual experiences.

8.6 Implications for research, policy, and practice

Understanding how social care is experienced at different levels, the fragmentation, inconsistency and unregulated social care provision, together with the conflicts and tensions within the policies, offers implications for policy and practice. These implications are essential when considering how best to design social care schemes and support each care system.

8.6.1Implications for policy

This study identified how responsibility assigned at the macro level impacts responsibility allocation and assumption of obligations at micro levels. First, it acknowledges that government should explore ways to assume greater responsibility for social care provision for older people. It is evident that the current policies are ineffective in addressing social care needs for older people in Uganda and by continuing to allocate social care responsibility to families and local governments who are constrained with resources, the status quo will remain and no positive impact will be achieved. Moreover, Uganda's development goals will not be achieved as limited attention to social care also contributes to older people's vulnerability and poorer socio-economic status. This study identified various social care services provided by different stakeholders. It is suggested, therefore, that government assume more responsibility in the following areas:

1. Government should increase social care provision in different geographical locations and diversify the care services beyond the one care home identified in central Uganda that the government runs.
2. Government should provide clear responsibility allocations between stakeholders and formal policy guidelines on care standards that care providers should adhere to. This could ensure that older people are not neglected, abused, discriminated against or prevented from accessing social care services.
3. Although social care is viewed as a pillar of social protection, continued disparities in budgetary allocations that prioritise social security over social care will hinder social protection goals. Therefore, the government should take responsibility for increasing funding for social care for older people. This can be achieved in

partnership with local and international actors. Addressing financial misappropriation of funds is an essential responsibility that government should undertake to enhance trust and collaboration with the various stakeholders.

4. Addressing the challenges that contribute to care disruptions is important for government to enhance the ability of other stakeholders and informal caregivers to fulfil their responsibilities for care provision for older people in rural areas.

8.6.2 Implications for practice

This study also identified significant implications for social care practice in rural Uganda. The introduction of social care practice in Uganda to increase professional responsibility for care will play an important role in improving the social care system. It was evident that those who provided direct or hands-on care were largely unskilled in terms of professional accreditation. As noted in this study, ethics of care could offer grounds for promoting applied research in social care practice and rural ageing studies. It could widen the boundaries beyond '*caring about* social problems of older people' and take on a degree of responsibility. This study found complexities in care practices, responsibilities, rural inequalities at the macro and micro levels in rural Uganda. However, it has implications for improving social care systems in other developing countries, especially in sub-Saharan Africa with similar social, economic, political and historical contexts.

8.7 Recommendations

As noted earlier, this thesis also contributes new insights into the ideal social care system that stakeholders, caregivers and older people expect. This research asked participants for their suggestions for solving problems that negatively impact on social care provision in rural areas. This transformative study prioritised marginalised voices (Mertens et al., 2009), the informal caregivers and older people in Uganda's rural areas. Responses from all systems were integrated based on the ecological framework. A fundamental finding from the participants' various expectations was that the family alone cannot shoulder social care responsibility, nor can the government or the community. Therefore, a collective effort is required to enable reforms in how society and governments should perceive, provide and organise care for older people in rural areas.

1. Policymakers need to formulate a Social Care for Older Persons Act that explicitly states the principles for improving social care for older people. This Act should also detail the guidelines and standardisation to ensure the quality of social care services

and ethical conduct for formal and informal service providers. Furthermore, this Act should establish a degree of responsibility between state and non-state (local and international) actors. Therefore, *assigning* responsibility for care of older people in rural areas is the best means of ensuring that these responsibilities are fulfilled.

2. Policy interventions need to focus beyond short-term piecemeal solutions and heavy donor reliance to more sustainable, realistic and achievable long-term social care services. These reliable care systems can be attained by considering each actor's moral positioning, the contextual factors (personal, cultural, environmental, social, economic, historical and political), and the policy actors and resources available at different administrative and ecological levels to yield positive policy outcomes. There is also a need to consider the heterogeneity of older people and rural communities. Scholars have noted that the continual viewing of older people and their environments as homogenous results in policies being less effective and generalised (Walsh et al., 2012).

3. Stakeholders expect the government to invest in expanding the care workforce through social care training of Village Health Teams (VHTs) and caregivers who work with older people in rural areas. The training needs to be tailored to the specific needs of rural older people, their caregivers and professional carers. Training of stakeholders in their organisations or companies is essential for preparing the rural workforce, which could contribute to professionalising the field of social care and social work in Uganda. Training could include delivering person-centred care, a care worker's role, stress management and delivering culturally competent care. Programs such as outreach services to older people in rural areas could be introduced, using existing VHTs programs to respond to the older people's needs as they and their families perceive them.

8.8 Limitations and strengths

This study considered only a small number of participants from the national level and two rural communities at the local level; therefore, it is not generalisable. Furthermore, this study was limited to rural settings, excluding urban locations. Hence, although this study contributed to understanding rural geographies of care in Uganda, older people in urban areas could experience social care differently. Their interactions with environments could differ, as could the services available to them, as most NGO and FBO offices are located

in urban areas. Further still, the cultural groups considered were the Langi and Baganda. This left out the cultures in western and eastern Uganda, which could have quite different cultural practices and care provision expectations. Another limitation related to language and communication in the study site, where I was an outsider and did not speak the native language. While some participants also spoke English, most of them did not. The research assistant shared notes during the FGDs and interviews to allow for probing. Carers who had engaged in paid work were not included in the FGDs, as interviews were conducted during the day, within working hours. This meant that the lived experiences of carers in formal employment were not explored in this study. Furthermore, while reference was made to young people's caregiving, no ethical approval to engage children as participants was sought, hence their lived experiences were not captured in this study.

The critical transformative inquiry using multiple data collection methods was a strength in this study. Using interviews, policy documents and FGDs were essential in gathering information from various sources, adding to the richness of the data within a limited timeframe and validating the findings. The transformative paradigm allowed for the application of various theories to understand responsibility allocation. A comprehensive investigation across different ecological environments captured different voices and perceptions of the vulnerable and marginalised populations. The critical aspect enriched the research findings and in-depth exploration of the social care problem, which revealed various challenges in taking up responsibility, thus contributing to the care theory of incorporating care disruptions within the care phases. Moreover, travelling back to Uganda enabled a personal experience in the study sites, which I had not been to before the research. Being in the field and experiencing some of the challenges that participants talked about (presented in Chapter Four) enhanced my understanding of the information about their experiences. Being an insider with the stakeholders in professional terms enhanced the recruitment and flexibility in the venue of interviews. Furthermore, being an insider, a Muganda, speaking the same language with participants, I understood the cultural environment of the research. Although I was an outsider in northern Uganda, having the historical background knowledge was beneficial in accessing and probing participants. The research assistant, who was very experienced in conducting research in the northern region and in navigating the study site, was a great strength who enabled the capture of gendered roles in two ethnic groups in Uganda.

8.9 Future research directions

The same ecological approach could be used to compare urban locations and day-to-day care practices in other cultures to obtain a comprehensive picture of social care in Uganda and would be essential in furthering our understanding of the geographies of care. The use of a quantitative inquiry to explore social care could further be conducted. The elements explored in this qualitative research could be essential concepts and variables in research on a wider scope and for developing questionnaires within an ecological systems framework. Given that not even two rural areas experience care the same way, exploring multiple rural areas across various regions of Uganda is necessary.

Further research could extend this study's findings by exploring how care disruptions are handled by care recipients, caregivers and professionals (social workers, health workers, and care workers). Research into care disruptions could further our understanding of how responsibility is continually renegotiated and the impacts of care disruptions on older care recipients. This exploration could improve debates associated with responsibility allocation and care responsiveness and improve social care provision in developing countries.

Applying EoC theory and CRG perspectives to widen our understanding of ageing in a low-income country context across ecological environments is essential for future research. Studies could consider:

i) Future investigations into social care systems in SSA across ethnic and geographical divides.
ii) The vulnerabilities and the call for social justice for older people and carers.
iii) How care disruptions manifest at different ecological levels and countries.
iv) Challenging the status quo that privileges some groups in society, a vital step in bringing care democratically from the private to the public domain.

8.10 Conclusion

This research has demonstrated that the social care system for older people in rural areas is inconsistent, underfunded, fragmented, under-resourced and unregulated. The responsibility for social care continues to be placed on families, and the roles or responsibilities of other stakeholders (in the private, public and voluntary sectors) remain unreliable and ambiguous. The study has highlighted that the element of responsibility impacts and is impacted by other EoC elements during care disruptions. It identified three essential issues to improve the social care system for older people in these rural

communities: (i) formulation of a social care policy where responsibility allocation and guidelines are clearly stipulated; (ii) training of caregivers and various actors and (iii) using available resources to address the care disruptions experienced in social care provision. The application of CRG to the EoC theory within an ecological approach has enhanced our understanding of why social care responsibility is continually shifted between actors and the implications of those shifts. A variety of factors, experiences and challenges for older people, caregivers and stakeholders within the interacting systems and environments previously discussed have contributed to this construction. This study has furthered my understanding that individuals' willingness to take on aged care responsibility is challenged despite their resilience in continuing to provide care.

Before this PhD, the geographical inequities in social care provision between urban and peri-urban areas were evident to me during my previous work in urban areas and volunteering sessions in rural communities. However, during this journey, I realised that the rural-rural geographical inequalities were more pronounced. EoC theory is essential in furthering debate and discussions about the responsibility allocation of social care for older people in developing countries like Uganda. Building long-term care systems for older people requires the consideration of ethics of care in geriatric social work practice, social policy, research and critical rural gerontology. The ability to address care disruptions is essential to improving care services, increasing the responsibility of actors, and enhancing older people's wellbeing and social justice in social care.

APPENDICES

Appendix One: Ethical Approval La Trobe University

From: humanethics@latrobe.edu.au <humanethics@latrobe.edu.au>

Sent: Friday, 23 November 2018 2:42 PM

To: Suzanne Hodgkin

Cc: DIANA ERINAH NABBUMBA; Jacqui Theobald; Rachel Winterton

Subject: HEC18466 - New Application - Approved

** This is an automatically generated email, please do not reply. Contact details are listed below.**

Dear Suzanne Hodgkin,

The following project has been assessed as complying with the National Statement on Ethical Conduct in Human Research. I am pleased to advise that your project has been granted ethics approval and you may commence the study.

Application ID: HEC18466
Application Status/Committee: University Human Ethics Committee

Project Title: EXPLORING THE SYSTEMIC NATURE OF SOCIAL CARE PROVISION AND EXPECTATIONS FOR OLDER PEOPLE IN RURAL UGANDA: A TRANSFORMATIVE QUALITATIVE STUDY

Chief Investigator: Suzanne Hodgkin

Other Investigators: Diana Erinah Nabbumba, Rachel Winterton, Jacqueline Theobald
Research Assistant: Ms Aduk Euphrasia

Date of Approval: 23/11/2018
Date of Ethics Approval Expiry: 23/11/2023

The following standard conditions apply to your project:

- Limit of Approval. Approval is limited strictly to the research proposal as submitted in your application.

- Variation to Project. Any subsequent variations or modifications you wish to make to your project must be formally notified for approval in advance of these modifications being introduced into the project.

- Adverse Events. If any unforeseen or adverse events occur the Chief Investigator must notify the UHEC immediately. Any complaints about the project received by the researchers must also be referred immediately to the UHEC.

- Withdrawal of Project. If you decide to discontinue your research before its planned completion, you must inform the relevant committee and complete a Final Report form.

- Monitoring. All projects are subject to monitoring at any time by the University Human Ethics Committee.

- Annual Progress Reports. If your project continues for more than 12 months, you are required to submit a Progress Report annually, on or just prior to 12 February. The form is available on the Research Office website. Failure to submit a Progress Report will mean approval for this project will lapse.

- Auditing. An audit of the project may be conducted by members of the UHEC.

- Final Report. A Final Report (see above address) is required within six months of the completion of the project.

You may log in to ResearchMaster (https://rmenet.latrobe.edu.au) to view your application.

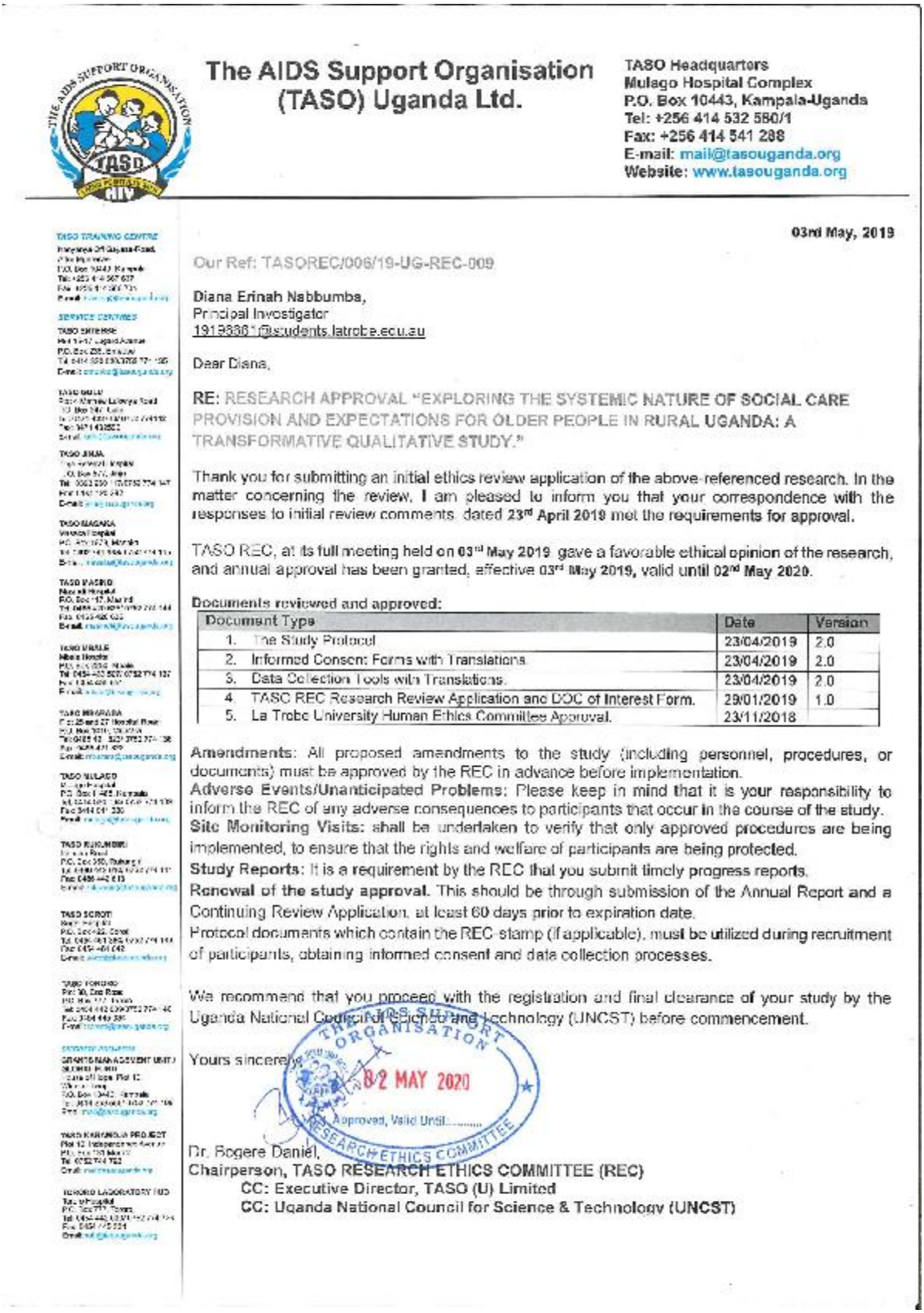
Should you require any further information, please contact the Human Research Ethics Team on:
T: +61 3 9479 1443| E: humanethics@latrobe.edu.au.

Warm regards,

Human Research Ethics Team

Ethics, Integrity & Biosafety, Research Office

Appendix Two: Ethical approval TASO ethics review board



The AIDS Support Organisation (TASO) Uganda Ltd.

TASO Headquarters
Mulago Hospital Complex
P.O. Box 10443, Kampala-Uganda
Tel: +256 414 532 580/1
Fax: +256 414 541 288
E-mail: mail@tasouganda.org
Website: www.tasouganda.org

03rd May, 2019

Our Ref: TASOREC/006/19-UG-REC-009

Diana Erinah Nabbumba,
Principal Investigator
19195361@students.latrobe.ecu.au

Dear Diana,

RE: RESEARCH APPROVAL "EXPLORING THE SYSTEMIC NATURE OF SOCIAL CARE PROVISION AND EXPECTATIONS FOR OLDER PEOPLE IN RURAL UGANDA: A TRANSFORMATIVE QUALITATIVE STUDY."

Thank you for submitting an initial ethics review application of the above-referenced research. In the matter concerning the review, I am pleased to inform you that your correspondence with the responses to initial review comments dated 23rd April 2019 met the requirements for approval.

TASO REC, at its full meeting held on 03rd May 2019 gave a favorable ethical opinion of the research, and annual approval has been granted, effective 03rd May 2019, valid until 02nd May 2020.

Documents reviewed and approved:

Document Type	Date	Version
1. The Study Protocol	23/04/2019	2.0
2. Informed Consent Forms with Translations	23/04/2019	2.0
3. Data Collection Tools with Translations.	23/04/2019	2.0
4. TASO REC Research Review Application and DOC of Interest Form.	29/01/2019	1.0
5. La Trobe University Human Ethics Committee Approval.	23/11/2018	

Amendments: All proposed amendments to the study (including personnel, procedures, or documents) must be approved by the REC in advance before implementation.
Adverse Events/Unanticipated Problems: Please keep in mind that it is your responsibility to inform the REC of any adverse consequences to participants that occur in the course of the study.
Site Monitoring Visits: shall be undertaken to verify that only approved procedures are being implemented, to ensure that the rights and welfare of participants are being protected.
Study Reports: It is a requirement by the REC that you submit timely progress reports.
Renewal of the study approval. This should be through submission of the Annual Report and a Continuing Review Application, at least 60 days prior to expiration date.
Protocol documents which contain the REC stamp (if applicable), must be utilized during recruitment of participants, obtaining informed consent and data collection processes.

We recommend that you proceed with the registration and final clearance of your study by the Uganda National Council of Science and Technology (UNCST) before commencement.

Yours sincerely,

02 MAY 2020
Approved, Valid Until.....

Dr. Bogere Daniel,
Chairperson, TASO RESEARCH ETHICS COMMITTEE (REC)
CC: Executive Director, TASO (U) Limited
CC: Uganda National Council for Science & Technology (UNCST)

Appendix Three: Ethical approval UNCST

Uganda National Council for Science and Technology

(Established by Act of Parliament of the Republic of Uganda)

Our Ref: HS322ES **26 August 2020**

Diana Nabbumba
Kitala Local council
Wakiso

Re: Research Approval: **Exploring the systemic nature of social care provision and expectations for older people in rural Uganda: A transformative qualitative study**

I am pleased to inform you that on **26/08/2020**, the Uganda National Council for Science and Technology (UNCST) approved the above referenced research project. The Approval of the research project is for the period of **26/08/2020** to **26/08/2021**.

Your research registration number with the UNCST is **HS322ES**. Please, cite this number in all your future correspondences with UNCST in respect of the above research project. As the Principal Investigator of the research project, you are responsible for fulfilling the following requirements of approval:

1. Keeping all co-investigators informed of the status of the research.
2. Submitting all changes, amendments, and addenda to the research protocol or the consent form (where applicable) to the designated Research Ethics Committee (REC) or Lead Agency for re-review and approval **prior** to the activation of the changes. UNCST must be notified of the approved changes within five working days.
3. For clinical trials, all serious adverse events must be reported promptly to the designated local REC for review with copies to the National Drug Authority and a notification to the UNCST.
4. Unanticipated problems involving risks to research participants or other must be reported promptly to the UNCST. New information that becomes available which could change the risk/benefit ratio must be submitted promptly for UNCST notification after review by the REC.
5. Only approved study procedures are to be implemented. The UNCST may conduct impromptu audits of all study records.
6. An annual progress report and approval letter of continuation from the REC must be submitted electronically to UNCST. Failure to do so may result in termination of the research project.

Please note that this approval includes all study related tools submitted as part of the application as shown below:

No.	Document Title	Language	Version Number	Version Date
1	consent form caregiver	English	1	
2	consent form caregivers	Luganda		
3	Consent form caregivers	Luo		
4	consent form key stakeholders	English		
5	Consent form older care recipients	Luganda		
6	Consent form older care recipients	English		
7	Consent form older care recipient	Luo		

8	FGD and interview guide	Luo		
9	FGD guide	English		
10	FGD guide	Luganda		
11	Key stakeholder interview guide	English		
12	Older care recipients interview guide	English		
13	Older care recipients interview guide	Luganda		
14	Project Proposal	English		
15	Approval Letter	English		0000-00-00
15	Consent form caregivers	English	3	14 November 2019
16	Consent form Key stakeholders	English	3	14 November 2019
17	Consent form older care recipients	English	3	14 November 2019
18	Confirmation of enrollment	English	1	10 August 2017
19	La Trobe HEC approval letter	English	1	23 November 2018

Yours Sincerely

Hellen Opolot
For: Executive Secretary
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

Appendix Four: Participant consent form and information statement (Stakeholders)

LA TROBE UNIVERSITY

Participant Information Statement and Consent Form

The research is being carried out in partial fulfilment of PhD under the supervision of Assoc. Prof. Suzanne Hodgkin. The following researchers will be conducting the study:

Role	Name	Organisation
Chief Investigator	Assoc. Prof. Suzanne Hodgkin	La Trobe University
Associate Investigator	Dr. Rachel Winterton	La Trobe University
Associate Investigator	Dr. Jacqui Theobald	La Trobe University
Student	Diana Nabbumba	La Trobe University
Research assistant	Euphrasia Aduk	

1. **What is the study about?**
   You are invited to participate in a study of the current state of social care for older people in rural areas of Uganda. We hope to learn about how the social care system is organised and the social care services that are available for older people in rural areas. The experiences of caregivers and older people in providing and seeking social care. The challenges they face and recommendation on how to solve them. This study will involve approximately 60 participants.

   Your contact details were obtained from your organisation website or key informant from the Ministry of Gender or your colleague *(state the name)*.

2. **Do I have to participate?**
   Being part of this study is voluntary. If you want to be part of the study we ask that you read the information below carefully and ask us any questions.

   You can read the information below and decide at the end if you do not want to participate. If you decide not to participate this won't affect your relationship with La Trobe University or any other listed organisation.

3. **Who is being asked to participate?**
   You have been asked to participate because:
   - You are knowledgeable about social care issues in Uganda.
   - You work with an organisation the supports older people in rural Uganda.

4. **What will I be asked to do?**
   If you want to take part in this study, we will ask you to some questions in an interview. It will take 60 minutes of your time to be part of this study.

5. **What are the benefits?**
   The benefit of you taking part in this study is that you may also gain a sense of purpose as information will be shared and published, increasing awareness of the plight of older people. The expected benefit to society in general is that results will be used to inform action for change. For your time and effort, you will be compensated with fifteen thousand (15.000) Uganda shillings.

6. **What are the risks?**
   With any study there are (1) risks we know about, (2) risks we don't know about, and (3) risks we don't expect. If you experience something that you aren't sure about, please contact us immediately so we can discuss the best way to manage your concerns. A compensation for your time will be provided to you.

Name/Organisation	Position	Telephone	Email
Diana Nabbumba La Trobe University	PhD Student		

You may experience some distress during the interview, if you do, the interview will be stopped immediately. You will be encouraged to contact your mental health provider or with your consent, the research assistant will contact your medical doctor or mental health provider.

7. **What will happen to information about me?**
We will collect and store information about you in ways that will not reveal who you are. This means you cannot be identified in any type of publication from this study.

We will keep your information for 5 years after the project is completed. After this time we will destroy all of your data.

We will collect, store and destroy your data in accordance with La Trobe Universities Research Data Management Policy which can be viewed online using the following link: https://policies.latrobe.edu.au/document/view.php?id=106/.

The information you provide is personal information for the purposes of the Privacy and Date Protection Act 2014 (Vic). You have the right to access personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the Information Privacy Act.

8. **Will I hear about the results of the study?**
We will let you know about the results of the study by emailing you through the email address you have provided.

9. **What if I change my mind?**
At any time you can choose to no longer be part of the study. You can let us know by:
1. Completing the 'Withdrawal of Consent Form' (provided at the end of this document);
2. Calling us;
3. Emailing us

Your decision to withdraw at any point will **not** affect your relationship with La Trobe University.

When you withdraw we will stop asking you for information. Any identifiable information about you will be withdrawn from the research study. However, once the results have been analysed we can only withdraw information, such as your name and contact details. If results haven't been analysed you can choose if we use those results or not.

10. **Who can I contact for questions or want more information?**
If you would like to speak to us, please use the contact details below:

Name/Organisation	Position	Telephone	Email
Diana Nabbumba La Trobe University	PhD Student		

11. **What if I have a complaint?**

If you have a complaint about any part of this study, please contact:

Ethics Reference Number	Name & Position	Telephone	Email
118939	Senior Research Ethics Officer	+61 3 9479 1443	humanethics@latrobe.edu.au
TASOREC/006/19-UG-REC-009	Dr. Bogere Daniel, Chairperson		

Consent Form – Declaration by Participant

I (the participant) have read (or, where appropriate, have had read to me) and understood the participant information statement, and any questions have been answered to my satisfaction. I agree to participate in the study, I know I can withdraw at any time. I agree information provided by me or with my permission during the project may be included in a thesis, presentation and published in journals on the condition that I cannot be identified.

I would like my information collected for this research study to be:
☐ Only used for this specific study;
☐ Used for future related studies;
☐ Used for any future studies

☐ I agree to have my interview audio and/or video recorded
☐ I would like to receive a copy of the results via email or post. I have provided my details below and ask that they only be used for this purpose and not stored with my information or for future contact.

Name	Email (optional)	Postal address (optional)

Participant Signature

☐ I have received a signed copy of the Participant Information Statement and Consent Form to keep

Participant's printed name	
Participant's signature	
Date	

Declaration by Researcher

☐ I have given a verbal explanation of the study, what it involves, and the risks and I believe the participant has understood;
☐ I am a person qualified to explain the study, the risks and answer questions

Researcher's printed name	
Researcher's signature	
Date	

* All parties must sign and date their own signature

THE AIDS SUPPORT ORGANISATION
02 MAY 2020
Approved, Valid Until:
RESEARCH ETHICS COMMITTEE

Withdrawal of Consent

I wish to withdraw my consent to participate in this study. I understand withdrawal will not affect my relationship with La Trobe University. I understand the researchers cannot withdraw my information once it has been analysed, and/or collected as part of a focus group.

I understand my information will be withdrawn as outlined below:

- ✓ Any identifiable information about me will be withdrawn from the study
- ✓ The researchers will withdraw my contact details so I cannot be contacted by them in the future studies unless I have given separate consent for my details to be kept in a participant registry.
- ✓ The researchers cannot withdraw my information once it has been analysed, and/or collected as part of a focus group

***if you have consented for your contact details to be included in a participant registry you will need to contact the registry staff directly to withdraw your details.*

I would like my already collected and unanalysed data

☐ Destroyed and not used for any analysis

☐ Used for analysis

Participant Signature

Participant's printed name	
Participant's signature	
Date	

Please forward this form to:

CI Name	Assoc. Prof. Suzanne Hodgkin
Email	s.hodgkin@latrobe.edu.au
Phone	
Postal Address	PO Box 821 Wodonga, Victoria Australia

Appendix Five: participant consent form (Caregivers)

LA TROBE UNIVERSITY

Participant Information Statement and Consent Form

The research is being carried out in partial fulfilment of PhD under the supervision of Assoc. Prof Suzanne Hodgkin. The following researchers will be conducting the study:

Role	Name	Organisation
Chief Investigator	Assoc. Prof. Suzanne Hodgkin	La Trobe University
Associate Investigator	Dr. Rachel Winterton	La Trobe University
Associate Investigator	Dr. Jacqui Theobald	La Trobe University
Student	Diana Nabbumba	La Trobe University
Research assistant	Euphrasia Aduk	
Research funder	This research is supported by in kind support by La Trobe University.	

1. **What is the study about?**
   You are invited to participate in a study of the current state of social care for older people in rural areas of Uganda. We hope to learn about how the social care system is organised and the social care services that are available for older people in rural areas. The experiences of caregivers and older people in providing and seeking social care. The challenges they face and recommendation on how to solve them. This study will involve approximately 60 participants.

   You have voluntarily offered your contact details.

2. **Do I have to participate?**
   Being part of this study is voluntary. If you want to be part of the study we ask that you listen to the information being read out to carefully, ask us any questions and decide at the end if you do or do not want to participate. If you decide not to participate this won't affect your relationship with La Trobe University or any service organisation in your local area.

3. **Who is being asked to participate?**
   You have been asked to participate because:
   - You are providing care to an older person.
   - You are knowledgeable about social care issues in your community.

4. **What will I be asked to do?**
   If you want to take part in this study, we will ask you to some questions in an interview. It will take 1 hour 30 minutes of your time to be part of this study.

5. **What are the benefits?**
   There will be no direct benefits to you personally but an opportunity to contribute your views and share your experiences, personal feelings and thoughts. You may also gain a sense of purpose as information will be shared and published, increasing awareness of the plight of social care for older people. The expected benefit to society in general is that results will be used to inform action for change in relation to social care in Uganda. For your time and effort on the study, you will be compensated with fifteen thousand (15.000) Uganda shillings.

6. **What are the risks?**
   With any study there are (1) risks we know about, (2) risks we don't know about, and (3) risks we don't expect. If you experience something that you aren't sure about, please contact us immediately so we can discuss the best way to manage your concerns. A compensation for your time will be provided to you.

Name/Organisation	Position	Telephone	Email
Diana Nabbumba La Trobe University	PhD Student		

We have listed the risks we know about below. This will help you decide if you want to be part of the study.

- It is possible that talking about your experiences may be upsetting for you. If you become upset during the course of the interview and you do not wish to continue, the researcher will stop the interview immediately. You will be referred to the Health centre III for medical attention.

7. What will happen to information about me?

We will collect and store information about you in ways that will not reveal who you are. This means you cannot be identified in any type of publication from this study.

We will keep your information for 5 years after the project is completed. After this time we will destroy all of your data.

We will collect, store and destroy your data in accordance with La Trobe Universities Research Data Management Policy which can be viewed online using the following link: https://policies.latrobe.edu.au/document/view.php?id=106/.

The information you provide is personal information for the purposes of the Privacy and Date Protection Act 2014 (Vic). You have the right to access personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the Information Privacy Act.

8. Will I hear about the results of the study?

We will let you know about the results of the study by inviting you to a meeting where the research assistant and Community Development Officer will you of the findings.

9. What if I change my mind?

At any time you can choose to no longer be part of the study. You can let us know by:

1. Completing the 'Withdrawal of Consent Form' (provided at the end of this document);
2. Calling us;

Your decision to withdraw at any point will **not** affect your relationship with La Trobe University.

When you withdraw we will stop asking you for information. Any identifiable information about you will be withdrawn from the research study. However, once the results have been analysed we can only withdraw information, such as your name and contact details. If results haven't been analysed you can choose if we use those results or not.

10. Who can I contact for questions or want more information?

If you would like to speak to us, please use the contact details below:

Name/Organisation	Position	Telephone	Email
Diana Nabbumba La Trobe University	PhD Student		

11. What if I have a complaint?

If you have a complaint about any part of this study, please contact:

Ethics Reference Number	Name & Position	Telephone	Email
118939 TASOREC/006/19-UG-REC-009	Senior Research Ethics Officer Dr. Bogere Daniel, Chairperson	+61 3 9479 1443	humanethics@latrobe.edu.au

THE AIDS SUPPORT ORGANISATION
RESEARCH ETHICS COMMITTEE
02 MAY 2020
Approved, Valid Until:

Consent Form – Declaration by Participant

I (the participant) have read (or, where appropriate, have had read to me) and understood the participant information statement, and any questions have been answered to my satisfaction. I agree to participate in the study, I know I can withdraw at any time. I agree information provided by me or with my permission during the project may be included in a thesis, presentation and published in journals on the condition that I cannot be identified.

I would like my information collected for this research study to be:
☐ Only used for this specific study;
☐ Used for future related studies;
☐ Used for any future studies

☐ I agree to have my interview audio and/or video recorded
☐ I would like to receive a copy of the results via email or post. I have provided my details below and ask that they only be used for this purpose and not stored with my information or for future contact.

Name	Email (optional)	Postal address (optional)

Participant Signature

☐ I have received a signed copy of the Participant Information Statement and Consent Form to keep

Participant's printed name	
Participant's signature	
Date	

Declaration by Researcher

☐ I have given a verbal explanation of the study, what it involves, and the risks and I believe the participant has understood;
☐ I am a person qualified to explain the study, the risks and answer questions

Researcher's printed name	
Researcher's signature	
Date	

* All parties must sign and date their own signature

THE AIDS SUPPORT ORGANISATION
RESEARCH ETHICS COMMITTEE
02 MAY 2020
Approved, Valid Until:

Withdrawal of Consent

I wish to withdraw my consent to participate in this study. I understand withdrawal will not affect my relationship with La Trobe University. I understand the researchers cannot withdraw my information once it has been analysed, and/or collected as part of a focus group.

I understand my information will be withdrawn as outlined below:

- ✓ Any identifiable information about me will be withdrawn from the study
- ✓ The researchers will withdraw my contact details so I cannot be contacted by them in the future studies unless I have given separate consent for my details to be kept in a participant registry.
- ✓ The researchers cannot withdraw my information once it has been analysed, and/or collected as part of a focus group

***if you have consented for your contact details to be included in a participant registry you will need to contact the registry staff directly to withdraw your details.*

I would like my already collected and unanalysed data
☐ Destroyed and not used for any analysis
☐ Used for analysis

Participant Signature

Participant's printed name	
Participant's signature	
Date	

Please forward this form to:

CI Name	Assoc. Prof. Suzanne Hodgkin
Email	s.hodgkin@latrobe.edu.au
Phone	
Postal Address	PO Box 821 Wodonga, Victoria Australia

THE AIDS SUPPORT ORGANISATION RESEARCH ETHICS COMMITTEE Approved, Valid Until: 02 MAY 2020

Appendix Six: Participant information form (Older people)

LA TROBE UNIVERSITY

Participant Information Statement and Consent Form

The research is being carried out in partial fulfilment of PhD under the supervision of Assoc Prof Suzanne Hodgkin. The following researchers will be conducting the study:

Role	Name	Organisation
Chief Investigator	Assoc. Prof. Suzanne Hodgkin	La Trobe University
Associate Investigator	Dr. Rachel Winterton	La Trobe University
Associate Investigator	Dr. Jacqui Theobald	La Trobe University
Student	Diana Nabbumba	La Trobe University
Research assistant	Euphrasia Aduk	

1. **What is the study about?**
   You are invited to participate in a study of the current state of social care for older people in rural areas of Uganda. We hope to learn about how the social care system is organised and the social care services that are available for older people in rural areas. The research will be informed by the experiences, challenges and recommendations of caregivers and older people who provide and seek social care. This study will involve approximately 60 participants.

   Your contact details were obtained from your caregiver.

2. **Do I have to participate?**
   Being part of this study is voluntary. If you want to be part of the study we ask that you listen to the information being read out to carefully and ask us any questions and decide at the end if you do or do not want to participate. If you decide not to participate this won't affect your relationship with La Trobe University or any service organisation in your local area.

3. **Who is being asked to participate?**
   You have been asked to participate because:
   - You are an older person receiving social care, hence have experiences in seeking care/assistance.
   - You are knowledgeable about social care issues in your community.

4. **What will I be asked to do?**
   If you want to take part in this study, we will ask you to participate in an interview. It will take 60 minutes of your time to be part of this study.

5. **What are the benefits?**
   There will be no direct benefits to you personally but an opportunity to contribute your views and share your experiences, personal feelings and thoughts. You may also gain a sense of purpose as information will be shared and published, increasing awareness of the plight of social care for older people. The expected benefit to society in general is that results will be used to inform action for change in relation to social care in Uganda. For your time and effort on this study, you will be compensated with fifteen thousand (15.000) Uganda Shillings.

6. **What are the risks?**
   With any study there are (1) risks we know about, (2) risks we don't know about, and (3) risks we don't expect. If you experience something that you aren't sure about, please contact us immediately so we can discuss the best way to manage your concerns. A compensation for your time will be provided to you.

Name/Organisation	Position		Telephone	Email
Diana Nabbumba La Trobe University	PhD Student			

We have listed the risks we know about below. This will help you decide if you want to be part of the study.

- It is possible that talking about your experiences may be upsetting for you. If you become upset during the course of the interview and you do not wish to continue, the researcher will stop the interview immediately. If you prefer, you can have a support person or trusted family member or friend nearby. You will be referred to the Health centre III for medical attention.

7. What will happen to information about me?

We will collect and store information about you in ways that will not reveal who you are. This means you cannot be identified in any type of publication from this study.

We will keep your information for 5 years after the project is completed. After this time we will destroy all of your data.

We will collect, store and destroy your data in accordance with La Trobe Universities Research Data Management Policy which can be viewed online using the following link: https://policies.latrobe.edu.au/document/view.php?id=106/.

The information you provide is personal information for the purposes of the Privacy and Date Protection Act 2014 (Vic). You have the right to access personal information held about you by the University, the right to request correction and amendment of it, and the right to make a complaint about a breach of the Information Protection Principles as contained in the Information Privacy Act.

8. Will I hear about the results of the study?

We will let you know about the results of the study by inviting you to a meeting where the research assistant and Community Development Officer will share with you the findings.

9. What if I change my mind?

At any time you can choose to no longer be part of the study. You can let us know by:

1. Completing the 'Withdrawal of Consent Form' (provided at the end of this document);
2. Calling us.

Your decision to withdraw at any point will **not** affect your relationship with La Trobe University.

When you withdraw we will stop asking you for information. Any identifiable information about you will be withdrawn from the research study. However, once the results have been analysed we can only withdraw information, such as your name and contact details. If results haven't been analysed you can choose if we use those results or not.

10. Who can I contact for questions or want more information?

If you would like to speak to us, please use the contact details below:

Name/Organisation	Position		Telephone	Email
Diana Nabbumba La Trobe University	PhD Student			

11. What if I have a complaint?

If you have a complaint about any part of this study, please contact:

Ethics Reference Number	Name & Position	Telephone	Email
118939 TASOREC/006/19-UG-REC-009	Senior Research Ethics Officer Dr. Bogere Daniel, Chairperson	+61 3 9479 1443	humanethics@latrobe.edu.au

THE AIDS SUPPORT ORGANISATION
RESEARCH ETHICS COMMITTEE
Approved, Valid Until:
02 MAY 2020

Consent Form – Declaration by Participant

I (the participant) have read (or, where appropriate, have had read to me) and understood the participant information statement, and any questions have been answered to my satisfaction. I agree to participate in the study, I know I can withdraw at any time. I agree information provided by me or with my permission during the project may be included in a thesis, presentation and published in journals on the condition that I cannot be identified.

I would like my information collected for this research study to be:
☐ Only used for this specific study;
☐ Used for future related studies;
☐ Used for any future studies

☐ I agree to have my interview audio and/or video recorded
☐ I would like to receive a copy of the results via email or post. I have provided my details below and ask that they only be used for this purpose and not stored with my information or for future contact.

Name	Email (optional)	Postal address (optional)

Participant Signature

☐ I have received a signed copy of the Participant Information Statement and Consent Form to keep

Participant's printed name	
Participant's signature	
Date	

Declaration by Researcher

☐ I have given a verbal explanation of the study, what it involves, and the risks and I believe the participant has understood;
☐ I am a person qualified to explain the study, the risks and answer questions

Researcher's printed name	
Researcher's signature	
Date	

* All parties must sign and date their own signature

Appendix Seven: Interview schedule (Key stakeholders): Note that translations versions are available on request

Key stakeholders Interview Guide

1. Name of participant:
2. Sex _____ Age _____
3. Organisation and/role of participant:
4. Date of interview:
5. Duration of interview:
6. Language(s) used:

1. What does the social care system in rural Uganda currently look like for older people?
   a) What social care services are usually required by older people in rural Uganda?
   b) How are social care services currently organised?
   c) Who is responsible for providing these?

2. Does your institution currently provide social care services to older people in rural Uganda? If no, go to question 3
   a) If yes, can you describe for me how they are provided and by whom?
   b) Who guarantees the quality of services provided?
   c) Who are the key actors that provide these social care services?
   d) Who finances these social care services?
   e) Who is eligible to receive these social care services?
   f) For how long can they receive these social care services?
   g) Are older people aware of the existence of these social care services and how to access them?

3. What sorts of gaps exist in current social care delivery for older people in rural areas?
   a) What challenges are experienced?
   b) What opportunities could be utilised? (Recommendations to address these gaps and challenges).

4. If you could imagine an ideal social care system for older people in rural Uganda- what would it entail?
   a) What sorts of social care service are required for older people in the future?
   b) Which key stakeholders should provide these social care services for older people?

Appendix Eight: Focus group discussion (care givers)

Group Narrative (Focus Group Discussion) Guide

1. DISTRICT
2. LOCATION OF DISCUSSION
3. MAIN LANGUAGE OF DISCUSSION
4. NUMBER OF PARTICIPANTS
5. MARITAL STATUS: MARRIED [__] UNMARRIED [__]
6. EMPLOYMENT STATUS OF PARTICIPANTS: EMPLOYED [__] UNEMPLOYED [__]
7. DATE OF DISCUSSION
8. DURATION OF DISCUSSION
9. FACILITATOR:
10. CO-FACILITATOR:

1. What are your caring responsibilities?
2. What were the circumstances that led to you take on the care responsibility? How did you assume responsibility? What were the driving factors? Why care?
3. What are your experiences in taking up social care responsibility?
4. Are there any other actors (community, practitioners, government) that help you?
5. If not, why is that so? If yes,
    a. Who are they? (current social care service providers)
    b. What services do they offer?
6. What are your positive experiences in providing social care?
7. What challenges have you experienced in providing social care?
8. What coping strategies have you put in place to overcome these challenges?
9. Do you know of any resources in the community that can be used to improve on social care
   i) for caregivers?
   ii) For older people?
10. What recommendation can you make to improve on social care provision in rural areas of Uganda?
11. How was social care provided in the past basing on culture (traditions, norms) and history?
12. In your opinion, what is the ideal future social care system for older people in rural Uganda?

Main themes

Aged care responsibility
Current services
Challenges
Coping strategies/ resources (local initiatives, community structures, cultural beliefs/practices, environment...)
Recommendations

Appendix Nine: Interview schedule (older people)

Older care recipients Interview Guide

1. Name:
2. Sex ____ Age:_____
3. Marital status:
4. Education level:
5. Number of household occupants and the relationship:
6. Duration of stay in locality:
7. Location:
8. Date of interview:
9. Duration of interview:

Questions

1. What have you liked most about growing older? *(warm up question)*
2. What do you like least about growing older?
3. How was social care provided in the past basing on culture (traditions, norms) and history?
4. Do you face any limitations in activities of daily living do you experience that require social care services? If NO.... Go to question 13
5. Do you currently access any services? *(List or specify the services)*
6. If yes, how do you access social care services?
7. Who is responsible for providing social care services to you?
8. Are there people in the community that assist you apart from your caregiver? If yes, who are they? What assistance is offered?
9. How often are these social care services provided to you?
10. Do you pay for these social care services? If yes, how much?
11. What challenges do you experience while seeking for social care services?
12. How have you been able to cope with these challenges? (Any strategies you have put in place?)
13. In your opinion, what is the ideal future social care system for older people in rural Uganda?
14. What resources do you know of that are available that can be tapped into to improve on social care in rural areas of Uganda?
15. Have you experienced any conflicts with caregivers/ social care providers/ organisations/ churches while seeking for social care services? If no... go to question 18
16. If yes, what was it about?
17. How was it solved?
18. What recommendations can you suggest to improve on social care for older people in rural Uganda? (To government, practitioners/ key stakeholders, caregivers, fellow older people, families and other actors?)

Appendix Ten: Care activity charts

Appendix Eleven: Stakeholder invitation letter

Dear…,

I hope this email finds you well. Am currently pursuing a PhD in Health Sciences (Rural Aged Care) at La Trobe University, Australia. I am at the data collection stage for my thesis, focusing on social care for older people (aged 60 years and above) in rural areas in Uganda.

I have contacted you because I believe you have valuable information about older persons and older persons' social care. I kindly request for an interview with you for approximately 30 minutes to 1 hour.

Our working definition of social care, as is in The National Social Protection Policy attains to services provided to care, support, protect and empower vulnerable persons who are unable to care for themselves fully. These include; personal care, rehabilitation, psychosocial support, respite care, protection services, provision of information and referral.

I seek your consent for an interview and schedule for a meeting if consent is affirmative.

Kind regards,
Diana Nabbumba

REFERENCES

Aboderin, I. 2017. Towards long-term care systems for Africa: setting agendas. *A resource document*. Geneva: World Health Organization.

Aboderin, I., & Hoffman, J. (2015). Families, Intergenerational Bonds, and Aging in Sub-Saharan Africa. *Canadian Journal on Aging / La Revue canadienne du vieillissement, 34*(3), 282-289. https//doi:10.1017/S0714980815000239

Aboderin, I., Mbaka, C., & Egesa, C. (2015). Human rights and residential care for older adults in sub-Saharan Africa: case study of Kenya. In *Towards Human Rights in Residential Care for Older Persons* (pp. 23-32). Routledge.

ABS. (2018). *Disability, Ageing and Carers, Australia: Summary of Findings.* Australian Buerau of Statistics. https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release.

Agyemang-Duah, W., Peprah, C., & Peprah, P. (2020). Factors influencing the use of public and private health care facilities among poor older people in rural Ghana. *Journal of Public Health, 28*(1), 53-63.

Alli, F., & Maharaj, P. (2013). The Health Situation of Older People in Africa. In P. Maharaj (Ed.), *Aging and Health in Africa* (pp. 53-89). Springer. https://doi:10.1007/978-1-4419-8357-2_3

Asiimwe, G. B. (2014). Of fundamental change and no change: pitfalls of constitutionalism and political transformation in Uganda, 1995-2005. *Africa Development, 39*(2), 21-46.

Baars, J., Dannefer, D., Phillipson, C., & Walker, A. (2016). *Aging, globalization and inequality: The new critical gerontology*: Routledge.

Baart, A. (2016). *Afterword: Discourses of care for older people in Sub-Saharan Africa: towards conceptual development*: Policy Press.

Band-Winterstein, T., Doron, I., & Naim, S. (2014). 'I take them with me'–reflexivity in sensitive research. *Reflective Practice, 15*(4), 530-539.

Bantebya-Kyomuhendo, G., & McIntosh, M. K. (2006). Women, work and domestic virtue in Uganda, 1900-2003. Oxford.

Barnes, M., Brannelly, T., Ward, L., & Ward, N. (2016). *Ethics of care : critical advances in international perspective*. Policy Press.

Bello-Schünemann, J., & Moyer, J. D. (2018). Structural pressures and political instability: Trajectories for sub-Saharan Africa. *ISS Africa Report, 2018*(9), 1-32.

Bengtson, V. L. (2001). Beyond the Nuclear Family: The Increasing Importance of Multigenerational Bonds. *Journal of Marriage and Family, 63*(1), 1-16.

Berger, R. (2015). Now I see it, now I don't: Researcher's position and reflexivity in qualitative research. *Qualitative research, 15*(2), 219-234.

Bergman, M. A., Johansson, P., Lundberg, S., & Spagnolo, G. (2016). Privatization and quality: Evidence from elderly care in Sweden. *Journal of Health Economics, 49*, 109-119. https://doi.org/10.1016/j.jhealeco.2016.06.010

Bilson, A., Nyeko, J., Baskott, J., & Rayment, C. (2013). *Developing social care and support services in Uganda*. http://www.socialserviceworkforce.org/system/files/resource/files/Developing%20Social%20Care%20and%20Support%20Services%20in%20Uganda%20%20A%20literature%20review.pdf.

Bird, K., Higgins, K., & McKay, A. (2010). Conflict, education and the intergenerational transmission of poverty in Northern Uganda. *Journal of International Development, 22*(8), 1183-1196. https://onlinelibrary.wiley.com/doi/10.1002/jid.1754

Bloeck, M. C., Galiani, S., & Ibarrarán, P. (2019). Long-Term Care in Latin America and the Caribbean. *Economía, 20*(1), 1-32.
Bond, J. E., Peace, S. E., Dittmann-Kohli, F. E., & Westerhof, G. J. (2007). *Ageing in society: European perspectives on gerontology*: Sage Publications Ltd.
Bryman, A. (2012). *Social Research Methods* (4th ed.). Oxford University Press.
Bukenya, B., & Hickey, S. (2019). The Politics of Promoting Social Protection in Uganda. *The Politics of Social Protection in Eastern and Southern Africa*, 202.
Bukuluki, P. (2013). "When I steal, it is for the benefit of me and you": Is collectivism engendering corruption in Uganda? *International Letters of Social and Humanistic Sciences*, (05), 27-44.
Bukuluki, P., Mukuye, R., Mubiru, J.-B., & Namuddu, J. (2016). Social protection and social work in Uganda. *The Handbook of Social Work and Social Development in Africa*, 256.
Burholt, V., & Scharf, T. (2019). Critical Social Gerontology And Rural Aging. *Innovation in Aging, 3*(Supplement1), S398-S398. https://doi:10.1093/geroni/igz038.1474
Burholt, V., & Scharf, T. (2020). Critical social gerontology and rural ageing. *Rural Gerontology: Towards Critical Perspectives on Rural Ageing*, 64.
Cantor, M. H. (1989). Social Care: Family and Community Support Systems. *The ANNALS of the American Academy of Political and Social Science, 503*(1), 99-112. doi:10.1177/0002716289503001008
Carpenter, S., Slater, R., & Mallett, R. (2012). *Social protection and basic services in fragile and conflict-affected situations*. (Vol. 8). London: Working Paper.
Cash, B., Hodgkin, S., & Warburton, J. (2013). Till death us do part? A critical analysis of obligation and choice for spousal caregivers. *Journal of Gerontological Social Work, 56*(8),657-674. http:// doi.org/10.1080/01634372.2013.823472
Cash, B., Hodgkin, S., & Warburton, J. (2017). A transformative approach to systems theory in caregiving research. *Qualitative Social Work*. doi:10.1177/1473325017749988
Christensen, J. (2010). Proposed enhancement of Bronfenbrenner's development ecology model. *Education Inquiry, 1*(2), 117-126.
Chung, H., Hrast, M. F., & Rakar, T. (2018). The provision of care: whose responsibility and why? In *Attitudes, Aspirations and Welfare* (pp. 183-214). Springer.
Cirillo, C., & Tebaldi, R. (2016). Social Protection in Africa: inventory of non-contributory programmes. *Brasília: International Policy Center for Inclusive Growth, United Nations Development Programme*.
Coe, C. (2017). Negotiating eldercare in Akuapem, Ghana: care-scripts and the role of non-kin. *87*(1), 137-154. https://doi:10.1017/S0001972016000735
Cohen, L., Manion, L., & Morrison, K. (2017). Observation. In *Research Methods in Education* (pp. 542-562). Routledge.
Collins, S. (2015). *The core of care ethics*. Palgrave Macmillan.
Connolly, M., Kiraly, M., McCrae, L., & Mitchell, G. (2017). A Kinship Care Practice Framework: Using a Life Course Approach. *The British Journal of Social Work, 47*(1), 87-105. https://doi:10.1093/bjsw/bcw041
Corbin, J. N. (2021). Effect of armed conflict and displacement on women's social, cultural and economic roles and responsibilities in Northern Uganda. *Journal of Refugee Studies, 34*(1), 830-850.
Cousins, S. (2020). Experts criticise Australia's aged care failings over COVID-19. *The Lancet, 396*(10259), 1322-1323.
Cox, C. (2020). The Sustainable Development Goals and Aging: Implications for Social Work. *Journal of Human Rights and Social Work, 5*(1), 39-47.
Creswell, J. W. (2018). *Qualitative inquiry & research design: choosing among five approaches* (4th. ed.). SAGE.

Creswell, J. W., & Poth, C. N. (2016). *Qualitative inquiry and research design: Choosing among five approaches*: Sage Publications.
Crotty, M. (1998). *The foundations of social research: Meaning and perspective in the research process*: SAGE.
Daly, M., & Lewis, J. (2000). The concept of social care and the analysis of contemporary welfare states. *The British journal of sociology, 51*(2), 281. https://doi:10.1111/j.1468-4446.2000.00281.x
Damskey, M. (2000). Views and visions: Moving toward culturally competent practice. *Therapeutic interventions with ethnic elders: Health and social issues*, 195-208.
Davis, N. J., Wyman, J. F., Gubitosa, S., & Pretty, L. (2020). Urinary Incontinence in Older Adults. *AJN The American Journal of Nursing, 120*(1), 57-62. https://doi:10.1097/01.Naj.0000652124.58511.24
Davis, S., & Bartlett, H. (2008). Review Article: Healthy ageing in rural Australia: Issues and challenges. *Australasian Journal on Ageing, 27*(2), 56-60. https://doi:10.1111/j.1741-6612.2008.00296.x
Denzin, N. K. (2012). Triangulation 2.0. *Journal of mixed methods research, 6*(2), 80-88.
Denzin, N. K., & Lincoln, Y. S. (2005). *The SAGE handbook of qualitative research* (3rd ed.). Sage Publications.
Denzin, N. K., & Lincoln, Y. S. (2011). *The Sage handbook of qualitative research* (4th ed.). SAGE.
Dhemba, J., & Dhemba, B. (2015). Ageing and care of older persons in Southern Africa: Lesotho and Zimbabwe compared. *Social Work & Society, 13*(2).
Djundeva, M., Dykstra, P. A., & Fokkema, T. (2019). Is living alone "aging alone"? Solitary living, network types, and well-being. *The Journals of Gerontology: Series B, 74*(8), 1406-1415.
Dyer, S. M., Valeri, M., Arora, N., Tilden, D., & Crotty, M. (2020). Is Australia over-reliant on residential aged care to support our older population?. *The Medical Journal of Australia, 213*(4), 156.
Eggers, T., Grages, C., & Pfau-Effinger, B. (2019). Self-Responsibility of the "Active Social Citizen": Different Types of the Policy Concept of "Active Social Citizenship" in Different Types of Welfare States. *American Behavioral Scientist, 63*(1), 43-64. https://doi:10.1177/0002764218816803
Engster, D. (2004). Care Ethics and Natural Law Theory: Toward an Institutional Political Theory of Caring. *The Journal of Politics, 66*(1), 113-135. https://doi:10.1046/j.1468-2508.2004.00144.x
Engster, D. (2007). *The heart of justice: Care ethics and political theory.* Oxford University Press on Demand.
Engster, D. (2015). *Justice, care, and the welfare state*: Oxford University Press.
Engster, D. (2019). Care Ethics, Dependency, and Vulnerability. *Ethics and social welfare, 13*(2), 100-114. https://doi:10.1080/17496535.2018.1533029
Erhard, F. (2019). The struggle to provide: how poverty is experienced in the context of family care. *Journal of Poverty and Social Justice, 28*(1). https://doi:10.1332/175982719X15728631102843
Esping-Andersen, G. (2009). *Incomplete revolution: Adapting welfare states to women's new roles.* Polity.
Esping-Andersen, G. (2016). *Families in the 21st Century*. SNS Förlag.
Estes, C. L. (2018). A first-generation critic comes of age revisited: Reflections of a critical gerontologist. *Critical gerontology comes of age: Advances in research and theory for a new century*, 19-34.
Estes, C. L. (2019). *Aging A-Z : Concepts Toward Emancipatory Gerontology*. Routledge.

Fang, M. L., Sixsmith, J., Sinclair, S., & Horst, G. (2016). A knowledge synthesis of culturally-and spiritually-sensitive end-of-life care: findings from a scoping review. *BMC geriatrics, 16*(1), 107.
Fitzgerald, M. (2020). Reimagining Government with the Ethics of Care: A Department of Care. *Ethics and social welfare, 14*(3), 248-265. https://doi:10.1080/17496535.2020.1746819
Flick, U. (2004). Triangulation in qualitative research. *A companion to qualitative research, 3*, 178-183.
Gardner, F. (2014). *Being critically reflective: Engaging in holistic practice*. Macmillan International Higher Education.
Gilbert, A. S. (2020). Conceptualising trust in aged care. *Ageing & Society*, 1-19.
Gilligan, C. (1977). In a different voice: Women's conceptions of self and of morality. *Harvard Educational Review, 47*(4), 481-517.
Gilligan, C. (2011). Ethics of care. *Entrevista concedida a Webteam em, 21*.
Gilligan, C. (2013). *Joining the Resistance*. Wiley.
Giunta, N., Chow, J., Scharlach, A. E., & Dal Santo, T. S. (2004). Racial and ethnic differences in family caregiving in California. *Journal of Human Behavior in the Social Environment, 9*(4), 85-109.
Glasby, J. (2017). *Understanding health and social care*: Policy Press.
Glendinning, C., & Kemp, P. (2006). *Cash and care : policy challenges in the welfare state*. Policy Press.
Golaz, V., Wandera, S. O., & Rutaremwa, G. (2017). Understanding the vulnerability of older adults: extent of and breaches in support systems in Uganda. *Ageing & Society, 37*(1), 63-89. https://doi:10.1017/S0144686x15001051
Goodin, R. E. (1995). *Utilitarianism as a public philosophy*. Cambridge University Press.
Goodin, R. E. (2018). Constitutive responsibility: Taking part, being part. *Analysis, 78*(1), 40-45.
Gouws, A., & van Zyl, M. (2014). Feminist ethics of care through a Southern lens. *Care in context: Transnational gender perspectives*, 99-125.
Gouws, A., & Van Zyl, M. (2015). Towards a feminist ethics of ubuntu: Bridging rights and ubuntu. *Care ethics and political theory*, 165-186.
Graf, C. (2008). The Lawton Instrumental Activities of Daily Living Scale. *American Journal of Nursing, 108*(4), 52-62. https://doi:10.1097/01.NAJ.0000314810.46029.74
Gray, M. (2016). *The handbook of social work and social development in Africa*: Taylor & Francis.
Greenfield, E. A. (2012). Using Ecological Frameworks to Advance a Field of Research, Practice, and Policy on Aging-in-Place Initiatives. *The Gerontologist, 52*(1), 1-12. https://doi:10.1093/geront/gnr108
Gresh, A., & Maharaj, P. (2013). Policy and Programme Responses. In *Aging and Health in Africa* (pp. 211-236). Springer.
Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation*: Sage.
Guba, E. G., & Lincoln, Y. S. (1994). Competing paradigms in qualitative research. *Handbook of qualitative research, 2*(163-194), 105.
Hankivsky, O. (2004). *Social policy and the ethic of care*. UBC Press.
Hankivsky, O. (2014). Rethinking care ethics: On the promise and potential of an intersectional analysis. *American Political Science Review, 108*(2), 252-264.
Hanrahan, K. B. (2015). Living Care-fully: The potential for an ethics of care in livelihoods approaches. *World Development, 72*, 381-393.
Hartman, A. (2000). In search of subjugated knowledge. *Journal of Feminist Family Therapy, 11*(4), 19-23.
Heiner, R. (2002). *Social problems: An introduction to critical constructionism*. Oxford University Press USA.

Held, V. (2006). *The ethics of care: Personal, political, and global*. Oxford University Press on Demand.
Herron, R. V., Rosenberg, M. W., & Skinner, M. W. (2016). The dynamics of voluntarism in rural dementia care. *Health & Place, 41*, 34-41. https://doi:10.1016/j.healthplace.2016.06.008
Herron, R. V., & Skinner, M. W. (2013). Using Care Ethics to Enhance Qualitative Research on Rural Aging and Care. *Qualitative Health Research, 23*(12), 1697-1707. https://doi:10.1177/1049732313509893
Hestevik, C. H., Molin, M., Debesay, J., Bergland, A., & Bye, A. (2020). Older patients' and their family caregivers' perceptions of food, meals and nutritional care in the transition between hospital and home care: a qualitative study. *BMC nutrition, 6*(1), 1-13.
Hockey, J., & James, A. (1995). Back to our futures: imaging second childhood. *Images of aging: Cultural representations of later life*, 135-148.
Hodgkin, S. (2008). Telling It All:A Story of Women's Social Capital Using a Mixed Methods Approach. *Journal of Mixed Methods Research, 2*(4), 296-316. https://doi:10.1177/1558689808321641
Hodgkin, S. (2014). Intergenerational solidarity: An investigation of attitudes towards the responsibility for formal and informal elder care in Australia. *Health Sociology Review, 23*(1), 53-64. https://doi:10.5172/hesr.2014.23.1.53
Hodgkin, S., Savy, P., Clune, S., & Mahoney, A.-M. (2020). Navigating the marketisation of community aged care services in rural Australia. *International Journal of Care and Caring*.
Hodgkin, S., Warburton, J., Savy, P., & Moore, M. (2017). Workforce crisis in residential aged care: insights from rural, older workers. *Australian Journal of Public Administration, 76*(1), 93-105.
Hollander, J. A. (2004). The social contexts of focus groups. *Journal of contemporary ethnography, 33*(5), 602-637.
Houghton, C., Casey, D., Shaw, D., & Murphy, K. (2013). Rigour in qualitative case-study research. *Nurse Researcher, 20*(4).
Hu, B., Li, B., Wang, J., & Shi, C. (2020). Home and community care for older people in urban China: Receipt of services and sources of payment. *Health & social care in the community, 28*(1), 225-235.
Hughes, M., & Heycox, K. (2005). Promoting reflective practice with older people: Learning and teaching strategies. *Australian Social Work, 58*(4), 344-356.
Humphries, R. (2015). Integrated health and social care in England – Progress and prospects. *Health Policy, 119*(7), 856-859. https://doi:10.1016/j.healthpol.2015.04.010
Ibnouf, F. O. (2020). The Ethics of Care and the Conceptualization of Unpaid Care Work. In *War-Time Care Work and Peacebuilding in Africa* (pp. 53-74): Springer.
Jeffries, C. (1943). Recent social welfare developments in British tropical Africa. *Africa, 14*(1), 4-11.
Jolkkonen, R. (2019). NGOs and their role in the welfare mix. In *Handbook of Social Policy and Development*: Edward Elgar Publishing.
Jootun, D., McGhee, G., & Marland, G. R. (2009). Reflexivity: promoting rigour in qualitative research. *Nursing Standard (through 2013), 23*(23), 42.
Kabuye, R. (2015). *Approaches to Fighting poverty among older persons in Uganda: A Study of Wakiso and Luwero Districts*. University of Kent.
Kago, M. K., Kavulya, J., & Mutua, D. M. (2017). Influence of institutionalized care on psychosocial well-being of the elderly in Kenya: A case of nyumba ya wazee Nairobi county, Kenya. *International Journal of Psychology, 1*(1), 30-48.
Kalabamu, F. T. (2019). Land tenure reforms and persistence of land conflicts in Sub-Saharan Africa–the case of Botswana. *Land use policy, 81*, 337-345.

Kaluya, M. D., & Elliott, E. W. (2018). Corruption in Uganda: A Comparative Study of Citizens' and Public Officials' Perceptions. *African Social Science Review, 9*(1), 4.
Kamanzi, A. (2011). Beyond the African HIV/AIDS discourse: engagement in a transformative educational paradigm. *health policy and development, 9*(1), 52-60.
Karnieli-Miller, O., Strier, R., & Pessach, L. (2009). Power relations in qualitative research. *Qualitative health research, 19*(2), 279-289.
Kaufman-Osborn, T., Hirschmann, N. J., Engster, D., Robinson, F., Yeates, N., & Tronto, J. C. (2018). Moral Boundaries: A Political Argument for an Ethic of Care. *Politics & Gender, 14*(4).
Keating, N., Eales, J., Phillips, J., Ayalon, L., Lazaro, M., de Oca, V. M., . . . Tyagi, P. (2020). 5 Critical human ecology and global contexts of rural ageing. *Rural Gerontology: Towards Critical Perspectives on Rural Ageing*, 52.
Keating, N., & Phillips, J. (2008). A critical human ecology perspective on rural ageing. *Rural ageing: A good place to grow old*, 1-10.
Keating, N. C. (2008). *Rural ageing: A good place to grow old?*. Policy Press.
Kemp, C. L., Ball, M. M., & Perkins, M. M. (2013). Convoys of care: Theorizing intersections of formal and informal care. *Journal of Aging Studies, 27*(1), 15-29. https://doi:10.1016/j.jaging.2012.10.002
Kittay, E. F. (2011). The ethics of care, dependence, and disability. *Ratio Juris, 24*(1), 49-58.
Kiyimba, A. (2005). Gendering social destiny in the proverbs of the Baganda: Reflections on boys and girls becoming men and women. *Journal of African Cultural Studies, 17*(2), 253-270.
Kloppers, J. M., Dyk, A. V., & Pretorius, L. (2015). The Experiences of the Elderly and Caregivers in Respect of Caring for the Elderly in Windhoek and Rehoboth Namibia: An Exploratory and Descriptive Study. *Open Journal of Nursing, 05*(03), 246-259. https://doi:10.4236/ojn.2015.53029
Kröger, T., & Bagnato, A. (2017). Care for older people in early twenty-first-century Europe: dimensions and directions of change. In *Social services disrupted*. Edward Elgar Publishing.
Krueger, R. A., & Casey, M. A. (2014). *Focus groups: A practical guide for applied research*. Sage Publications.
Kyazike, E. (2016). Gender, socialization & construction of a Buganda woman identity. *Being & becoming: Gender. Culture & shifting identity in Sub-Saharan Africa*, 49.
Lalor, K., & Share, P. (2013). Understanding social care. In K. Lalor & P. Share (Eds.), *Applied social care: An introduction for students in Ireland* (3rd ed.). Gill and Macmillan.
LaPierre, T. A., & Keating, N. (2013). Characteristics and contributions of non-kin carers of older people: a closer look at friends and neighbours. *Ageing & Society, 33*(8), 1442-1468.
Laverack, G. R., & Brown, K. M. (2003). Qualitative research in a cross-cultural context: Fijian experiences. *Qualitative Health Research, 13*(3), 333-342.
Lebeuf, A. M. (1963). The role of women in the political organization of African societies. *Women of Tropical Africa*, 93-119.
Legard, R., Keegan, J., & Ward, K. (2003). In-depth interviews. *Qualitative research practice: A guide for social science students and researchers*, 138-169.
Leu, A., & Becker, S. (2017). A cross-national and comparative classification of in-country awareness and policy responses to 'young carers'. *Journal of Youth Studies, 20*(6), 750-762.
Lewis, J. (2003). Design issues. *Qualitative research practice: A guide for social science students and researchers*, 47-76.

Liamputtong, P. (2008). Doing Research in a Cross-Cultural Context: Methodological and ethical challenges. In P. Liamputtong (Ed.), *Doing Cross-Cultural Research: Ethical and Methodological Perspectives* (pp. 3-20). Springer, Dordrecht. https://doi:10.1007/978-1-4020-8567-3_1

Lie, J. H. S. (2015). Developmentality: indirect governance in the World Bank-Uganda partnership. *Third World Quarterly, 36*(4), 723-740. https://doi:10.1080/01436597.2015.1024435

Lloyd-Sherlock, P. (2019). Long-term Care for Older People in South Africa: The Enduring Legacies of Apartheid and HIV/AIDS. *Journal of Social Policy, 48*(1), 147-167.

Lor, M., Crooks, N., & Tluczek, A. (2016). A proposed model of person-, family-, and culture-centered nursing care. *Nursing Outlook, 64*(4), 352-366.

Manyire, H., & Asingwire, N. (1998). The State of Dynamics of Social Policy Practice and Research in Uganda. *Journal of Social Development in Africa, 13*(2), 75-83.

Matovu, S. N., & Wallhagen, M. I. (2020). Perceived Caregiver Stress, Coping, and Quality of Life of Older Ugandan Grandparent-Caregivers. *Journal of Cross-Cultural Gerontology*, 1-18.

McClelland, A., & Smyth, P. (2014). *Social policy in Australia : understanding for action* (3rd. ed.). Oxford University Press.

McEwan, C., & Goodman, M. K. (2010). Place Geography and the Ethics of Care: Introductory Remarks on the Geographies of Ethics, Responsibility and Care. *Ethics, place and environment, 13*(2), 103-112. https://doi:10.1080/13668791003778602

McKenzie, J. A. (2016). An exploration of an ethics of care in relation to people with intellectual disability and their family caregivers in the Cape Town metropole in South Africa. *Alter, 10*(1), 67-78.

Meier zu Selhausen, F. (2014). Missionaries and female empowerment in colonial Uganda: new evidence from Protestant marriage registers, 1880–1945. *Economic History of Developing Regions, 29*(1), 74-112.

Meiers, S. J., & Tomlinson, P. S. (2003). Family–nurse co-construction of meaning: a central phenomenon of family caring. *Scandinavian Journal of Caring Sciences, 17*(2), 193-201.

Menec, V., Bell, S., Novek, S., Minnigaleeva, G. A., Morales, E., Ouma, T., . . . Winterton, R. (2015). Making Rural and Remote Communities More Age-Friendly: Experts' Perspectives on Issues, Challenges, and Priorities. *Journal of Aging & Social Policy, 27*(2), 173-191. https://doi:10.1080/08959420.2014.995044

Mertens. (2008). *Transformative research and evaluation*. Guilford Publications.

Mertens, & Ginsberg, P. E. (2009). *The handbook of social research ethics*. SAGE.

Mertens, D. M. (2007). Transformative paradigm: Mixed methods and social justice. *Journal of mixed methods research, 1*(3), 212-225.

Mertens, D. M. (2013). What does a transformative lens bring to credible evidence in mixed methods evaluations? *New directions for evaluation, 2013*(138), 27-35.

Mertens, D. M. (2016). Advancing social change in South Africa through transformative research. *South African Review of Sociology, 47*(1), 5-17.

Mertens, D. M. (2018). Ethics of qualitative data collection. *The SAGE handbook of qualitative data collection*, 33-48.

Mertens, D. M., & Ginsberg, P. E. (2008). Deep in ethical waters: Transformative perspectives for qualitative social work research. *Qualitative social work, 7*(4), 484-503.

Mertens, D. M., Holmes, H. M., & Harris, R. L. (2009). Transformative research and ethics. *The handbook of social research ethics*, 85-101.

MGLSD. (2009). *National Policy for Older Persons: Ageing with Security and Dignity*. Ministry of Gender Labour and Social Development. https://scacfu.org/wp-content/uploads/2020/11/national_policy_for_older_persons.pdf

MGLSD. (2012). *National Plan of Action for Older Persons 2012/13-2016/17: Ageing with security and dignity*. Kampala, Uganda. http://kwesiga.ugmirror.com/wp-content/uploads/2019/05/NATIONAL-PLAN-OF-ACTION-FOR-OLDER-PERSONS.pdf

MGLSD. (2015a). *The National Social Protection Policy: Income security and dignified lives for all*. Ministry of Gender, Labour and Social Development. http://socialprotection.go.ug/wp-content/uploads/2016/07/National-Social-Protection-Policy-uganda.pdf

MGLSD. (2015b). *Programme Plan of Interventions for Implementation of The Uganda National Social Protection Policy Fiscal Years 2015/16 – 2019/20*. Ministry of Gender, Labour and Social Development. Retrieved from http://socialprotection.go.ug/mdocs-posts/programme-plan-of-interventions-for-implementation-of-the-uganda-national-social-protection-policy-fiscal-years-2015-16-2019-20/?mdocs-file=1627&mdocs-url=false

MGLSD. (2015c). *Programme Plan of Interventions for Implementation of the Uganda National Social Protection Policy Fiscal Years 2015/16 – 2019/20*. Ministry of Gender, Labour and Social Development. http://socialprotection.go.ug/mdocs-posts/programme-plan-of-interventions-for-implementation-of-the-uganda-national-social-protection-policy-fiscal-years-2015-16-2019-20/

MoFPED. (2004). Poverty Eradication Action Plan (2004/5–2007/8).

Moran-Ellis, J., Alexander, V. D., Cronin, A., Dickinson, M., Fielding, J., Sleney, J., & Thomas, H. (2006). Triangulation and integration: processes, claims and implications. *Qualitative research*, *6*(1), 45-59.

Mugisha, Schatz, E., Seeley, J., & Kowal, P. (2015). Gender perspectives in care provision and care receipt among older people infected and affected by HIV in Uganda. *Ajar-African Journal of Aids Research*, *14*(2), 159-167. https://doi:10.2989/16085906.2015.1040805

Mugisha, J. O., Schatz, E. J., Negin, J., Mwaniki, P., Kowal, P., & Seeley, J. (2016). Timing of Most Recent Health Care Visit by Older People Living With and Without HIV: Findings From the SAGE Well-Being of Older People Study in Uganda. *The International Journal of Aging and Human Development*, *85*(1), 18-32. https://doi:10.1177/0091415016680071

Mugisha., Schatz, E. J., Randell, M., Kuteesa, M., Kowal, P., Negin, J., & Seeley, J. (2016). Chronic disease, risk factors and disability in adults aged 50 and above living with and without HIV: findings from the Wellbeing of Older People Study in Uganda. *Global health action*, 9(1), 31098.

Museveni, Y. (2016). NRM Manifesto 2016-2021: steady progress: taking Uganda to modernity through jobs-creation & inclusive development.

Mushavi, R. C., Burns, B. F. O., Kakuhikire, B., Owembabazi, M., Vořechovská, D., McDonough, A. Q., . . . Tsai, A. C. (2020). "When you have no water, it means you have no peace": A mixed-methods, whole-population study of water insecurity and depression in rural Uganda. *Social Science & Medicine*, *245*, 112561.

Musisi, S. (2015). Caring for the Elderly with Dementia in Africa. In *Brain Degeneration and Dementia in Sub-Saharan Africa* (pp. 287-297). Springer.

Musisi, S., & Jacobson, S. (2015). *Brain Degeneration and Dementia in Sub-Saharan Africa*. Springer.

Najjumba-Mulindwa, I. (2003, April). Chronic poverty among the elderly in Uganda: perceptions, experiences and policy issues. In CPRC conference (pp. 7-9).

Namuli, J. D. (2015). A Case of Alzheimer's Dementia in Uganda. In *Brain Degeneration and Dementia in Sub-Saharan Africa* (pp. 247-254). Springer.

Negin, J., Geddes, L., Brennan-Ing, M., Kuteesa, M., Karpiak, S., & Seeley, J. (2016). Sexual Behavior of Older Adults Living with HIV in Uganda. *Archives of Sexual Behavior, 45*(2), 441-449. https://doi:10.1007/s10508-015-0582-5

Njuki, C. (1999). Poverty and Economic Development: Implications for Work and Elder Care in Uganda. In V. Lechner & M. Neal (eds.), Work and Caring for the Elderly: International Perspective (Chapter 12). Brunner/Mazel.

Noxolo, P., Raghuram, P., & Madge, C. (2012). Unsettling responsibility: Postcolonial interventions. *Transactions of the Institute of British Geographers, 37*(3), 418-429.

NPA. (2010). *The National Development Plan, Uganda 2010/11 – 14/15*. Uganda, Kampala http://www.npa.go.ug/wp-content/uploads/2020/08/NDP2.pdf

Nzabona, A., & Ntozi, J. (2015). The Role of Older Persons in Uganda: Assessing Socio-demographic Determinants of Older Persons' Value. *Africa Development/Afrique et Développement, 40*(4), 113-135.

Okoth, P. G. (1992). Africa's development nightmare: Uganda's case. *Journal of Eastern African Research & Development*, 132-149.

Oppong, C. (2006). Familial Roles and Social Transformations. *Research on Aging, 28*(6), 654-668. https://doi:10.1177/0164027506291744

Ouma, S. O. (1991). Corruption in public policy and its impact on development: The case of Uganda since 1979. *Public Administration and Development, 11*(5), 473-490.

Ouma, S. O. A. (1995). The role of social protection in the socioeconomic development of Uganda. *Journal of Social Development in Africa, 10*(2), 5-12.

Pagone, T., & Briggs, L. (2020). *Royal Commission into Aged Care Quality and Safety Consultation Paper 2, June 2020. Financing aged care,*. Commonwealth of Australia. https://agedcare.royalcommission.gov.au/sites/default/files/2020-06/consultation_paper_2_-_financing_aged_care_0.pdf

Park, J.-D. (2019). Assessing the Role of Foreign Aid, Donors and Recipients. In *Re-Inventing Africa's Development* (pp. 37-60): Springer.

Parsons, E., Kearney, T., Surman, E., Cappellini, B., Moffat, S., Harman, V., & Scheurenbrand, K. (2021). Who really cares? Introducing an 'Ethics of Care' to debates on transformative value co-creation. *Journal of Business Research, 122*, 794-804. https://doi.org/10.1016/j.jbusres.2020.06.058

Pashmdarfard, M., & Azad, A. (2020). Assessment tools to evaluate Activities of Daily Living (ADL) and Instrumental Activities of Daily Living (IADL) in older adults: A systematic review. *Medical Journal of the Islamic Republic Of Iran, 34*(1), 224-239. https://doi:10.34171/mjiri.34.33

Patton, C. V. (2016). *Basic methods of policy analysis and planning* (3rd ed.). Routledge.

Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Sage Publications.

Pease, B. (2020). From privileged irresponsibility to shared responsibility for social injustice. *The Routledge Handbook of Critical Pedagogies for Social Work*.

Petersen, M., & Minnery, J. (2013). Understanding Daily Life of Older People in a Residential Complex: The Contribution of Lefebvre's Social Space. *Housing Studies, 28*(6), 822-844. https://doi:10.1080/02673037.2013.768333

Philip, G., Rogers, C., & Weller, S. (2012). Introduction: thinking with care. *Critical Approaches to Care: Care Relations, Identities and Cultures*, Routledge.

Powell, M. A. (2007). *Understanding the mixed economy of welfare*. Policy Press/Social Policy Association.

Prevost, E. E. (2010). *The Communion of Women: Missions and Gender in Colonial Africa and the British Metropole*. Oxford University Press.

Punch, K. F. (2013). *Introduction to social research: Quantitative and qualitative approaches*. SAGE.

Pype, K. (2016). Caring for people 'without'value: movement, reciprocity and respect in Kinshasa's retirement homes. In *Ageing in Sub-Saharan Africa: Spaces and Practices of Care* 43-68

Raghuram, P. (2016). Locating care ethics beyond the global north. *ACME: An International Journal for Critical Geographies, 15*(3), 511-533.

Raghuram, P., Madge, C., & Noxolo, P. (2009). Rethinking responsibility and care for a postcolonial world. *Geoforum, 40*(1), 5-13.

Ritchie, J., & Lewis, J. (2003). *Qualitative research practice : a guide for social science students and researchers*. SAGE.

Ritchie, J., Lewis, J., & Elam, R. G. (2013). Selecting samples. *Qualitative research practice: A guide for social science students and researchers, 111*.

Robertson, R., Gregory, S., & Jabbal, J. (2014). The social care and health systems of nine countries. *The King's Fund*.

Rothman, J. (2018). *Social work practice across disability*. Routledge.

Rubongoya, J. (2007). *Regime Hegemony in Museveni's Uganda Pax Musevenica.* Palgrave Macmillan.

Rummery, K. (2011). A comparative analysis of personalisation: balancing an ethic of care with user empowerment. *Ethics and Social Welfare, 5*(2), 138-152.

Rummery, K., & Fine, M. (2012). Care: A Critical Review of Theory, Policy and Practice. *Social Policy & Administration, 46*(3), 321-343. https://doi:10.1111/j.1467-9515.2012.00845.x

Rutakumwa, R., Zalwango, F., Richards, E., & Seeley, J. (2015). Exploring the Care Relationship between Grandparents/Older Carers and Children Infected with HIV in South-Western Uganda: Implications for Care for Both the Children and Their Older Carers. *International Journal of Environmental Research and Public Health, 12*(2), 2120-2134. https://doi:10.3390/ijerph120202120

Saldaña, J. (2013). *The coding manual for qualitative researchers* (2nd . ed.). Sage Publications.

Sapountzaki, K. (2007). Social resilience to environmental risks. *Management of Environmental Quality: An International Journal, 18*(3), 274-297.

Sapountzaki, K. (2012). Vulnerability management by means of resilience. *Natural Hazards, 60*(3), 1267-1285.

Scharlach, A. E., Kellam, R., Ong, N., Baskin, A., Goldstein, C., & Fox, P. J. (2006). Cultural attitudes and caregiver service use: lessons from focus groups with racially and ethnically diverse family caregivers. *Journal of Gerontological Social Work, 47*(1-2), 133-156. https://doi:10.1300/J083v47n01_09

Schneider, R. C. (2020). White Urban Immersion, Intersubjectivity, and an Ethics of Care in South Africa. *Journal of Religious Ethics, 48*(4), 620-641.

Sedgley, D., Pritchard, A., & Morgan, N. (2011). Tourism and ageing: A transformative research agenda. *Annals of Tourism Research, 38*(2), 422-436.

Seeley, J., Dercon, S., & Barnett, T. (2010). The effects of HIV/AIDS on rural communities in East Africa: a 20-year perspective. *Tropical Medicine & International Health, 15*(3), 329-335. https://doi:10.1111/j.1365-3156.2009.02458.x

Sejjaaka, S. (2004). A political and economic history of Uganda, 1962–2002. In *International Businesses and the Challenges of Poverty in the Developing World* (pp. 98-110). Palgrave Macmillan, London.

Sevenhuijsen, S. (1998). *Citizenship and the ethics of care: Feminist considerations on justice, morality, and politics*: Psychology Press.

Sevenhuijsen, S. (2000). Caring in the third way: the relation between obligation, responsibility and care in Third Way discourse. *Critical Social Policy, 20*(1), 5-37.

Sevenhuijsen, S. (2003). The place of care: The relevance of the feminist ethic of care for social policy. *Feminist Theory, 4*(2), 179-197.

Sevenhuijsen, S. (2004). Trace: A method for normative policy analysis from the ethic of care. *The Heart of the Matter. The Contribution of the Ethic of Care to Social Policy in Some New EU Member States*, 13-46

Sevenhuijsen, S. (2018). Care and attention: the ethics of care & academic development. *South African Journal of Higher Education, 32*(6), 19-30.

Sevenhuijsen, S., Bozalek, V., Gouws, A., & Minnaar-McDonald, M. (2003). South African social welfare policy: an analysis using the ethic of care. *Critical Social Policy, 23*(3), 299-321.

Sidorenko, A., & Walker, A. (2004). The Madrid International Plan of Action on Ageing: from conception to implementation. *Ageing and Society, 24*(2), 147-165. https://doi:10.1017/S0144686X03001661

Sidorenko, A., & Zaidi, A. (2018). International policy frameworks on ageing: assessing progress in reference to the Madrid International Plan of Action on Ageing. *Zhurnal Issledovanii Sotsialnoi Politiki= The Journal of Social Policy Studies, 16*(1), 141-154G.

Sihto, T. (2020). Dividing Responsibility for Care: Tracing the Ethics of Care in Local Care Strategies. *Social Policy and Society*, 1-16. https://doi:10.1017/S1474746420000585

Sims-Gould, J., & Martin-Matthews, A. (2008). Distance, privacy and independence: rural homecare. *Rural ageing: a good place to grow old?*, 43-51.

Skinner, M., Winterton, R., & Walsh, K. (2020). *Rural Gerontology: Towards Critical Perspectives on Rural Ageing*. Routledge.

Skinner, M. W. (2008). Voluntarism and long-term care in the countryside: the paradox of a threadbare sector. *The Canadian Geographer / Le Géographe canadien, 52*(2), 188-203. https://doi:10.1111/j.1541-0064.2008.00208.x

Skinner, M. W., Andrews, G. J., & Cutchin, M. P. (2017). *Geographical Gerontology: Perspectives, Concepts, Approaches*: Routledge.

Skinner, M. W., & Winterton, R. (2018). Interrogating the Contested Spaces of Rural Aging: Implications for Research, Policy, and Practice. *The Gerontologist, 58*(1), 15-25. https://doi:10.1093/geront/gnx094

Söderman, M., & Rosendahl, S. P. (2016). Caring for ethnic older people living with dementia–Experiences of nursing staff. *Journal of cross-cultural gerontology, 31*(3), 311-326.

Spall, S. (1998). Peer debriefing in qualitative research: Emerging operational models. *Qualitative Inquiry, 4*(2), 280-292.

Spencer, L., & Snape, D. (2011). The foundations of qualitative research. In *Qualitative research practice: A guide for social science students and researchers* (pp. 1-26): SAGE Publications Ltd.

Ssejjoba, E. (2020, 4th July 2020). Gov't rolls out sh26.92b senior citizen grant. *New Vision*. New Vision. https://www.newvision.co.ug/news/1522053/gov-rolls-sh26-92b-senior-citizen-grant

Ssengonzi, R. (2007). The plight of older persons as caregivers to people infected/affected by HIV/AIDS: evidence from Uganda. *Journal of Cross-Cultural Gerontology, 22*(4), 339-353. https://link.springer.com/content/pdf/10.1007%2Fs10823-007-9043-5.pdf

Ssengonzi, R. (2009). The impact of HIV/AIDS on the living arrangements and well-being of elderly caregivers in rural Uganda. *AIDS care, 21*(3), 309-314.

Ssentongo, J. S., & Okok, S. (2020). Rethinking anti-corruption strategies in Uganda: an ethical reflection. *African Journal of Governance & Development, 9*(1), 66-88.

Suitor, J. J., Gilligan, M., Pillemer, K., Fingerman, K. L., Kim, K., Silverstein, M., & Bengtson, V. L. (2017). Applying Within-Family Differences Approaches to Enhance Understanding of the Complexity of Intergenerational Relations. *The Journals of Gerontology: Series B, 73*(1), 40-53.

Surbone, A., & Baider, L. (2013). Personal values and cultural diversity. *Journal of Medicine and the Person, 11*(1), 11-18.
Švab, A. (2007). Combining Work and Family Life in Slovenia: An Ethic of care perspective for normative policy analysis. *Društvena istraživanja: časopis za opća društvena pitanja, 16*(4-5 (90-91)), 965-987.
Tamale, S. (2018). *When hens begin to crow: Gender and parliamentary politics in Uganda*: Routledge.
Thelen, T. (2015). Care as social organization: Creating, maintaining and dissolving significant relations. *Anthropological Theory, 15*(4), 497-515.
Theobald, J., Gardner, F., & Long, N. (2017). Teaching critical reflection in social work field education. *Journal of Social Work Education, 53*(2), 300-311.
Timonen, V., Conlon, C., Scharf, T., & Carney, G. (2013). Family, state, class and solidarity: Re-conceptualising intergenerational solidarity through the grounded theory approach. *European Journal of Ageing, 10*(3), 171-179.
Tronto, J. (2017). There is an alternative: homines curans and the limits of neoliberalism. *International Journal of Care and Caring, 1*(1), 27-43.
Tronto, J. C. (1993). *Moral boundaries : a political argument for an ethic of care*. Routledge.
Tronto, J. C. (1998). An ethic of care. *Generations: Journal of the American Society on Aging, 22*(3), 15-20.
Tronto, J. C. (2010). Creating caring institutions: Politics, plurality, and purpose. *Ethics and social welfare, 4*(2), 158-171.
Tronto, J. C. (2013). *Caring democracy: Markets, equality, and justice.* NYU Press.
Tronto, J. C. (2014). Care ethics. *The encyclopedia of political thought*, 442-443.
Tronto, J. C. (2015a). Democratic caring and global care responsibilities. *Ethics of care: Critical advances in international perspective*, 21-30.
Tronto, J. C. (2015b). *Who cares?: how to reshape a democratic politics*. Cornell University Press.
Turinawe, E. B., Rwemisisi, J. T., Musinguzi, L. K., de Groot, M., Muhangi, D., de Vries, D. H., . . . Pool, R. (2015). Selection and performance of village health teams (VHTs) in Uganda: lessons from the natural helper model of health promotion. *Human Resources for Health, 13*(1). https://doi:10.1186/s12960-015-0074-7
Tutu, D. (1999). *No future without forgiveness*. Rider.
Twigg, J., & Martin, W. (2014). The Challenge of Cultural Gerontology. *The Gerontologist, 55*(3), 353-359.
UBOS. (2016). *The National Population and Housing Census 2014 – Main Report, Kampala, Uganda:U.B.O.Statistics*. https://www.ubos.org/onlinefiles/uploads/ubos/NPHC/NPHC%202014%20FINAL%20RESULTS%20REPORT.pdf
UBOS. (2017a). *The National Population and Housing Census 2014* Kampala, Uganda. https://www.ubos.org/onlinefiles/uploads/ubos/2014CensusProfiles/BUIKWE.pdf
UBOS. (2017b). *The National Population and Housing Census 2014* Kampala, Uganda. http://www.ubos.org/onlinefiles/uploads/ubos/2014CensusProfiles/APAC.pdf
UBOS. (2017c, September 2017). *Uganda National Household Survey 2016/17*. Uganda. http://www.ubos.org/2017/09/27/uganda-national-household-survey-201617-report/
UN. (2017). *State of the Least Developed Countries*. http://unohrlls.org/custom-content/uploads/2017/07/State-of-the-LDCs_2017.pdf
UNCST. (2007). *National Guidelines for Research involving Humans as Research Participants*. Kampala - Uganda http://research.ciu.ac.ug/files/National_Guidelines_for_Research_Involving_Human_Participants.pdf
Ungerson, C. (2003). Commodified care work in European Labour Markets. *European Societies, 5*(4), 377-396. https://doi:10.1080/1461669032000127651

United Nations, D. o. E. a. S. A., Population Division. (2017). *World Population Prospects: The 2017 Revision, Key Findings and Advance Tables.* (Working Paper No. ESA/P/WP/248). https://esa.un.org/unpd/wpp/Publications/Files/WPP2017_KeyFindings.pdf

Urban, P., & Ward, L. (2020). *Care Ethics, Democratic Citizenship and the State*. Springer International Publishing AG.

Van der Geest, S. (2002). Respect and reciprocity: Care of elderly people in rural Ghana. *Journal of Cross-Cultural Gerontology, 17*(1), 3-31. https://doi:10.1023/a:1014843004627

Van der Geest, S. (2016). Will families in Ghana continue to care for older people? Logic and contradiction in policy. *Ageing in Sub-Saharan Africa: Spaces and Practices of Care*, 21-42.

van Groenou, M. I. B., & De Boer, A. (2016). Providing informal care in a changing society. *European Journal of Ageing, 13*(3), 271-279.

van Nistelrooij, I., & Visse, M. (2019). Me? The invisible call of responsibility and its promise for care ethics: a phenomenological view. *Medicine, Health Care and Philosophy, 22*(2), 275-285.

Vergunst, R., Swartz, L., Hem, K.-G., Eide, A. H., Mannan, H., MacLachlan, M., . . . Schneider, M. (2017). Access to health care for persons with disabilities in rural South Africa. *BMC health services research, 17*(1), 1-8.

Verick, S. (2014). Female labor force participation in developing countries. *IZA World of Labor*.

Vik, K., & Eide, A. (2013). Older adults who receive home-based services, on the verge of passivity: the perspective of service providers. *International Journal of Older People Nursing, 8*(2), 123-130. https://doi:10.1111/j.1748-3743.2011.00305.x

Vlachantoni, A., Robards, J., Falkingham, J., & Evandrou, M. (2016). Trajectories of informal care and health. *SSM - Population Health, 2*(Supplement C), 495-501. https://doi.org/10.1016/j.ssmph.2016.05.009

Vlachantoni, A., Shaw, R. J., Evandrou, M., & Falkingham, J. (2013). The determinants of receiving social care in later life in England. *Ageing and Society, 35*(2), 321-345. https://doi:10.1017/S0144686X1300072X

Vosman, F., Baart, A. J., & Hoffman, J. (2020). *The Ethics of Care: The State of the Art*: Peeters.

Walker, A. (2005). 25th volume celebration paper Alan Walkers paper, Towards a political economy of old age, was published in Volume 1 of Ageing Society (part 1: 7394). *Ageing and Society, 25*(6), 815-839. https://doi:10.1017/S0144686X05004307

Walsh, K., O'Shea, E., & Scharf, T. (2019). Rural old-age social exclusion: a conceptual framework on mediators of exclusion across the lifecourse. *Ageing & Society*, 1-27.

Walsh, K., O'Shea, E., Scharf, T., & Murray, M. (2012). Ageing in changing community contexts: Cross-border perspectives from rural Ireland and Northern Ireland. *Journal of Rural Studies, 28*(4), 347-357.

Wamara, C. K. (2017). Corruption in Uganda: Does this Have Anything to Do with Social Work? *Journal of Human Rights and Social Work, 2*(1), 52-61.

Wandera, S. O., Kwagala, B., & Ntozi, J. (2015). Prevalence and risk factors for self-reported non-communicable diseases among older Ugandans: a cross-sectional study. *Global Health Action, 8*(1), 27923.

Wandera, S. O., Ntozi, J., & Kwagala, B. (2014). Prevalence and correlates of disability among older Ugandans: evidence from the Uganda National Household Survey. *Global Health Action, 7*(1), 25686.

Warburton, J., Cowan, S., Savy, P., & Macphee, F. (2015). Toward the Development of a More Integrated Aged Care Assessment Process for Rural Older Australians:

Practitioners' Perspectives. *Journal of Gerontological Social Work, 58*(5), 503-520. https://doi:10.1080/01634372.2015.1041667
Warburton, J., & Jeppsson Grassman, E. (2011). Variations in older people's social and productive ageing activities across different social welfare regimes. *International Journal of Social Welfare, 20*(2), 180-191.
Wardell, S. (2018). 'A Stranger in the Name of Jesus': Exploring Cosmopolitan Ethics in a Ugandan Christian Care Community. *Sites: a journal of social anthropology and cultural studies, 15*(2).
Watson, R., McKenna, H., Cowman, S., & Keady, J. (2014). *Nursing Research: Designs and Methods E-Book*, Elsevier.
White, S. L. (1999). Colonial-Era Missionaries' Understanding of the African Idea of God as Seen in Their Memoirs. *Anglican and Episcopal History, 68*(3), 397-414.
WHO. (2015). *World Report on Ageing and Health*. Retrieved from http://apps.who.int/iris/bitstream/10665/186463/1/9789240694811_eng.pdf?ua=1
WHO. (2017). *Towards long-term care systems in sub-Saharan Africa* (Licence: CC BY-NC-SA 3.0 IGO.). Retrieved from http://www.who.int/ageing/long-term-care/WHO-LTC-series-subsaharan-africa.pdf
WHO. (2018). *WHO country cooperation strategy at a glance: Uganda*.
Wiegratz, J., Martiniello, G., & Greco, E. (2018). Introduction: Interpreting change in neoliberal Uganda. *Uganda: The dynamics of neoliberal transformation*, 1-39.
Wild, K., Wiles, J. L., Allen, R. E., Warburton, J., Ng, S. H., & Shardlow, S. M. (2013). Resilience: thoughts on the value of the concept for critical gerontology. *Ageing and Society, 33*(1), 137.
Wiles, J. (2004a). Home as a new site of care provision and consumption. In *Ageing and place* (pp. 95-113): Routledge. https://doi:10.4324/9780203694510
Winterton, R., & Chambers, A. H. (2017). Developing sustainable social programmes for rural ethnic seniors: perspectives of community stakeholders. *Health & Social Care in the Community, 25*(3), 868-877. https://doi:10.1111/hsc.12373
Winterton, R., Walsh, K., & Skinner, M. (2020). *Rural Gerontology: Towards Critical Perspectives on Rural Ageing*. Routledge.
Winterton, R., & Warburton, J. (2011). Does place matter? Reviewing the experience of disadvantage for older people in rural Australia. *Rural Society, 20*(2), 187-197. https://doi:10.5172/rsj.20.2.187
Winterton, R., Warburton, J., Keating, N., Petersen, M., Berg, T., & Wilson, J. (2016). Understanding the influence of community characteristics on wellness for rural older adults: A meta-synthesis. *Journal of rural studies, 45*, 320-327.
Winterton, R., Warburton, J., & Oppenheimer, M. (2013). The future for Meals on Wheels? Reviewing innovative approaches to meal provision for ageing populations. *International Journal of Social Welfare, 22*(2), 141-151. https://doi:10.1111/j.1468-2397.2012.00889.x
Won, C. W., Yang, K. Y., Rho, Y. G., Kim, S. Y., Lee, E. J., Yoon, J. L., ... & Lee, Y. S. (2002). The Development of Korean Activities of Daily Living (K-ADL) and Korean Instrumental Activities of Daily Living (K-IADL) Scale. Journal of the Korean Geriatrics Society, 6(2), 107-120.
Wrisdale, L., Mokoena, M. M., Mudau, L. S., & Geere, J.-A. (2017). Factors that impact on access to water and sanitation for older adults and people with disability in rural South Africa: An occupational justice perspective. *Journal of Occupational Science, 24*(3), 259-279.
Xiao, L. D., Wang, J., He, G.-P., De Bellis, A., Verbeeck, J., & Kyriazopoulos, H. (Xiao2014). (2014). Family caregiver challenges in dementia care in Australia and China: a critical perspective. *BMC Geriatrics, 14*(1), 6. https://doi:10.1186/1471-2318-14-6

Yeates, N. (2012). Global care chains: a state-of-the-art review and future directions in care transnationalization research. *Global Networks, 12*(2), 135-154.

Yeatman, A., Dowsett, G. W., Fine, M. D., & Gursansky, D. (2008). *Individualization and the Delivery of Welfare Services : Contestation and Complexity*. Palgrave Macmillan.

Young, E., & Quinn, L. (2002). Writing effective public policy papers. *Open Society Institute, Budapest*.

Zhang, B. (2020, May). A Critical Analysis on Confucian Sexism Through the Lens of Care Ethics: A Case of Domestic Labor Division. In *6th International Conference on Humanities and Social Science Research (ICHSSR 2020)* (pp. 358-363). Atlantis Press.

Zhao, C., Zhou, X., Wang, F., Jiang, M., & Hesketh, T. (2017). Care for left-behind children in rural China: a realist evaluation of a community-based intervention. *Children and Youth Services Review, 82*, 239-245.

Zhou, J. S., & Walker, A. (2016). The need for community care among older people in China. *Ageing & Society, 36*(6), 1312-1332. https://doi:10.1017/S0144686x15000343