Chronic Life-Limiting Illness and Informal Care in Ghana: Experiences of Older People and Their Family Carers

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Chronic Life-Limiting Illness and Informal Care in Ghana: Experiences of Older People and Their Family Carers

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Submitted in fulfillment of the requirement of the degree of Doctor of Philosophy

December 2020
Abstract

Background

In Ghana, just as in many African countries, informal care for older people is derived from a shared culture of social responsibility, reciprocity and love. With a global increase in the older population and an increase in chronic life-limiting illness among older people, there is evidence of the emerging health, social and economic needs of older people living with chronic life-limiting illness. In rural Ghana, where there is limited access to adequate support services for chronic life-limiting illness management, the effect of globalisation on social change is impacting on the ability of the Ghanaian family systems to continue the historical culture of informal care for older people. However, there is limited evidence on the experiences of older people and their family carers with respect to chronic life-limiting illness and informal care in rural Ghana.

Aim

To explore the experiences of older people and their family carers on chronic life-limiting illness and informal care in rural Ghana.

Method

Underpinned by the transformative paradigm, a critical ethnographic research design was used as the logical framework for data collection and analysis of results. The research was conducted during 6 months of fieldwork in the Gomoa West District, Ghana. Four groups of participants, including 15 older people, 15 family carers and 5 health care professionals from a local hospital at the Gomoa West District, and 5 health care professionals from a national Palliative Care Clinic, were purposively sampled to participate in this research. An
ethnographic interview method supported with daily fieldnote notes was used for data collection. The thematic analysis procedure suggested by Braun and Clarke (2013) was used for the analysis of each data set. Subsequently, conclusions were drawn based on the themes and their interpretation.

**Findings**

Primary analysis of the data related to older people’s subjective experiences with chronic life-limiting illness included an increasing awareness of illness in the body, limitations in meaningful activities being experienced as loss of independence and dependency relationships being experienced as vulnerable. Themes related to experiences with informal care included sustaining family and social networks for care and support, the multiple roles of being a family carer, enablers to informal care, and the burden of, and resilience and barriers to, informal care.

**Problems identified for transformative change**

Older people’s subjective experiences with chronic life-limiting illness were negative. Some older people were faced with a nuanced decision to self-isolate from society due to an increasing awareness of illness in the body. There were experiences of challenging social identity and self-worth because of loss of independence to maintain self-care activities and to meet personal social and economic role expectations. Furthermore, existing health, social and economic structures did not ensure inclusiveness of older people living with chronic life-limiting illness; thereby, increasing vulnerability in unlimited health, social and economic needs in the rural community. Dependency on inconsistent informal care increased vulnerabilities to loneliness, isolation, abuse, neglect and uncertainties. Also, the negative
perception of older people who have become dependents induced feelings of shame, failure, burden and sadness among those with problematic social identity and self-worth.

There was an existential difference between traditional care and informal care specific for older people living with chronic life-limiting illness due to evidence of demographic, epidemiological and social change that worsened the burden of care on family carers. Thus, the capacity of family carers did not match the required needs of their recipients, although the ability of family carers to remain resilient sustained care. Given the extended roles family carers play and the burden of care in informal care, the lack of specific services to support family carers manage chronic life-limiting illness for their care-recipients were notable.

**Conclusion**

Rapid social change renders older people less powerful, and makes them vulnerable to social isolation, losses and challenging social identity and self-worth. Older people living with chronic life-limiting illness have unlimited unmet health, social and economic needs; thus, dependence on an inconsistent informal care is inadequate and may expose both older people and their family carers to marginalisation. The findings highlight the significant need for effective inclusive policy that take into consideration the impact of demographic, epidemiological and social changes on older people living with chronic life-limiting illness. As a society, we should ascribe the same importance of resourcing the health and social systems to supporting family carers to provide informal care, since both support structures work hand in hand to enhance the quality of life of older people living with chronic life-limiting illness. Additionally, it is imperative that further research among this group of people consider the factors that make them marginalised.
Keywords: Older people, chronic life-limiting illness, informal care, family carers, critical social theory, marginalisation, value-critical policy analysis, national ageing policy, critical ethnography, transformative change, rural, Ghana, Africa
Statement of Originality

This work has not previously been submitted for a degree or diploma in a university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself.

Barbara Adonteng-Kissi

December 2020
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# Glossary of Abbreviations and Definition of Key Terms

This list of words are the key terms and abbreviations used throughout this thesis.

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<td>ADLs</td>
<td>Activities of daily living</td>
</tr>
<tr>
<td>Cedis</td>
<td>The official currency of Ghana</td>
</tr>
<tr>
<td>CHPS</td>
<td>Community Based Health Planning and Services</td>
</tr>
<tr>
<td>CHRAG</td>
<td>Christian Health Association of Ghana</td>
</tr>
<tr>
<td>Chronic disease</td>
<td>The type of disease that is not completely cured by medication and has generally prolonged progression.</td>
</tr>
<tr>
<td>Chronic illness</td>
<td>The subjective experience of the influence of a chronic disease on the individual’s well-being, encompassing physical, psychological and social dimensions.</td>
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<tr>
<td>Chronic life-limiting illness</td>
<td>The many periodic health crisis and the gradual deterioration in functional abilities, with its associative long stays in hospital, which makes a person living with chronic illness more dependent in terms of their care needs and the possibility of premature or sudden death.</td>
</tr>
<tr>
<td>CST</td>
<td>Critical social theory</td>
</tr>
<tr>
<td>Term</td>
<td>Description</td>
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<tr>
<td>Demography</td>
<td>The scientific study of populations and their changes over time.</td>
</tr>
<tr>
<td>Epidemiology</td>
<td>The branch of science that studies the incidence, distribution and control of diseases among different populations.</td>
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<tr>
<td>FGM</td>
<td>Female genital mutilation</td>
</tr>
<tr>
<td>Fufu</td>
<td>Staple food made from boiled cassava and plantain</td>
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<tr>
<td>GDP</td>
<td>Gross Domestic Product</td>
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<tr>
<td>GHS</td>
<td>Ghana Health Service</td>
</tr>
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<td>GSS</td>
<td>Ghana Statistical services</td>
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<td>Instrumental activities of daily living</td>
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<td>MoESW</td>
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<td>MoH</td>
<td>Ministry of Health</td>
</tr>
<tr>
<td>NHIS</td>
<td>National health insurance scheme</td>
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<tr>
<td>NSF</td>
<td>National Service Framework for Older People in the United Kingdom</td>
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</table>
Plantain  Green or cooking banana

SLCH  St. Luke Catholic Hospital

UDHR  Universal Declaration on Human Rights

UNDESA  United Nation’s Department of Economic and Social Affairs

Welfare system  The system of support developed to provide assistance to marginalised groups through public policy and state institutions.

WHO  World Health Organisation
Dedication

I dedicate this thesis to my grandfather, the late James Kojo Sarsah. Paapa, thank you for your care and love. It is unfortunate that you didn’t live long to know the woman that I have become. I know you are resting in peace and you are giving me the encouragement I need to continue practicing the morals you taught me. I love you forever.

I also dedicate this thesis to all older people who willingly shared their experiences in this research. It is my hope that this thesis begins to provoke national conversations in Ghana that will lead to the implementation of needed policies and resources to support successful ageing.
Acknowledgement

I would like to acknowledge the wonderful people in my life who have helped me through to completion of my thesis.

Foremost, I would like to give God Almighty the glory for giving me the wisdom and strength to complete journey. It has not been an easy one, but God has been faithful.

I would like to acknowledge my supervisors, Associate Professor Laurie Grealish and Professor Wendy Moyle in a special way. In my culture, when a child hurt themselves, the mother would angrily send the child to the grandmother and the grandmother will nurse the wound with the hottest boiling water, herbs and ointment, but gently. People usually ask who is harsher in this scenario: the mother who takes the child or the grandmother who nurses the wound? Throughout my PhD journey, I experienced both Laurie and Wendy playing these roles alternately. Like a child with a wound, their constructive criticisms were difficult and painful, but I knew they were for my own good since this thesis is the best that it can be. Because of that, I say thank you very much to them both. I appreciate their guidance and support. Thank you for believing in me and encouraging me, especially in moments when I felt overwhelmingly stacked. I appreciate the opportunity to learn under you both.

Special thanks also go to my external supervisors, Dr. Nathan Davis for his immerse support during the analysis and interpretations of results, and to Professor Ama de-Graft Aikins for her support during the fieldwork.

I would like to thank Griffith University for supporting my PhD study by granting me the Griffith University International Postgraduate Research scholarship and the Griffith University Postgraduate research scholarship as well as providing the needed library and
health resources to enable me to undertake this research. I would also like to acknowledge the roles of Professor Marion Mitchell as the HDR convenor and other supporting staff members. I express my gratitude to all my HDR colleagues for their cordial relationship and support.

Professional editor, John McAndrew, provided copyediting and proofreading services, according to the guidelines laid out in the university-endorsed national “Guidelines for Editing Research Theses”.

Further, I would like to thank the Omanhene of Apam traditional area, the CEO of St Luke Catholic Hospital, and all the participants from the Gomoa West District who took part in this research. Special thanks to my cousin Rachel and my classmates Joseph, Howard and Rosina for their individual contributions to this thesis.

To Dr Edwina Opare-Lokko, Dr Mawuli Gyakobo and Professor Akye Essuman and all health care professionals from Palliative Care Clinic and Geriatric clinic of the Korle Bu Teaching Hospital, thank you for sharing your time and knowledge with me.

Finally, I would like to thank my husband Obed, for being the best dad to our children when I was not available. I count his support in thousand folds throughout this journey. To my girls, Akosua and Nana, thank you for your understanding. Then to my family in Ghana, especially my grandmother, thank you for your diverse support. I love you all.
Dissemination of Study Results

Peer-Reviewed Publications


Conference Presentations


List of Approved Publications in this Thesis

Section 9.1 of the Griffith University Code for the Responsible Conduct of Research ("Criteria for Authorship"), in accordance with Section 5 of the Australian Code for the Responsible Conduct of Research, states:

To be named as an author, a researcher must have made a substantial scholarly contribution to the creative or scholarly work that constitutes the research output and be able to take public responsibility for at least that part of the work they contributed. Attribution of authorship depends to some extent on the discipline and publisher policies, but in all cases, authorship must be based on substantial contributions in a combination of one or more of:

- conception and design of the research project;
- analysis and interpretation of research data; and
- drafting or making significant parts of the creative or scholarly work or critically revising it to contribute significantly to the final output.

Section 9.3 of the Griffith University Code ("Responsibilities of Researchers"), in accordance with Section 5 of the Australian Code, states:

Researchers are expected to:

- offer authorship to all people, including research trainees, who meet the criteria for authorship listed above, but only those people;
- accept or decline offers of authorship promptly in writing;
- include in the list of authors only those who have accepted authorship;
- appoint one author to be the executive author to record authorship and manage correspondence about the work with the publisher and other interested parties; and
• acknowledge all those who have contributed to the research, facilities or materials but who do not qualify as authors, such as research assistants, technical staff, and advisers on cultural or community knowledge, and obtain written consent to name individuals.

Included in this thesis is one paper, in Chapter 3, which was co-authored with my supervisors. My contribution to this co-authored paper is outlined at the front of the relevant chapter. The bibliographic details of this paper including all authors are:

Chapter 3

Published


Appropriate acknowledgements of those who contributed to the research but did not qualify as authors are included in the paper.

(Signed) (Date)

Barbara Adonteng-Kissi

(Countersigned) (Date)
Co-Principal Supervisor: Associate Professor Laurie Grealish

(Countersigned) (Date)

Co-Principal Supervisor: Professor Wendy Moyle
Chapter 1

Introduction

Population ageing is an emerging significant global and national demographic challenge. According to the United Nation’s Department of Economic and Social Affairs, a combination of drivers, such as a decrease in fertility rates, an increase in early childhood survival rates and an estimated increase in life expectancy to an average of 70.5 years at birth, account for the global ageing population (UNDESA, 2017). Current global statistics suggests that in 2015, the total number of older people, that is, those 60 years and older globally was 901 million (UNDESA, 2015). This number is expected to increase to 1.4 billion in 2030 and to 2.1 billion just two decades after (UNDESA, 2015). Alarmingly, it is estimated that by 2050, the older populations will exceed the number of children under 15 year in the world (UNDESA, 2015).

However, high life expectancy does not suggest that older people are living healthy and quality lives. The World Health Organisation (WHO) identifies that older people are disproportionately affected by an increase in chronic disease (WHO, 2018). Chronic disease is the type of disease which is not completely cured by medication and has generally prolonged progression (WHO, 2018). According to Kuuiire et al. (2020), chronic diseases accelerate disability, functional decline and vulnerability to multiple morbidities, especially during late life.

The WHO’s global strategy and action plan on ageing and health (WHO, 2017) reports these demographic and epidemiological changes have unprecedented health, social and economic implications, owing to the changing health, social and economic needs of older people. These changes have serious consequences for health and social policy expenditure. For example, a
global review on population and health care expenditure conducted by Asl and Abbasabadi (2020) found that population ageing accounts for a significant increase in health expenditure across the globe. One of the articles included in this review found that in the United States of America (USA), gross domestic product (GDP) per capita health expenditure in older people is five times higher than in children (Lassman et al., 2014). With chronic disease, health expenditure is reviewed as even higher (Thu et al., 2020).

Ageing with chronic disease in older people is directly related to changes in economic and social activity participation; thereby, increasing the need for innovation in social policies, with more government expenditure on social security and social welfare for this population group (Cristea et al., 2020). While in most developed countries health care and social welfare expenditure may be advancing (Cylus et al., 2020), it is the reverse in most developing countries, including those in Africa.

Africa is projected to be home to almost half of the world’s ageing population by 2050 (UNDESA, 2017), which means that African governments will need to develop policies to meet the unprecedented challenges that arise alongside the ageing population of older people with chronic disease. The challenge is compounded because in Africa the implementation of health, social and economic policies are heavily dependent on an irregular taxation and international donor funding systems (Kuuiire et al., 2020). Thus, older people living with chronic disease in African countries are at an increased risk of experiencing limited access to necessary health, social and economic support services (WHO, 2013, 2014).

The geographical context under consideration in this research is the African country of Ghana, which is of special interest to me because of my national affiliation. Ghana is in the western part of Africa, situated along the Atlantic Ocean, the Gulf of Guinea and close to the
Equator (Amponsah & Frimpong, 2020). It shares international borders with Burkina Faso to the north, Togo to the east and la Cote d’Ivoire to the west (Amponsah & Frimpong, 2020).

Accra is the capital of Ghana, a city of 1,963,264 people in a country of 31.07 million people (Worldometer, 2020). In Ghana, the term ‘older people’ refers to those who are sixty years of age and older. Older people represent 7.2% of the population, and this is expected to increase to 12% by 2030 (WHO, 2013). Older people predominantly live in the rural areas of Ghana (Osei Asibey & Agyemang, 2017), representing about two-thirds of the total population in rural Ghana (Oppong, 2016; Osei Asibey & Agyemang, 2017), with more than half of them being women (Fenny, 2017).

As an African women and social worker, my interest in the experience of older people in rural Ghana is shared in this personal reflective account:

For several months, he battled with multiple chronic conditions. The doctors could not tell us exactly what was wrong with him, but he had issues related to his cognition, memory and heart. In the middle of one night, I heard my grandfather bemoaning in his sleep, saying, “Oh God, I am in pain... I don’t have money... What is happening to me? What will happen to my family…? Please come to my aide”. These were the very last words he spoke before he died 8 days later with family prayers but without medical treatment and care, because neither I nor my grandmother understood his situation or how I could help him to deal with it. I cannot help but feel my grandmother and many other older people living in similar or even worse conditions in Ghana will have similar experiences. This is of concern to me as I have left my country, leaving my grandmother without an active family carer and no one to assist her in times of future need.
Ghana: Changing Demography and Epidemiology

The migration of young adults to the urban centres is the leading factor contributing to the ruralisation of older people in Ghana (Poku-Boansi & Afrane, 2016). The inverse of rural-urban migration, which is the return of older people back to the villages from the cities when they retire from active work, also contributes to the ruralisation of older people in Ghana (Amuakwa-Mensah et al., 2016). Ruralisation can contribute to social isolation among rural older people in African communities (Ojagbemi et al., 2020). Ruralisation and isolation contribute to limited access to necessary health, social and economic support services for rural older people (Banchani et al., 2020). Rural older people have poor health (Osei Asibey & Agyemang, 2017; WHO, 2014). Poverty (Ackuaku-Dogbe et al., 2015), inadequate government expenditure on health countrywide (only 3.2% of 2019 GDP (Gumah & Aziabah, 2020)) further alienate rural people from sufficient support services.

Although there is inadequate research on Ghana’s epidemiology, available evidence indicates that chronic disease is on the increase. About 63.9% of older people in Ghana are currently living with one or more chronic diseases (Fonta et al., 2017). Currently, highly recorded chronic diseases include cardiovascular disease, diabetes, cancers, stroke, respiratory diseases, chronic malnutrition, arthritis, anaemia, osteoporosis, hearing and sight problems (Fonta et al., 2017). Epidemiological research indicates that Ghana is gradually transitioning from the burden of infectious diseases to the burden of non-infectious diseases, and the rate at which this is happening suggests the healthcare system should put measures in place to manage the changing needs of older people, especially those in the rural areas whose population is expected to double by 2050 (Minicuci et al., 2014).
The health changes associated with chronic disease cause distress and interfere with the social functioning of older people (Nobles et al., 2016). That is when a chronic disease becomes a chronic illness. According to the WHO, chronic illness “minimises the role of the human capacity to cope autonomously with life’s ever changing physical, emotional, and social challenges and to function with fulfilment and a feeling of wellbeing with a chronic disease” (Huber et al., 2011, p. 2). We say a disease or an illness is life-limiting or life-threatening because of the possibility of sudden death (Kaes & Risola, 2017).

Chronic life-limiting illness in older people, which is the focus of this thesis, is the subjective experience of the influence of a chronic illness on the individual’s well-being, encompassing the physical, psychological and social dimensions (Vaske et al., 2017). It is the major cause of disability burden and gradual deterioration in functional abilities in older people. Its periodic health crises are associative of long stays in hospitals and make older people more dependent in terms of their care needs (Gill et al., 2010; Mayston et al., 2017).

**What Support is Available**

Traditionally, older people in Ghana have been cared for by a well-structured informal care system, which ensured and protected the individual’s quality of life. Informal care is care provided by a family member or a significant other to an older person with or without support from government (Olasoji et al., 2017). In Ghana, the extended family, as well as members of the community, provide care voluntarily to older people, without remuneration, since such care is deemed to be a social responsibility.
Historically, adults in most traditional societies contributed to the political, social, cultural and economic development of their societies. They made rules to guide the behaviour of younger people and provided the health and socioeconomic needs of younger people; in terms of meeting their basic needs of survival, such as feeding, clothing and providing shelter and the environment or atmosphere for one to realise his or her potential. In the event where older people become frail or sick, the younger generation used to take over the mantle of care, as it is believed it is their time to pay for the services rendered by the older people. The values which sustained the informal care system were a sense of respect, love, mutuality and reciprocity, community and continuity (Avendal, 2015).

In recent times, informal care for older people is gradually fading or changing and the cause is attributed to social change driven by the forces of globalisation (Apt, 2013). Social change refers to changes in the rules, value system and direction of society as a result of power from both internal and external sources, which brings alteration in the structure and culture of any society (Portes, 2010). Social change is a global phenomenon, with its impact being felt in several parts of the world (Brown, 2014; Yankuzo, 2014). The major implications of social change on informal care for older people are the associated loss of vital societal values such as love, respect and interaction, sense of belonging and reciprocity, loss of the younger workforce through rural-urban and international migration, in addition to increasing poverty (Apt, 2013; Yankuzo, 2014).

Nonetheless, living with a chronic illness has the potential to negatively influence the life of a person. Klindtworth et al. (2015) explain that people living with chronic heart problems express pain, tiredness and fear, and they experience social isolation and a reduced ability to perform daily activities, such as cooking, eating, bathing, shopping, etc. Also, people with
chronic illness have problems relating to love and belongingness, social networks, culture, spirituality, and finances (Waldrop et al., 2015) in addition to information and medication needs (Klindtworth et al., 2015; Waldrop et al., 2015).

In Ghana, especially in rural areas where the majority of older people live, chronic life-limiting illness specialised services are minimal. This is different in Australia and other developed countries, where there is greater access to specialist palliative care for people with highly complex clinical and psychosocial needs and a simple management or palliative approach for people requiring more standard care. Also, support, in the form of family carer income, services (respite), resources (webpages, community networks/groups) and information are available to family members who provide informal care for people with chronic illness (Cash et al., 2019), to better provide care, owing to the challenges associated with providing informal care to older people living with chronic life-limiting illness. Developed countries also can offer adequate information and appropriate communication and these resources are linked with family carers’ and care recipients’ confidence in symptom management (Dionne-Odom et al., 2017; Edwin et al., 2016). These support services are inaccessible in Ghana for family carers. Although there is a National Ageing Policy (MoESW, 2010), which outlines the benefits available to older people and their family carers, implementation remains problematic (Kpessa-Whyte & Tsekpo, 2020).

Given the increasing number of older people and those living with chronic life-limiting illness in rural Ghana, a supply deficit of standard and general specialised services, as well as decreasing informal support due to social change, this thesis identifies the social problem of marginalisation in health and social care among older people and their family carers when it comes to chronic life-limiting illness and informal care in rural Ghana. In addition, it is not
really known what the experiences of older people and their family carers are in rural Ghanaian communities. It is in the context of this background that research on chronic life-limiting illness and informal care is necessary, as a way of bringing to light challenges faced by older people and their family carers in rural Ghana.

Research Aim and Objectives

The broad aim of the study is to examine the experiences of older people and their family members around chronic life-limiting illness and informal care in rural Ghana. Hence, the study’s specific objectives were as follows:

1. explore the experience of older people living with chronic life-limiting illness in rural Ghana;

2. assess the informal care for older people living with chronic life-limiting illness in rural Ghana; and

3. investigate ways of strengthening social structures to enhance the quality of lives of older people with chronic life-limiting illnesses in rural Ghana.

Research Questions

1. what are the experiences of older people with chronic life-limiting illness in rural Ghana?

2. what are the structures and processes of informal care for older people living with chronic life-limiting illness in rural Ghana?
3. in what ways could social structures be strengthened to enhance the quality of life for older people with chronic life-limiting illness in rural Ghana?”

How this Document is Organised

There are eight chapters in this thesis. In Chapter 2, I present a narrative review of the literature on social change in Ghana and how it affects older people and their care. In Chapter 3, an integrative literature review on informal care for older people with chronic life-limiting illness in Africa is presented. The fourth chapter is the methodology chapter, where I make a step-by-step presentation of the paradigms and processes in which the research was carried out. Chapters 5 and 6 present the findings of the ethnographic research. Chapter 7 shows the distinctive features of critical ethnography, where I used the tenets of critical social theory and the transformative paradigm to explicate the central problem of the thesis and make a recommendation for a transformative change. The final chapter is the conclusion and implications for study, policy, practice and community education chapter, where I also present a brief summary, key contributions of the research and the limitations of the research.

Summary of Chapter 1

Global evidence on chronic disease suggests that it is increasing among older populations and it is the leading cause of suffering among older people. Chronic life-limiting illness is the subjective experience of the influence of a chronic disease on the individual’s physical, social and psycho-emotional wellbeing and has a high likelihood of premature death. In Ghana, the older population is expected to increase from 7.2% to 12% in the next 10 years. Chronic life-
limiting illness and its impact are also expected to increase, alongside an older population increase. In Ghana, not only is chronic life-limiting illness a problem, ruralisation and access to vital support services for chronic life-limiting illness management are also problematic.

In addition, informal care is a vital resource for the management of physical, psycho-emotional and social needs associated with chronic life-limiting illness, but very limited information is available on how it is organised within Ghana. Informal care is the care provided by a family member without support from government. In recent times, social change is reducing the traditional form of support for older people in Ghana. In the time of epidemiological and demographic changes, changes in family could impact on care, both now and in future care. However, just like older people living with chronic life-limiting illness, access to support services for family carers are problematic. Based on this background and the researcher’s personal experiences with older people’s care in rural Ghana, the central aim of this research was to explore the experiences of older people and their family carers on chronic life-limiting illness and informal care in rural Ghana.

In the next chapter, I present a literature review using an historical analysis lens to examine the impact of social change on the general care of older people in Ghanaian society. Also, based on a social problem of marginalisation identified in this thesis, I present a policy review on selected Ghanaian policies relevant to chronic illness in Ghana and a justification for critical social theory, which underpins this research.
Chapter 2

Literature review

Introduction

In the previous chapter, I demonstrated that for demographic and epidemiological reasons, the number of older people expected to experience chronic life-limiting illness will increase in Ghana. For this demographic group, care is paramount, but combined with social change, care for older people, especially those in the rural Ghanaian communities, is changing significantly, but there is limited access to support services.

In this chapter and the following chapter, I present a literature review to examine the structures and processes of care, respectively, for this study. This chapter on structures is organised under three main sections. In the first section, I provide a brief historical analysis of social change through the lens of globalisation as it influences the changing structures of care for older people in rural Ghanaian societies. In the second section, as I indicated in Chapter 1, I identify the social problem of marginalisation, and I use the value-critical policy framework for analysing public policies to present a preliminary analysis of four Ghanaian policies relevant to the study population in the areas of health, chronic illness, ageing and social welfare. Finally, operationalising oppression as marginalisation, I justify using critical social theory as an overarching theoretical framework for this thesis in the third section. The chapter ends with a section on knowledge gaps and a brief summary of the chapter.
Society, Social Change and its Impacts on Care of Older People

Society is an important aspect of human existence. In a broader sense, society is a group of people who share certain commonalities, such as common social identity (Thomas et al., 2019) and common culture, that is, the description of their way of life (Page & Shimeles, 2015; Riddell & Watson, 2014). Culture ensures the continuity of a society through values and principles, as portrayed in the people’s art, language, religion, occupation and history (Riddell & Watson, 2014). Over time, every society goes through process of change (Yusuf, 2003). This process can be gradual, such as during human evolution (de la Sablonnière, 2017), or precipitous in the social order, such as the recent national lockdowns to control the spread of the global novel coronavirus epidemic (Benach, 2020). The process of social change affects the rules, value system and direction of society, due to the exercise of power from both internal and external sources, which can bring alteration in the structure and norm of any society (Portes, 2010).

In this section, I present a brief historical analysis of social change as a result of globalisation and the emerging changes in the structures of care of rural older Ghanaians. Historical analysis is a qualitative approach of presenting historical facts through the description of historians (Thies, 2002). I adopted a causal narrative style (White, 1965) of description because of its plausible logical explanation of historical events (Dray, 1985). This method was suitable because there is limited documented evidence from African scholars who have lived experience of globalisation and its associated changes in Africa (Osei et al., 2020).

I emphasise globalisation in this thesis because of its significant impact on society and emerging changes in care structures (Anderson & Obeng, 2020; Busemeyer & Garritzmann, 2019). Globalisation is the “opening of international borders to increasingly fast flows of
goods, services, finance, people and ideas; and the changes in institutions and policies at national and international levels that facilitate or promote such flows” (Ofori-Asenso & Garcia, 2015, p. 67). Using three-time frames–pre-colonial, colonial and post-colonial eras–to ground the context of this history, I focus on the state, community and family structures as care emerged. I discuss changes in the political, economic and family culture to illustrate the impact of globalisation on care of older people.

**Ghanaian Political Culture**

Before the coming of the Europeans in 1874, Ghana’s traditional societies were governed by chieftaincy institutions, where a chief was the leader, and together with his council of elders, was responsible for maintaining values and norms in small localised communities (Tieleman & Uitermark, 2018). The council of elders was made up of older people who were usually heads of various extended families in the community (MacLean, 2002). According to Adotey (2019), the functions of the chieftaincy institution mirrored the functions of the arms of modern government, where the chief and his council of elders enacted norms, values and laws to control social behaviour and settled family disputes (Adonteng-Kissi et al., 2020). The chieftaincy institution exerted enormous power and control, and their roles put prominence on preserving and promoting lives in their local communities, towns or villages (Dwumah et al., 2018), especially from recurrent intra-inter ethnic and racial conflicts that used to exist before colonial rule (Boateng & Afranie, 2020). People in communities held allegiance to the chieftaincy institution because of shared ethnic or racial identities as well as the values and norms which bound them together and protected their lives (Béland et al., 2018).
In addition to the governing roles, older people in Ghanaian traditional communities played significant social and cultural roles (Michel et al., 2019). In other words, older people played significant roles in the accumulation of cultural capital of younger people in most traditional societies because they were responsible for socialising and initiating younger people into society’s institution, such as marriage, childbirth, employment, education, health and religion (Dwumah et al., 2018). Older people were custodians of social norms and values, and the younger generations learnt accepted behaviours from them (Agyemang, 2014).

For example, older women played significant roles in those communities where female genital mutilation (FGM) was practised. Before it was officially outlawed in 1994, FGM was seen as a form of ethnic or racial identity for communities who practised it (Nonterah et al., 2019). Older women supervised the practice and handed over the responsibility from one generation to another. The social and cultural roles older women played in FGM also included socialising young circumcised girls into adulthood, teaching them how to be morally upright women, and good mothers and wives (Sakeah et al., 2019). Additionally, in traditional societies, formal education was limited, and young people learnt customary law and family occupation through interaction with the older people, which were passed on by their predecessors (Avendal, 2015; Chirwa & Rushwaya, 2019; Dwumah et al., 2018).

Because of the political, social and cultural roles of older people in pre-colonial Ghanaian societies, Agyemang (2014) suggests that growing older was associated with wisdom and the younger generation revered older people for that wisdom. The benefit of playing these important political, social and cultural roles was the care offered through the community and extended family system when older people retired (Apt, 2002). Care for older people was a
commitment, negotiated among families and the entire community, described by Coe (2017) as both kin-scripts and non-kin-scripts.

Globalisation and political change that weakened the chieftaincy institution has led to experiences of loss of vital political, social and cultural positions and the associated changes in the family and community care structure for older people in traditional Ghanaian societies. The beginning of political change in Ghanaian traditional societies may be ascribed to British colonialism. British colonial rule was started by an attack on the then largest established kingdom – the Ashanti kingdom in 1874, and gradually spread to other parts of the country until the whole country was subdued (Cobbinah et al., 2020).

This change initiated a shift from chieftaincy rule to indirect colonial rule, where the British ruled the local people through the local chiefs, and then to direct colonial rule by the British colonial administration, where the British controlled the politics, commerce, health and religion of the entire country (Cobbinah et al., 2020). Through the establishment of similar modern systems of British government in Ghana, such as central government and court systems, successive British colonial governments continued to ensure that the functioning of traditional chiefs and their council of elders’ power and control over community people and resources diminished (Boateng & Afranie, 2020).

In addition, Christianity, formal education, technology and human rights introduced by the coming of colonial masters led to some of the social and cultural activities in pre-colonial Ghana being banned/outlawed (e.g., FGM) or modernised (e.g., childbirth and health care practice) (Boateng & Afranie, 2020). Older people responsible for expanding the cultural capital of the younger generation through the practice of these activities lost their roles and consequently their position as leaders in these communities (Sakeah et al., 2019).
Change in political structure also resulted in change in care structure during the colonial era. Colonial government instituted state sponsored or social welfare, however, the state sponsored care or social welfare during the colonial era was limited in scope. It focused on providing wage protection and health care for the colonial government officials and civil servants (Mkandawire, 2020). MacLean (2002) explains that the political ideology underlying the provision of social welfare was self-sufficiency. In furthering the self-sufficiency ideology, Fowler and Mati (2019) added that the British colonial masters emphasised that economically, private institutions, the community, extended families, churches and volunteers provided social welfare for vulnerable individuals, including older people.

After Ghana’s independence in 1957, three major coup d’états and corresponding military rules since 1992, which Charway and Houlihan (2020) explain as resulting from economic difficulties, such as inflation and an increase in taxes, ultimately paved the way for democratic rule and the election of presidents (Asekere, 2020). However, neither the military nor successive democratic governments restored the pre-colonial political power of traditional rulers. Much research on Ghana’s chieftaincy institutions suggest that although a succession procedure existed to elect new rulers (Tieleman & Uitermark, 2018), the mode of succession was sometimes a source of conflict among royal families in the communities, towns or villages (Adonteng-Kissi et al., 2020; Adotey, 2019; Yaro & Ngmenkpieo, 2020). In addition, Rathbone (2000) suggests that the involvement of the chieftaincy institution in indirect and direct rule made some chiefs liable to bribery and corruption. Other views show that the ultimate peaceful transition from military to democratic government in 1992 (Boateng & Afranie, 2020), as well as the formalisation of government institutions, such as the judiciary, policing and electoral commission (Marfo & Musah, 2018), suggest the chieftaincy institution had overlived its political significance. The post-colonial governments
built on the legacies of the colonial masters to run a central government system and established other state agencies to govern the people at the local level, such as the environmental protection agency, which had the responsibility to develop policies to protect the environment from pollution, a role which hitherto, was reserved for the chief and his council of elders (Boateng & Afranie, 2020). Even till this day, chiefs in Ghana operate as traditional leaders, but they do not have any political influence.

Loss of political influence also affected the influence of the chieftaincy institution on care of older people in the community. Changes in chieftaincy roles resulted in accelerated changes in the well-established family and community care structures under the demographic government. Further, there was little effort by the post-colonial governments to expand the colonial social welfare to cover the local people, possibly due to limited economic capacity and some economic decisions pertaining to globalisation. These increased poverty for rural older people, and this is discussed in detail in the next section.

In summary, Western political values and norms have influenced Ghanaian society, and thereby shifted the political culture in local communities, where older people who formed councils advising the chief and conducted socially and culturally important procedures now have no or limited power in a globalised Ghana.

*Ghanaian Economic Culture*

In this section, I describe the effects of globalisation on the emerging poverty among rural older people, from pre-colonial Ghana to the present. Ghana’s economic structure, like many countries in Africa in pre-colonial era (before 1874), was sustained by subsistence
agricultural and mining activities overseen and managed by the existing traditional political system (Boateng, 2017). Subsistence agriculture and mining refer to community-based and family farming, livestock rearing, fishing and small-scale mining of natural minerals using manual tools, where the main purpose was for the consumption of the local people and self-sufficiency (Inikori, 2013).

The historical account of Van der Geest et al. (2010) on migration in the pre-colonial era, suggests that population growth and the quest for independence led to the migration of some families and communities and the discovery of other habitable, cultivable and natural resource-rich lands in Ghana. They added that these discoveries introduced the idea of specialisation in agricultural and minerals production (Van der Geest et al., 2010). Migration and these discoveries played a significant role in the commercialisation of Africa’s subsistence economy, where communities and families produced different crops or natural resources based on the land type, but in larger quantities. After taking what they consumed locally, the local people used the surplus to engage in intra- and inter-community and regional trade (Inikori, 2013). The trade was by barter, that is, goods were exchanged for other goods (Rönnbäck, 2020). Specialisation in production and barter trade indicate the simplicity of economic activities and ease in maintaining community and family care structures for older people in pre-colonial Ghanaian society (Coe, 2017).

The simplicity of economic activities changed during the colonial era. Industrialisation, which was increasing in Europe and the Americas, allowed the process of transformation and significant expansion in the manufacturing and production of goods and services (Barbieri et al., 2020). However, scholars on economic activities during the colonial era indicate that by the time colonial rule was in full force, the colonial government refused to support
industrialisation in Ghana, based on their control of supply of raw materials for their home industries (Bjornlund et al., 2020). Consequently commercial agricultural and mining activities concentrated on production and export of a very limited selection of agricultural produce, such as cocoa and minerals such as gold, during the colonial era (Bjornlund et al., 2020).

With population growth, high exportation of raw materials, and the lack of colonial support for industrialisation, increased the importation of large amounts of manufactured products produced from exported materials to Africa (Akpalu et al., 2017), in particular textiles, alcohol, firearms, tobacco and beads (Rönnbäck, 2020). Historical evidence on colonial economic activities alluding to the exploitation of labour and the imposition of high-income taxes (Hart, 2014; Osei et al., 2020) resulted in impoverishment of the local people, especially those in the rural areas, where all farming and mining sites were located during the colonial era. With the gradual introduction of, and dependence on, money as the medium for trade exchange, poor economic conditions in not just the agricultural sector but the entire country significantly contributed to the fight for independence from the colonial masters (Osei et al., 2020).

Right after independence (i.e., 1957) and building on some of the legacies of the colonial masters, such as formal state institutions, formal education, technology transfer, railways and road networks expansion and the construction of harbours (Osei et al., 2020), the new government concentrated on advancing Ghana’s industrialisation, leading to the establishment of some industries, such as textiles, brewery, and cannery factories, etc., in the post-colonial era (Boafo, 2019; Frimpong, 2020). According to Frimpong (2020), the post-colonial government’s focus on industrialisation underpinned the enactment of some
economic reforms to facilitate the exchange of goods and services between and among other nation states. These reforms included financial support for the expansion of both private and state owned small-scale manufacturing industries, large-scale importation of goods and services and removal of all forms of trade restrictions and opening up the borders (Frimpong, 2020). These economic policies solidified Ghana’s participation in global trade (Charway & Houlihan, 2020).

An analysis by Yaro (2013) also indicates that some of these economic policies favouring industrial development resulted in poor policy support for the local agricultural and mining sector. While the local production sector suffered significantly, some local industries that depended on the local produce sector also suffered, and dependence on foreign companies increased (Boafo, 2019; Goodman, 2019), affecting the rural people who depended on it for their daily living.

Moreover, industries in post-colonial Ghana were concentrated in major cities and towns in Ghana’s capital of Accra, which were close to the harbour and were already urbanising because Accra was the seat of the central government. Urbanisation is the process whereby people move from rural areas to settle in cities or towns (Apt, 2001). Increasing industries, and dependence on money as a medium of exchange served as the push factors for many young people from the rural parts of the country to settle in the cities and towns where the industries were, rapidly making these places more urbanised (Ayinde et al., 2019). In other words, industrialisation resulted in the initiation of rural migration and urbanisation (Apt, 2001).

The rise of industries led to the formation of trade unions to fight for better conditions of service and social welfare (Hart, 2014). Thus, the concentration of government sponsored
social welfare was on people in the government and industrial sector, such as income security as well as facilities such as government housing projects, building of hospitals, urban electrification projects and portable water (Apt, 2001; Hart, 2014). Those in the rural areas, were mostly older people. They were disproportionately affected by the process of globalisation but as they were not part of any trade union, they could not access these social welfare services.

As already stated, political instability in post-colonial Ghana led to the collapse of many state owned industries (Goodman, 2019). Apt (2001) explains that younger Ghanaians cannot find sustainable jobs in less available industries in the urban centres, yet they abandon agriculture and migrate to the cities to look for jobs, which are not there in the first place or are inadequate to employ large numbers of them. The older people left in the rural areas cannot sustain the commercial agricultural activities because of their labour-intensivity. These factors combine to contribute to experiences of poverty among older people in rural areas (Ayinde et al., 2019; Barbieri et al., 2020; Fu et al., 2019; Vercillo et al., 2020).

In summary, the implications of globalisation on the collapse of the commercial agricultural economy, and emergence of industrialisation, urbanisation, trade unionisation, and the concentration of social welfare in the formal and industrial sectors contribute to the poverty experiences of rural older Ghanaians. In the next section, the implication of globalisation on the family and community care structures of older people are presented.
Ghanaian Family Culture

The previous section on globalisation and political change demonstrates the loss of political, social and cultural power of older people. In the second section, globalisation and the loss of economic power without social welfare among older people was portrayed. In the following section, I show another dimension of social change and its impact on older people; that is globalisation and the rise of an informal economy as well as the rise in technology has affected the sustainability of the community, and in particular, family care structures for older people.

Labour exploitation and the lack of support for industrialisation in the colonial era, as discussed earlier, were pivotal for focusing on industrialisation by the post-colonial governments. However, when there is a mismatch between industrialisation and urbanisation, an exposure to urban poverty is inevitable (Ayinde et al., 2019). The removal of border restrictions led to the proliferation of imported goods from other industrialised countries, resulting in the advent of Ghana’s predominant informal economy of petty trading of imported goods (Fayomi et al., 2017; Yeboah, 2017). An informal economy is one that is characterised by activities which are “unrecorded in the official statistics such as the gross domestic product and/or the national income accounts” (Fayomi et al., 2017, p. 15). Petty trading is a business activity of purchasing and sale of general consumables in small quantities and in small market spaces (Yendaw, 2019). Unlike the trade unions and income protection of industrial workers discussed in previous section, people in the informal economy work without benefits or social protection. As already indicated in the previous chapter, the inverse of rural-urban migration that increases ruralisation of older people in
Ghana suggests that rural older people who previously worked in the informal sector as petty traders do not have any income security.

In addition, the widespread use of informal economic activities in Ghana limited the state’s ability to advance social welfare services, because the state could not amass adequate taxes since it could not manage the activities of the informal economy due to the unavailability of legal frameworks (Packard et al., 2012). With poverty in urban populations, the economic capacity of the family to continue pre-colonial family care for older people back in the rural areas is limited, leaving older people in most rural communities with few active family carers and in poverty (Apt, 2001; McLigeyo, 2002).

Apart from the economic implication of globalisation on family care, some Ghanaian values and beliefs have been rendered invisible and replaced by Western values due to globalisation. According to Yankuzo (2014), the process of globalisation synchronises different cultures and beliefs and creates a singular dominant culture which supports the global trade. For example, the rise of global communication through the internet proliferates access to information generated in the West, which is made available through the internet on digital television, radio, and smart telephone devices (Yusuf, 2003).

Information access has influenced the abandonment of cultural values and principles, which were the pivots around which the organisation of traditional Ghanaian societies evolved. As emphasised in Chapter 1, and explained earlier in this chapter, political and social changes have contributed to generational isolation, which is accentuated with the rise of social media. According to Yusuf (2003), children no longer listen to teachings of the older people in the moonlight because the media offers all the answers to their problems. Also, young people find it is easier to look at their mobile phones than to find an older person to talk to,
decreasing the love, respect and interaction that used to exist among children and older
people. As older people are not adopters of the internet, therefore their views on social
matters are not visible to the wider community. This means that the expertise of older people,
like languages and social skills, are rendered invisible.

Another impact of globalisation on Ghanaian care culture is the changes in the family
structure, which alters the family care processes for older people. Families provide
relationships and identity for their members (Bott & Spillius, 2014). As noted in earlier
sections, Ghanaian society is made up of different communities, and these communities are
also made up of different units of extended families. The extended family refers to a
collective of people who share relations extending beyond their immediate kin, and they are
bound by roles and responsibilities towards each other (Agyemang et al., 2018), such as
providing assistance in the form of material, monetary, emotional and moral support to each
other (Avendal, 2015; Nortey et al., 2017) in a reciprocal manner (Small et al., 2017). An
extended family is comprised of great- and grandparents, great- and grandchildren, uncles
and aunties, cousins, parents, siblings, stepfamily, in-laws and all other kin relations
(Aboderin, 2004). However, in Africa and many other cultural environments, such as among
the Aborigines in Canada and Australia, the meaning and composition of family is usually
cultural, and may be dependent on living arrangements and proximity (Tam et al., 2017). The
uniqueness of family culture may make it difficult to fit the composition of an African family
into one category or the other in one time (Tam et al., 2017).

That notwithstanding, the major benefit of the extended family system is its collective and
wider ability to provide care for its vulnerable members, specifically, older people, persons
with disabilities and children (Makiwane et al., 2017). The traditional chief and his council of
elders ensured adequate social welfare was available, due to the perceived roles older people played in society (Apt, 2002). However, the extended family system is waning along with changes in Ghana’s political and economic cultures. The period of post-colonial industrialisation, migration and poverty and the associated change in the family structure has reduced the power of the extended family to ensure continuous care of its members (Avendal, 2015).

According to Apt (2001), and based on an analysis of the impact of globalisation on culture by Yusuf (2003), post-colonial urban Ghanaian society is characterised by diverse cultural values with less sense of ethnic or racial community, thus the more society becomes diverse, the more the structure of care for older people is placed in jeopardy (Apt, 2001). Rural-urban migration and urbanisation affected the extended family structure by necessitating a shift from the extended family system to the immediate family system through the movement of people from their original geographical locations (Apt, 2002). Waning of the extended family breaks the family into different sections of immediate families, which do not include great-and grandparents, great- and grandchildren, uncles, aunties and cousins (Aboderin, 2004). Further depletion of the immediate family puts an emphasis of family on just a husband, his wife and their offspring, otherwise known as the nuclear family (Aboderin, 2004).

In addition to the changing roles of women as primary family carers of older people in Ghanaian homes, the nuclear family has also been subjected to review, with some African writers describing the current African family system as evolving (Magezi, 2018; Makiwane et al., 2017). Recent migration and feminist literature cites the proliferation of women migrants, the changing women’s economic autonomy or power in societies and their impact on changing family structure (Apatinga et al., 2020). The evolving African family system gives
rise to modern family systems such as the single-parent and female-headed families as well as children only families.

These new family dynamics are amongst the emerging changes that impact upon the availability of care for older people in Ghanaian communities. With chronic life-limiting illness emerging as a significant global health problem affecting many of the older population, as discussed in Chapter 1, it has become critical to intentionally revise the structures within which care occurs for older Ghanaians, with special emphasis on those living in rural areas, in light of the socio-economic vulnerabilities discussed previously. Key points to consider if family remain the long-term care structure for this population group are:

- Older people’s political, social and cultural power in rural communities has shifted due to the influence of Western values related to globalisation.
- Young people have left rural communities to work in city-based industries emerging from globalisation.
- Petty trading has emerged as a way of life as due to the limitations of Western industrialisation in Ghana, but there is no security or social welfare in petty trading.
- Rural families have evolved from tight extended families to nuclear and distributed families.
- Family distribution has been enhanced by the same communication technologies (including money transfer technologies) that have advanced globalisation.
- These historical factors generate present day challenges in the care structures, which are beyond the control of older people and their families.
In the next section, I use the value-critical policy analysis framework to analyse four relevant Ghanaian health and social policies to identify areas for transformative change in light of these emerging problems.

**Analysis of Ghanaian Policies Relevant to Chronic Life-Limiting Illness and Older People**

Again, as mentioned earlier, the democratic system of Ghana significantly influenced the availability of state sponsored care for vulnerable older people. During the first republic of Ghana in the 1960s, in an attempt to build on the legacies of the colonial masters, analysed by (Mkandawire, 2020), social protection policies such as a free national health service, improved water and sanitation facilities, implementation of national social security schemes, old age income support and affordable housing for all were made available for all but especially for vulnerable Ghanaians (Béland et al., 2018). Béland et al. (2018) added that in the beginning of the 1980s until now, constant political instabilities and implementation of structural adjustment policies in Ghana in response to national and global economic crisis and the proliferation of informal petty trading activities led to the cancellation of all of the social welfare policies, leaving Ghanaians who depended on these programs more impoverished and vulnerable.

However, and as already explained in Chapter 1, in line with the World Health Organisation (WHO) global strategy and action plan for ageing and health, the need for government social policy on health, social and economic care of older people, generally, and those living with chronic life-limiting illness in rural Ghana specifically is unequivocally important. More so in
Ghana where older people in rural areas have been significantly affected by globalisation induced social change. The purpose of this section is to present an analysis of Ghanaian government policies, to determine their effectiveness in addressing the health, social and economic needs for older people living with a chronic life-limiting illness in rural Ghana.

Given the focus of this research on older people living with chronic illness in rural Ghana and the historical analysis presented in earlier section, Ghanaian policies which focus on health and social welfare are worthy of review. These are the National Health Policy, National Policy for the Prevention and Control of Chronic Non-Communicable Diseases in Ghana, National Ageing Policy and the National Health Insurance Scheme. These four policies were selected because, at the time of writing, there is no single policy that addresses the health and social needs of the ageing Ghanaian population. The four policies are outlined briefly in Table 2.1.
<table>
<thead>
<tr>
<th>Policy title/year</th>
<th>Number of pages</th>
<th>Responsible department</th>
<th>Goal</th>
<th>Objectives</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Ghana National Health Policy/ 2007.</td>
<td>66</td>
<td>The Ghana Health Service under the Ministry of Health.</td>
<td>“Ensure a healthy and productive populations that reproduces itself” (MoH, 2007, p. 32).</td>
<td>Ensure that people live long, healthy and productive lives and reproduce without an increased risk of injury or death. Reduce the excessive risk and burden of morbidity, mortality and disability, especially in the poor and marginalised groups. Reduce inequalities in access to [sic] health, populations and nutrition services and health outcomes (p. 33).</td>
</tr>
<tr>
<td>National Policy for the Prevention and Control of Chronic Non-Communicable Diseases in Ghana/2012.</td>
<td>24</td>
<td>Ministry of Health.</td>
<td>“Ensure that the burden of NCDs is reduced to the level of barest minimum so as to render NCDs not a public health concern or an obstacle to socio-economic development” (MoH, 2012, p. 9).</td>
<td>Reduce the incidence and prevalence of chronic NCDs. Reduce exposure to the risk factors that contribute to NCDs. Reduce morbidity associated with NCDs. Improve the overall quality of life in persons with NCDs (p. 10).</td>
</tr>
</tbody>
</table>
practicable to participate fully in the national development process” (MoESW, 2010, p. 29).

Ministry of Health.

“Generate funds for the operation of the health sector in Ghana” (MoH, 2012, p. 17).

If no objectives, then outline strategies that are proposed to generate funds.

National Health Insurance Scheme (NHIS)/2012.

Improve health, nutrition and well-being of older persons.
Improve housing and living environment of older persons.
Strengthen the family and community to provide support to older persons.
Improve income security and enhanced social welfare for older persons.
Provide adequate attention to gender variations in ageing.
Strengthen research, information gathering and processing, and coordination and management of data on older persons.
Enhance capacity to formulate, implement, monitor and evaluate policies on ageing.
Improve financing strategies [sic] to ensure sustainability of implementation of policies and programmes of older persons (p. 29).

There are no specific objectives of the NHIS; however, the scheme is open to all Ghanaians; those who are registered under the scheme get the benefit of free health care consultation in most public health institutions as well as medications listed under the essential medicine list.

Registered Ghanaians are required to renew their subscription annually through their local health districts to receive the benefits.
Some categories of people are exempted from the annual payment, including dependent children and pensioners who are 70 years and above.
Value-Critical Policy Analysis Framework

The value-critical policy analysis framework developed by Chambers and Wedel (2009) was used to analyse the policies. Value-critical policy analysis uses value-based or judgment criteria to determine whether features of a social policy are problematic or beneficial in relation to a defined social problem (Chambers & Wedel, 2009). The value-critical policy analysis approach combines both analytic and judgement perspectives to determine the suitability of aspects of social policy to solve a social problem (Chambers & Wedel, 2009). The value-critical policy analysis framework is suitable for evaluating public policies used to provide critical services by experts in the social services profession, such as social workers, therapists and counsellors (Ricciardelli & Jaskyte, 2019). The six main criteria for analysing public policy based on the value-critical framework are: goals and objectives, forms of benefits and services, eligibility rules, administration and service delivery, financing and interaction (Chambers & Wedel, 2009, p. 40). The first five criteria are emphasised in this thesis. Table 2.2 gives a brief overview of the value-critical policy analysis framework.

Table 2.2

Value-Critical Policy Analysis Framework (Adapted from Chambers and Wedel (2009))

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Definition</th>
<th>Value-critical analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goal and objectives.</td>
<td>Goals are general statements; indicative of what to do for the mission and vision of the policy to be achieved.</td>
<td>Clarity.</td>
</tr>
</tbody>
</table>
The Social Problem Overview

For a problem to be considered as a social problem, some conditions must be met. Social problems should be considered as undesirable, affect a significant number of the population and be identified by influential or powerful sources as a problem (Chambers & Wedel, 2009). Social problems must have a historical background and occur within social structures; thus, they require social policy to be solved (Barretti, 2020; Miller & Hamler, 2019).

As indicated in Chapter 1 (p. 7) this thesis identifies the social problem of marginalisation in health and social care among older people living with chronic life-limiting illness in rural Ghana. Marginalisation may be as a result of historical disadvantages in older age that

<table>
<thead>
<tr>
<th>Forms of benefits and services.</th>
<th>Objectives are specific statements indicative of what to do for the goal to be achieved.</th>
<th>Target population.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Material and non-material assistance originating from the social policy in relation to the social problem.</td>
<td>Measurability.</td>
</tr>
<tr>
<td>Eligibility rules.</td>
<td>Regulating or limiting policy benefits and services for the target population.</td>
<td>Reference to timeline.</td>
</tr>
<tr>
<td></td>
<td>Inclusion and exclusion, that is, target population of the health-related policies and fit of benefit in the social problem analysis.</td>
<td>Expert services.</td>
</tr>
<tr>
<td></td>
<td>Positive discrimination to address past inequality.</td>
<td>Reference to timeline.</td>
</tr>
<tr>
<td>Administration and service delivery.</td>
<td>Agencies to plan, implement and manage policy benefits for the target populations.</td>
<td>Accessibility of agencies.</td>
</tr>
<tr>
<td></td>
<td>Integrated service provision.</td>
<td>Integrated service provision.</td>
</tr>
<tr>
<td>Financing.</td>
<td>Funding sources of social policy.</td>
<td>Adequacy.</td>
</tr>
<tr>
<td></td>
<td>Government.</td>
<td>Equity.</td>
</tr>
<tr>
<td></td>
<td>Individuals.</td>
<td>Efficiency.</td>
</tr>
</tbody>
</table>
increase isolation and losses in rural ageing Ghanaian populations. Marginalisation as a social problem is born out of a series of historical and social disadvantages, such as those described in society, social change and its impacts on care of older people in section 1 of this chapter (p. 12-27), that when combined with ageing with chronic life-limiting illness work to prevent older people and their family carers from accessing the necessary resources, and thereby can be considered discriminatory. In this thesis, I use the conceptualisation of marginalisation put forward by Mowat (2015) to describe how older people and their family carers experience marginalisation when it comes to managing chronic life-limiting illness with informal care. Marginalisation, as queried by Mowat (2015), is the feeling of a tension between an individual’s set of values interacting with the values of the broader society, and how society’s “risks and protective factors” influence this tension to shape the experiences of the individual in society (Mowat, 2015, p. 467).

In examining the social problem of marginalisation, I address the five criteria for analysing social policy of Chambers and Wedel (2009). Table 2.3 gives an analytical summary of the four policies that focus on health and social welfare in Ghana.
Table 2.3

**Ghanaian Policies Analysis Based on the Value-Critical Policy Analysis Framework**

(Target population: older people and their families; setting: rural communities)

<table>
<thead>
<tr>
<th>Policy</th>
<th>Goal &amp; Objectives</th>
<th>Forms of Benefits</th>
<th>Eligibility rules</th>
<th>Administrations and service delivery</th>
<th>Financing</th>
</tr>
</thead>
<tbody>
<tr>
<td>National Health Policy.</td>
<td>The goal is clear but highly abstract. Objectives. Indicative of a broad target population. Not indicative of how the objectives will be measured. No reference to timeline. No reference to chronic or ageing related illness.</td>
<td>Access and rural inclusivity to basic health care and nutrition support. No specific reference to chronic or ageing related expert services.</td>
<td>Targets the youthful population. No specific mention of older people or their families in terms of ageing or chronic illness.</td>
<td>Planning and implementing health programs are undertaken by the Ghana Health Service (GHS) under the Ministry of Health. Addresses accessibility - the GHS run on decentralised systems, that is, district and regional levels.</td>
<td>Individual contribution from taxes, and out-of-pocket expenses. NHIS. Government expenditure (GDP).</td>
</tr>
<tr>
<td>National Policy for the Prevention and Control of Chronic Non-Communicable Diseases in Ghana/2012.</td>
<td>The goal is clear but highly abstract. Objectives. Outcomes clearly stated, that is, prevention and promotion.</td>
<td>Prevention and promotion interventions targets youthful population. The fourth objective has potential to benefit older people, that is,</td>
<td>Benefits target youthful population. Not clear on inclusiveness of older people. Expert services for older people and</td>
<td>Implemented in line with the operations of the GHS. There is no specific agency on chronic illness within the GHS.</td>
<td>All Ghanaians contribution from taxes, and out-of-pocket expenses NHIS.</td>
</tr>
<tr>
<td>National Ageing Policy</td>
<td>Not indicative of measurability and timelines.</td>
<td>QoL but not very clear on measurability and timelines. No reference to support for families and/or communities.</td>
<td>chronic illness not included.</td>
<td>Some services offered by the primary health care system.</td>
<td>Government expenditure (3.2% of GDP on health).</td>
</tr>
<tr>
<td>------------------------</td>
<td>-----------------------------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------</td>
<td>-----------------------------</td>
<td>----------------------------------------------------------</td>
<td>--------------------------------------------------</td>
</tr>
</tbody>
</table>

Goal is broad and ambiguous, containing words with several meanings. Objectives. Appear clear on what the social and economic outcomes should be. No specific objective on chronic illness or ageing related illness. Not indicative of measurability and timelines.

Social and economic support specifically target older people. Addresses social and economic positive discrimination. Recognises the role of families and communities to support older people care. Issue on prior contribution not addressed. Benefits fit into one aspect of the social problem; expert services on chronic illness is not addressed.

Managed by the Department of Social Welfare under the Ministry of Gender, Children and Social Protection. Access to services limited; no specific government ageing related agency exist to implement the policy. Issue on integrated service delivery not addressed. No indication of how individual older people or families can make prior contribution to the operation of the policy. Government funding limited. There is no evidence of budgetary allocation in the current budget.

<table>
<thead>
<tr>
<th>National Health Insurance Scheme (NHIS)</th>
<th>Goal is clear and direct. Scheme is ongoing and operational.</th>
<th>Access to primary health care in public hospitals. Some laboratory and diagnostic services as well as allied health services such as social work, physiotherapy,</th>
<th>All Ghanaians are eligible to be enrolled in the scheme.</th>
<th>National Health Insurance Authority. District and regional level service delivery. Rural and remote access to service is limited.</th>
<th>Individual prior contribution. that is, annual subscription Government taxes and levies.</th>
</tr>
</thead>
</table>
psychology services not covered.
Advance health services such as geriatrics and palliative care not covered.
People exempted from paying annual subscription fees include children and older people who are 70 years and above.

QoL = Quality of life; GDP = Gross domestic product; NHIS = National Insurance Scheme; GHS = Ghana Health Service
Criterion 1: Goals and Objectives of the Ghanaian Policies

The question related to the goals and objectives of the policies is, “Do the goals and objectives of the program or policy system fit a social problem as defined?” (Chambers & Wedel, 2009, p. 42). Chambers and Wedel (2009) suggest that for social policy to be considered as fit (i.e., provides the best solution to the social problem under review), the goals and objectives must be clear, and indicative of measurability and a timeline for the objectives. The goal of the National Health Insurance Scheme is clear, and the goal and objectives of the National Ageing Policy is also clear on what to achieve, that is, the social, economic and cultural inclusivity for older people extending to the rural and poor older people (MoESW, 2010).

With the exception of the National Health Policy, which gave a timeline of 2015, there is no specification on timeline or measurability of objectives in the National Ageing Policy or the National Policy for the Prevention and Control of Chronic Non-Communicable Diseases. Specifying the how and when to measure outcomes are important, because it helps to give implementers of each policy some form of timeframe to achieve the overall goal and objectives of the policies (Fisher et al., 2020). Consequently, specific policies surrounding how and when to measure the actions and outcomes of the National Policy for the Prevention and Control of Chronic Non-Communicable Diseases and the National Ageing Policy are required to enhance the determination of fit.

Moreover, there is no specific objective targeting chronic illness in older populations in the National Health Policy or the National Policy for the Prevention and Control of Chronic Non-Communicable Diseases. The target populations of these two policies are the youth, pregnant women and children. However, the statistics for non-communicable diseases in Ghana
presented in Chapter 1 (p. 4) suggest that chronic illness are higher in older people and older people make up a significant number of health care service users (Agyeman et al., 2019; Agyemang-Duah et al., 2019; Agyemang-Duah et al., 2020; Kpessa-Whyte, 2018). Targeting the youthful population groups can amount to poor resource allocation and unequal health outcomes in older population groups (AHMAC, 2017). In this case, the lack of focus on older people, especially those in rural areas may reduce their access to needed health services.

The goal and objectives of the National Ageing Policy (MoESW, 2010) can address the social and economic exclusiveness of older people from rural Ghanaian communities, but there is no objective on chronic illness, and it does not provide a good analysis of fit. The National Service Framework for older people from the United Kingdom (NSF, 2001) identifies cardiovascular diseases and their comorbidities as the disease burden in older people, and the framework makes specific provisions for treating and enhancing outcomes. Therefore, restructuring the objectives of the National Ageing Policy to include chronic illness outcome can help manage the limitations in the National Health Policy and the National Policy for the Prevention and Control of Chronic Non-Communicable Diseases and provide a criterion of good fit for the social problem of marginalisation of health and social care for older people in Ghanaian rural communities.

**Criterion 2: Forms of Benefits and Services of the Ghanaian Policies**

This criterion addresses the material and nonmaterial benefits of a social policy. Forms of benefits emanating from the policy must specifically target the population identified as experiencing the social problem under review (Chambers & Wedel, 2009). The question raised to address the criteria on policy benefit as fit to the social problem under review is
“Can this form of benefit produce a significant impact on the causal factors believed to produce the social problem?” (Chambers & Wedel, 2009, p. 42). To some extent, the answer to this question is yes, and it is based on access to basic health care service, as presented in Table 2.3. For example, a policy programme of community-based health planning and services (CHPS programme) based on the National Health Policy, has enabled basic health care infrastructure and bridging the health care gap between rural and urban Ghana (GSS, 2014). Also, with the NHIS accessibility to health care services among people of low-socio-economic status (older people, especially those in the rural areas fall within this category) has improved (GSS, 2014; Osei Asibey & Agyemang, 2017). But in terms of older people and chronic life-limiting illness, there are limitations that need to be addressed to enhance the benefits in expert services and provide a good fit of policy to address social problems. Expert service in terms of managing chronic life-limiting illness is inadequately available, especially to the rural poor older people (Ankrah et al., 2019).

**Criterion 3: Eligibility rules of the Ghanaian Policies**

This criterion examines how policy benefits and services can be limited to the target population. Chambers and Wedel (2009, p. 42) question the fit of the eligibility rules to the social problem as “Do the eligibility rules direct benefits at the entire population defined to have the social problem, or do they only reach a subgroup?”. In other words, value-critical policy analysis raises questions on whether a social policy has equal entitlements for all population groups it aims to serve.

To some extent, the answer to this question is no, and it is based on the demographic description of Ghanaians presented in the National Health Policy and National Policy for the
Prevention and Control of Chronic Non-Communicable Diseases in Ghana targeting women, children and the youth. As indicated in Chapter 1, the average global life expectancy is 70.5 years (UNDESA, 2017), but in Ghana, it is 64.9 years with the male-to-female ratio being 61:64 years (Statista, 2018), which is relatively young. Based on this demographic description, the eligibility rules of these two policies may unintentionally exclude the health concerns of older people living with chronic life-limiting illness. For example, as part of the benefits of the National Health Policy, programmes such as maternal and infant health and nutrition services are available for mothers and children (Kumordzie et al., 2019). Older people also need nutritional support (Steiner-Asiedu, 2019), but currently the nutritional needs of this population is not adequately acknowledged in the National Health Policy.

In terms of a health approach, the intervention focus of health prevention and promotion, targeting pregnant women, infants and the youth in the National Health Policy and National Policy for the Prevention and Control of Chronic Non-Communicable Diseases in Ghana (MoH, 2007, 2012) may exclude the trajectory of ageing and chronic life-limiting illness. The trajectory of ageing and chronic life-limiting, as illustrated in Chapter 1, requires a different health intervention approach, such as treatment or management through the chronic care model and palliation, both of interest to older people living with chronic life-limiting illness. Some ageing policies, for example, the National Service Framework for older people in the UK (NSF, 2001) highlight a management and palliation approach to improve inclusiveness of older people’s health outcomes. Therefore, due to poor eligibility rules, the objectives and forms of benefits of the National Health Policy and National Policy for the Prevention and Control of Chronic Non-Communicable Diseases in Ghana do not indicate what or how resources would be made available for chronic disease management or palliation.
Criterion 4: Administration and Service Delivery of the Ghanaian Policies

Administration and service delivery criteria examine the agencies responsible for planning and implementing policy benefits for the target population. In terms of the social problem under review, Chambers and Wedel (2009) suggest that administration and service delivery should be accessible and integrated to the target population. The policies under review are operationalised separately. Fragmented service delivery can limit the impact of the policies, and, with particular reference to community-dwelling older people, a fragmented system of service delivery has high cost implications; it can serve as a disincentive to health care service access and produces unsurmountable burden on family carers (Mann et al., 2020).

Criterion 5: Financing of the Ghanaian Policies

The final criteria for the value-critical policy is financing, that is, adequacy, equity and efficiency. Each of these concepts are explained and analysed below.

Criterion 5.1: Adequacy

Adequacy refers to the judgement of available resources to meet the required outcome of the policy (Chambers & Wedel, 2009). The adequacy of public policy is measured based on multi-factorial indicators (Gumah & Aziabah, 2020). One indicator is the implementation and evaluation of the goals and objectives. The financial cost of planning and implementing these actions, what resources are needed and how these resources are accessed, can also determine the adequacy of the policy (Stenberg & Rajan, 2016). Currently, and as already stated in Chapter 1, government expenditure on health remains minimal in Ghana (Osei Asibey &
Agyemang, 2017). The current health expenditure per gross domestic product (GDP) is 3.2%, and this is a decrease from 9.72% in 2012 (Gumah & Aziabah, 2020). Although funding (resources) has been low, there has been improvement in health infrastructure and health financing, especially with the introduction of NHIS (Adua et al., 2017). However, several structural challenges have been identified as impeding health care access with the NHIS that require extra governmental funding (Fenny et al., 2016; Zhang et al., 2019).

The realisation of the goals and objectives of all public policies to enhance their benefits for the target population, therefore, warrants government commitment to providing adequate resources to deliver the policies. Critically, the cost of achieving middle-income status as the National Health Policy envisions suggests that all people, including older people are healthy enough to contribute to Ghana’s productivity and production. To achieve the criteria on adequacy of public policy, it will require an increase in health infrastructure and human resource to deliver quality health care and to manage and prevent chronic diseases (Baatiema et al., 2020; Zhang et al., 2019).

As discussed in relation to globalisation and the economic culture in Ghana in a previous section (p. 16), the challenges for the state to secure money in taxes, due to the widespread informal economy, to implement welfare policies can render health and social policies inadequate for significant health and social outcomes. As the WHO evidence on chronic disease presented in Chapter 1 suggest (p. 1), older people are disproportionately affected by non-communicable diseases (NCDs) (WHO, 2018), an increase in the number of older people and chronic diseases in older Ghanaians will require designating resources, such as education and human resource in geriatrics and chronic illness services, to meet health needs. Current
research on ageing in Ghana suggests that services such as geriatrics, nutrition, social work, physiotherapy, palliative services are limited (Baatiema et al., 2020; Essuman et al., 2018).

**Criterion 5.2: Equity**

The aim of equity is to assess whether the distribution of the benefits of public health policy promotes fairness for all target population groups (Chambers & Wedel, 2009). Fairness is “equity in health outcomes, in access to all forms of care and in financing” (Norman et al., 2000, p. 740). Based on the goals and objectives, eligibility rules and forms of benefits criteria presented earlier, the National Health Policy and National Policy for the Prevention and Control of Chronic Non-Communicable Diseases in Ghana do not deliberately promote fairness for older people living with chronic life-limiting illness. Both policies create an avenue for inequality in health outcomes in terms of mortality and morbidities against older people and older people living with chronic life-limiting illness. For example, geographical location further isolates older people living with chronic life-limiting illness in rural communities from advanced geriatrics and palliative services. The majority of Ghana’s older populations live in rural areas (Gumah & Aziabah, 2020; Osei Asibey & Agyemang, 2017). Most of the advanced services are located in cities and urban centres. Policy implementation appears to address urban and youthful populations rather than rural areas, and therefore access to those services is limited for people in rural settings.

Although the National Ageing Policy could serve as a bridge to close the equity gap, its equity is dependent on implementation, and this is yet to be achieved. The National Ageing Policy iterate the establishment of district ageing departments as well as the establishment of
an “active ageing fund” to provide financial resources to fund the policy’s goal and objectives, and they are yet to be fully launched (Sossou & Yogtiba, 2016).

As already identified under adequacy of health resources and expenditure (p. 41), expert services for chronic illness management in rural areas needs to be enhanced. To enhance the criterion on equity of expenditure may require including a chronic illness management approach that is in the geriatrics interests and allows access to the benefits and services. An example of a management approach that is in the geriatrics interests is the chronic and services care model (CCM). The CCM focuses on using a multidisciplinary approach, community resources, evidence-based guidelines, policy structures and self-care management approaches to managing the clinical and functional needs of older people living with chronic illness (Timpel et al., 2020). These services are not only limited and expensive, that is, not covered under the NHIS, but also, they are situated in the cities (Essuman et al., 2018), therefore excluding the majority of older people in the rural areas of Ghana.

**Criterion 5.3: Efficiency**

Efficiency of a public policy is determined by the effectiveness of an intervention approach and timeline (Chambers & Wedel, 2009). As already indicated in Chapter 1, older people currently represent 7.2% of Ghana’s 30 million population. Given the youthful population, a combination of the health-related policies may be efficient for a positive health outcome, with adequate resource allocation, implementation and evaluation of implementation strategies. However, the efficiency of the policies seems unlikely, due to the progressive nature of chronic illness and the possibility of sudden death, as discussed in Chapter 1 and earlier paragraphs of this section. Therefore, expert service delivery is inaccessible. A disjointed
health service delivery system may serve as a disincentive to accessibility, limiting the efficiency of the policy to address social problems (Chambers & Wedel, 2009). A policy analysis such as in this thesis can help to identify what needs to be improved. Also, without a restructuring of the National Ageing Policy, adequate resource allocation, implementation and evaluation of implementations strategies, the efficiency of the National Ageing Policy cannot be determined.

Summary of the Ghanaian Policies Analysis

The social problem identified in this thesis is the historical losses and isolation that increases vulnerabilities in older age and the global rise in chronic life-limiting illness in ageing populations, raising the larger social problem of marginalisation in health and social care in older populations. Despite an increase in the older population and chronic life-limiting illness in Ghana, there has not been significant improvement in the available social and health services through policy and policy led action to correspond to the growing needs of older people living with chronic life-limiting illness or to support family members to provide social welfare. The complexities of living with chronic life-limiting illness in a rural setting require the intersection of adequate, efficient and equitable health and social policy that provide a good fit for the social problem. This value-critical analysis of Ghanaian health and ageing policies suggests that there is an opportunity to achieve this outcome.

In the next section, I use Freeman and Vasconcelos (2010) explanation of critical social theory as the theoretical framework for this study.
Theoretical Framework - Critical Social Theory

This thesis identifies the social problem of marginalisation in health and social care in older people as arising because of the historical disadvantages in old age that increases isolation and losses in rural ageing Ghanaian populations. This understanding makes it appropriate to discuss marginalisation from a power perspective, and critical social theory (CST) as an appropriate means to examine this area. Historically, CST originated from the Frankfurt School in Germany in the 1920s and 1930s (Freeman & Vasconcelos, 2010). Although now used in health, sociology and education research, CST has its philosophical foundation in Karl Marx’s economic theory (Bohman, 2005). Political, social and economic circumstances in the 19\textsuperscript{th} and the 20\textsuperscript{th} centuries resulted in Frankfurt ideologists shifting from traditional Marxists perspective to a more diverse theoretical and cultural perspective (Freeman & Vasconcelos, 2010). The primary purpose of CST is to develop a preventive critique against economic, social and political oppression or injustice. CST provides a critically reflective and reassessment approach to examining the relationship between people’s real life experiences and society’s political, social and economic structures (structures of modern society) within which people’s real life experiences occur (Freeman & Vasconcelos, 2010).

CST seeks to create awareness of the existence of an oppressive situation with the aim of engaging the people who are experiencing the oppressive situation in a process to bring about change (Leonardo, 2004). According to Dant (2003), structures of modern society create oppression or injustice by promoting one absolute truth or method as the way of thinking or doing things. In doing so, people’s experiences and desires are presented in a biased way. Therefore, CST aims to establish a critique against anti-democracy and unjust, exploitative or oppressive structures of modern society (Sherman, 2003). The critical social theorists claim
that human existence and human desires cannot thrive within oppressive political, social and economic structures, thus human beings must engage in a reflective ideological critique of modern society in order to develop unorthodox but supportive social structures for people to thrive in (Dant, 2003; Freeman & Vasconcelos, 2010).

Four sub-theories are embedded in critical social theory: theory of false consciousness, crisis theory, theory of transformative action and theory of education. These sub-theories are explained below.

*Theory of False Consciousness*

Theory of false consciousness is the process of internalising the beliefs, values and ideologies of an oppressive system (Freeman & Vasconcelos, 2010). It is a state an individual or a group of people find themselves as a result of oppressive social circumstances or processes, which are of no benefit to them (Marriott-Statham et al., 2018). The state of false consciousness makes people willingly cooperate with their oppressors as a way of maintaining the status quo (Freeman & Vasconcelos, 2010). The theory makes the assumption that the emphasis should be on helping people experiencing false consciousness to develop critical consciousnesses. Critical consciousness is the “intentional cultivation of self-awareness in context that attends to the dynamics of power in relationships and the structural environment invoking action toward social justice” (O’Neill, 2015, p. 626). Developing critical consciousness is operational and a continuous process of reflecting on meanings of experiences and developing new meanings to experiences with a social justice focus. Freeman and Vasconcelos (2010) explain that critical consciousness can be achieved, first, by
identifying the condition of false consciousness and second, examining the social structures which contributed to the development of false consciousness.

**Theory of Crisis**

Crisis is an identified false consciousness (Freeman & Vasconcelos, 2010). Crisis is created by the organisation of an oppressive social system. Freeman and Vasconcelos (2010) explain that the organisation of the structures of an oppressive social system generate crisis for people who depend on them by creating distinctions between “normal people” and those who are not and blaming those who are considered not normal for their situation, instead of blaming the system for labelling people as not normal. Crisis limits peoples’ agency and autonomy to critically determine and assess the impact of an oppressive system.

**Theory of Transformative Action**

Transformative action is the hallmark of social justice, and it is achieved by advocating for society to reorganise its structures to address exclusion for the marginalised. As already stated in the section on marginalisation previously, the process of identifying a crisis and implementing a solution play equal roles to bring about liberation or enlightenment for people in crisis (Leonardo, 2004). By promoting transformative change, social justice is achieved for people who depend on oppressive social structures (Leonardo, 2004). Freeman and Vasconcelos (2010) explain that through education and intervention, transformative change is achievable, but the change process must be open to, and incorporate different
interests, needs and cultures. Also, change agents should be aware that their influence can marginalise others, so they must be self-reflective and self-critical throughout the process and work to empower marginalised groups. The process and outcome of change are equally important; therefore, democratic beliefs should underpin the decision-making process.

Theory of Education

The theory of education is concerned with the process of teaching and learning, not just in the classroom setting, but also in the social environment (Freeman & Vasconcelos, 2010; Freire & Ramos, 2009). It emphasises problem posing and dialoguing as necessary to bring about transformative change for people experiencing crisis. Problem posing encourages people to question the status quo and explore alternative realities, bringing to bear the is/ought dichotomous debate (Freire & Ramos, 2009). Participating in dialogue persuades oppressed people to express themselves and reflect on their lived experiences (Freeman & Vasconcelos, 2010). The process of critical education for transformative change is based on the commitment to love for people, humanity and in the cause of liberation (Freeman & Vasconcelos, 2010).

Relevance of Critical Social Theory to this Research

Contemporary research uses CST to explain the impact of health and social marginalisation among minority groups such as lesbians, gays, bisexuals, transgender and queer (LGBTQ) (Fabbre et al., 2019), older people in resource-poor settings (Walsh et al., 2019), and racial and ethnic minority older people (Lee, 2019). While most of these studies are related to
social, ethnic and racial minorities from Western countries, very few studies have focused on older minority groups in Africa, and Ghana to be precise. Although these studies were conducted in Western countries, they can represent challenges oppressed older minority groups face in Ghana.

The functioning of social structures, such as the health policies previously presented, often misrepresents and distorts people’s experiences, creating a system where marginalised people are oppressed (Freeman & Vasconcelos, 2010; Reeve, 2019). Marginalisation of older people described as the social problem in this thesis, is a system of oppression of older people. As already indicated in the social problem overview (p. 32), the conceptualisation of Mowat (2015) on marginalisation is used in this thesis. Marginalisation alludes to relativity. As echoed by Mowat (2015), using the ecological perspective, social values, risks and protective factors are ethnographically contextual; they depend on the setting and the timeframe within which they occur; and they are subject to the matter of power in society. Her conceptualisation of marginalisation indicates some conditionalities that we might come to think of in a group as marginalised, that make it relevant in this study. She examined marginalisation through ecological and psychological perspectives on resilience among young school children in Europe. She examined the processes that led to a group of young children considered to be marginalised, and how they developed protective measures against multiple levels of societal risks encountered in their daily lives. She found that poverty, feelings of inadequacy or limitedness, and struggling to fit in a school environment ultimately affected students’ ability to cope. She concluded that these factors shape the interpretation of the individual identity and are relevant to how they remain resilient.
It is acknowledged that the focus, sampling population and the geographical location emphasised by Mowat (2015) are different; however, the similarities in marginalisation outcome makes Mowat (2015)’s theory of marginalisation relevant to this study. The historical analysis, presented in the first section of this chapter, reports older people’s identities in precolonial era were set in the vital political, social and economic roles they played, which changed over the course of history. Mowat (2015) suggests, to understand marginalisation is to understand how and what separates a group of people. She encapsulates two underlying assumptions of marginalised groups that sheds light on the identification and manifestation of marginalisation. These assumptions are shared conceptualisation of ideals and stereotypical characterisations. In terms of shared conceptualisation of ideals, Mowat (2015) explained that anyone who cannot uphold ideals such as social norms and expectations deemed as relatively valuable to them and their social environment are perceived to be not ‘normal’, hence, marginalised. In addition, marginalised groups share relative stereotypical characterisation, such as vulnerability, lack of access to social resources, poverty, geographical disenfranchisement, disability, and government policy disenfranchisement.

The historical analysis presented in the previous section showed the disproportionate losses among older Ghanaians. Drawing on this, and the policy analysis presented in previous sections of this chapter, older population form a minority group in Ghana. As such, the goals and objectives, as well as the eligibility rules, of the health-related policies may exclude them from accessing existential benefits and services. The process of historical disadvantages and the politics of resource distribution favouring the majority demographic group acts as the power of oppression (marginalisation) against older people. CST provides a framework within which oppression is expressed and helps the understanding of how culture, rurality,
ageing and social change affect how older people feel normal or society ascribe normal identity to older people living with chronic life-limiting illness in rural Ghana.

The CST approach combines both constructionist and critical techniques to promote self-awareness of how social structures contribute to marginalisation of older people and their family carers in rural areas, who are already affected by other social change as induced by globalisation discussed previously in section one (Fonta et al., 2019). Finally, CST provides a framework to assess the structures and processes of caring for older people with chronic life-limiting illness in a rural community setting, and how these structures and processes challenge informal care continuity. CST provides a framework to assess ways to reorganise social structures to assist families to improve care and reduce the burden of care in a transformative spirit (Freeman & Vasconcelos, 2010), and how social structures promotes marginalisation of specific groups. The principles of the WHO global strategy and action plan for ageing on health (WHO, 2017) provides an ideal plan to achieve inclusiveness for older people to age healthily in Ghanaian rural communities, and these will be explored later in Chapter 7.

Summary of Chapter 2 and Gaps in the Literature

African literature on ageing is steadily progressing; however, there is not much research literature on older people living with chronic life-limiting illness in Ghana. With an increasing older population, chronic life-limiting illness and an increase in the number of older people living with chronic life-limiting illness, there is still inadequate support services
available to meet the increasing needs of older people living with chronic life-limiting illness in rural Ghana.

This thesis identifies the social problem of historical losses and isolation that increases vulnerabilities in older age and the global rise in chronic life-limiting illness in ageing populations, speaking to the larger social problem of marginalisation in health and social care in older populations. Perhaps, because older people in Ghana form the minority population, they may be marginalised when it comes to how Ghana’s social structures function. It has been demonstrated that marginalised minority groups have very poor health outcomes when it comes to chronic life-limiting illness. Apart from health exclusion, older people in Ghana are affected by low socioeconomic status and rurality. However, there is limited primary research on the subjective impact of ageing, chronic life-limiting illness, social change, globalisation and changing social welfare on older people living with chronic life-limiting illness in rural Ghana.

The plight of older people is worsened by political, social and economic changes which reduced the wider ability of the family to maintain support. Despite the volume of research indicating epidemiological changes and the dwindling of family support for older people, the family remains the main provider of care. Informal care is an important resource for chronic life-limiting illness management, but the literature review demonstrates that there is little evidence on how social change and globalisation impact the efficiency of Ghana’s informal care. Given the increasing needs of older people living with chronic life-limiting illness and the lack of support, providing informal care can be challenging, but there is no evidence of the subjective impact on family members in Ghana.
To conclude, there is a need to understand the subjective experiences of older people and their family carers when it comes to chronic life-limiting illness and informal care in rural Ghana. An understanding of the subjective experiences will help to determine which of Ghana’s social structures needs to be reorganised to improve older people and their families’ experiences with chronic life-limiting illness and informal care. While Africa is expected to experience an exponential increase in the older population and an increase in older people living with chronic life-limiting illness, literature on how informal care is used to support those older people is limited.

In the next chapter, I present an integrative review conducted to assess the existing literature on how informal care is used as support for older people living with chronic life-limiting illness in Africa communities. All countries in Africa were included to gain a broader regional perspective on how informal care is used to support older people living with chronic life-limiting illness.
Chapter 3

An Integrative Review of the Literature

Introduction

This chapter presents a published integrative review conducted as a part of the literature review for this thesis.

The aim of this integrative review was to assess the existing literature on the informal care for older adults with chronic life-limiting illness in Africa. Following the integrative review an update of the literature is presented.

Within the published manuscript, the findings of the review on managing chronic life-limiting illness in African communities are reported. This paper has been published in the *International Social Work Journal*.

Statement of Contribution to Co-authored Published Paper

This chapter includes a co-authored paper. The bibliographic details of the co-authored paper, including all authors are:


My contribution to the paper involved conceptualising and development of search strategy, undertaking systematic searches and screening, data extraction, carrying out the critical
review of the literature, presenting results, interpreting the results and critical evaluation of the literature to inform the discussion, writing of the draft manuscript, and revision of the manuscript for important intellectual content, and approval of the final version.

Minor modifications have been applied to the original publication to fit the thesis formatting.

(Signed) (Date) 24/12/2020

Barbara Adonteng-Kissi

(Countersigned) (Date) 21/12/2020

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(Countersigned) (Date) 24/12/2020

Co-principal supervisor: Professor Laurie Grealish

(Countersigned) (Date) 24/12/2020

Co-principal supervisor: Professor Wendy Moyle
Informal Care of Older Adults with Chronic Life-Limiting Illness in Africa: An Integrative Review


Abstract

Informal care is recognised as a significant resource in the care of older adults living with a chronic life-limiting illness. This review aimed to assess the existing literature on how informal care is used to support older people living with chronic life-limiting illness in Africa. A four-step integrative review framework was used to produce three themes inductively: chronic illness management is a social as well as a clinical matter; burden of care can be relieved by connection with the church; and cultural obligations for informal care are contingent on the availability of people and resources. Social policies should be structured to support caregivers and older adults to strengthen the ties between community social organisations and their families.

*Keywords*: Older adults, family carers, chronic life-limiting illness, Africa
**Introduction: Purpose of the Review**

There are increases in chronic illness and the number of older adults living with chronic illness worldwide (Zaman et al., 2017). Chronic illness is life-limiting; it is the type of illness that is not entirely curable by medication and has a generally prolonged progression with the possibility of premature death (Rizzuto et al., 2017). Chronic illness consists of periodic health crises and a gradual deterioration in functional abilities, with associated hospital stays, which make older adults more dependent in terms of their psychosocial needs (Gill et al., 2010; Mayston et al., 2017). Chronic illness has the potential to influence quality of life negatively.

As people living with chronic illness age, and their disease progresses, their dependence on others for care increases. Informal care is an essential resource in the improvement of quality of life of older adults living with a chronic life-limiting illness, helping to meet psychosocial needs (Klindtworth et al., 2015; Waldrop et al., 2015). Informal care is non-professional care; it is that care provided by a family member or a significant other to a person who is incapacitated due to an illness with or without support from the government (Olasoji et al., 2017).

A culture of the provision of informal care has a long history in Africa. Traditionally, African families practised the extended family system, different from the Western individualised nuclear family system (Furstenberg, 2019).

The extended family system was the type in which a generation of three or more families cohabited in the same home and was bound by roles and responsibilities towards each other. In most African homes, the extended family members play vital roles in the care of older adults.
by providing material, monetary, emotional and moral support for the sustainability and protection of lives (Nortey et al., 2017). Members of the extended family, as well as the community, provide active care voluntarily, without question or remuneration, since such care is deemed to be a cultural responsibility, supported by social values, such as respect, reciprocity and sense of community (Tomini et al., 2016). More recently, traditional African family structure and practice have been changing in response to global social changes.

Global social change refers to the advent of industrialisation, urbanisation and colonialism, bringing a shift from socialism to capitalism, which began about 300 years ago (King, 2015). Global social change and the associated influence and dominance of Western culture have overshadowed vital societal values which bound African families together. For example, while rural-urban and international migration due to industrialisation, advanced education and conflict have contributed to changes in family structure, and thereby an associated loss of the active family carers, increasing poverty reduced the financial ability of family members to provide adequate care (Apt, 2013). Yankuzo (2014) suggests that members of the extended family have become more hostile and disunited, with some people dominating and seeking their own interests at the expense of more vulnerable family members. As a result, the influence and dominance of Western culture make some people feel African culture is inferior and should not continue.

Africa is predicted to experience a substantial increase in the older population, with those 60 years and older increasing from about 50 million presently to almost 200 million in the next three decades (Hall, 2017; UNDESA, 2017). By more than ten years improvement in life-expectancy in Africa between 2000 and 2016 (Oghagbon & Giménez-Llort, 2014), the present life expectancy for an African is 61.2 years, with the male to female ratio being 61:64
years (Statista, 2018). With the population increase and an increase in life expectancy, there is an increase in chronic illness. In Africa, one in three adult lives with at least one chronic condition (Hajat & Stein, 2018).

Statistics indicate that apart from alterations in the day-to-day life functioning, chronic illness is responsible for up to 80% of the global 38 million annual deaths among people in Africa and other developing countries (Nyaaba et al., 2017). However, actions for chronic illness management in Africa remain slow to put into effect (Owusu et al., 2019). Currently, the most common chronic illnesses among older Africans include cardiovascular disease, diabetes, cancers, respiratory diseases, chronic malnutrition, arthritis, anaemia, and osteoporosis (Fonta et al., 2017; WHO, 2014). As the African older population and life expectancy increase, the numbers of people living with a chronic illness is also expected to increase. In the context of changing family structures, the reliance on families for informal care for symptoms management bears further investigation.

A palliative approach is recommended for older people diagnosed with a chronic life-limiting illness to help with symptoms management from the beginning. According to WHO (2014), palliative care can be explained as reducing pain and managing other physical, psychosocial and spiritual characteristics of chronic illness. The palliative approach focuses on providing comfort and improving the quality of life of people living with chronic life-limiting illness and their families, using a team of experts, such as medical professionals, social workers, pharmacists, psychologists and sometimes spiritual leaders (Yosick et al., 2019). In Western countries, these services are accessible to people requiring both complex clinical and psychosocial needs and more standard symptom management and psychosocial care.
In Africa, only a few countries, especially where improvement in medication has turned HIV/AIDS and tuberculosis into chronic illness, have adopted a palliative approach for the management of clinical and psychosocial needs in people living with chronic life-limiting illness (Edwin et al., 2016; Irumba & Evelyn, 2012). Because of limited access to, and inadequately trained professionals in palliative services, older adults living with chronic life-limiting illness in Africa often rely on family carers for their physical and psychosocial needs (Nortey et al., 2017). Given the recent social changes in Africa and the expected increase in older people living with a chronic life-limiting illness, it is essential to assess how informal care is used to support older people living with chronic life-limiting illness in Africa.

**Design and Methods**

This review is guided by the integrative review process of Whittemore and Knafl (2005). The choice of an integrative literature review allowed qualitative and quantitative studies to be integrated in an attempt to collate existing knowledge (Tobiano et al., 2015). In this case, the aim is to assess the existing qualitative and quantitative studies on how informal care is used to support older adults living with chronic life-limiting illness in African countries. The process of the review was problem identification, literature search, data evaluation and data analysis (Whittemore and Knafl (2005)).
**Problem Identification**

While the international literature identifies some of the challenges associated with providing informal care, including the resources and support available (Cash et al., 2017; den Hertog & Gilmoor, 2017), there is limited literature on the phenomenon in African countries. Therefore, this review aims to assess the existing literature on how informal care is used to support older adults living with chronic life-limiting illness in Africa.

The review question is: How is informal care used to support older adults living with chronic life-limiting illness in Africa?

The question and the search strategy have been registered with the International Prospective Register of Systematic Review (PROSPERO) with registration number CRD42018089498

**The Selection Process**

The first reviewer (BAK) developed a database search, with the help of a university health librarian, in consultation with the two other reviewers (WM and LG). Details of keywords used for the searches are shown in Table 3.1. Searches were performed on title, abstract and keywords. Peer-reviewed primary studies, conducted in any country from Africa on older adults (those 60 years and over) with chronic life-limiting illness, who are totally or partially dependent due to the chronic life-limiting illness and are receiving some informal care from family members, taking the perspectives of either older adults, the caregivers or both on
informal care were selected. Articles selected were those published only in English but were not limited by date, to capture all of the existing literature on the phenomenon. The excluded articles were those that did not meet the above inclusion criteria.

Table 3.1

<table>
<thead>
<tr>
<th>Key concepts and key words used for search</th>
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<tbody>
<tr>
<td><strong>Key concepts</strong></td>
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<tr>
<td>combined with Boolean AND Africa</td>
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<tr>
<td>Palliative</td>
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<tr>
<td>Caring</td>
</tr>
<tr>
<td>Older adults</td>
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<tr>
<td>Databases</td>
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<tr>
<td>Limits</td>
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</table>

The first author (BAK) conducted the searches in all databases and imported results into Endnote X7, for reference management, then duplicates were removed. The search resulted in
1,251 articles of which 633 remained after duplicates were removed. Then, the title and abstract of all the articles were screened to the inclusion and exclusion criteria by BAK and LG separately, and they then met to compare the results. Twenty-eight articles were identified and proceeded to full-text screening, and articles that further met the inclusion criteria were selected. Where conclusions could not be drawn for the inclusion of an article, all reviewers met and discussed until agreement was made. Eventually, five articles were selected to be part of the integrative review. Two articles were from Scopus and one each from CINAHL, Medline and PubMed Central. See Figure 3.1 for full details of the selection process.
Figure 3.1

The Selection Process

- Records identified through database searching (n = 1,251)
- Records after duplicates removed
- Records screened for title and abstract (n = 633)
- Records excluded with reasons of not meeting inclusion criteria (n = 605)
- Full-text articles assessed for eligibility (n = 28)
- Full-text articles excluded, with reasons:
  - Not informal care (14)
  - Not O. P or O. P less than 60 years (6)
  - Recipients not mentioned (3)
  - Study not in Africa (1)
- Studies included
  - Qualitative (4)
  - Quantitative (1)
Data Extraction and Evaluation

The validity and reliability of methodologies of all articles included were evaluated by the criteria set by the Mixed Method Assessment Tool (MMAT) 2011 version and were assigned quality scores ranging from low (*) to high (****). The use of the MMAT was mastered through the tutorials offered online. In agreement with all authors, BAK and WM conducted the evaluation independently and met to discuss the results of the evaluations. There were no major differences in the evaluation results, except minor ones which were discussed, and an agreement was reached through discussion. Data was extracted to an Excel spreadsheet under headings which give distinct features of the studies that were relevant to this review. The headings were the author(s)/country, the aim of the study, study design, population, sample size, and what the findings mean to this review.

Data Analysis

Thematic analytic procedures suggested by Braun and Clarke (2013) were employed in the inductive analysis of data. First, each article was reviewed by the authors. Then, BAK and LG coded the data from the articles reviewed and identified patterns among the codes. The patterns were grouped under theme names. In a series of meetings, the themes were revised to present the underlying stories from the included studies.
Presentation of Results

This section presents the results of the five articles reviewed that meet the study inclusion criteria. All articles were primary studies. Four were qualitative studies (Dotchin et al., 2014; Ibanez-Gonzalez & Tollman, 2015; Mayston et al., 2017; Mthembu et al., 2016) and one was a quantitative study (Uwakwe et al., 2009). Two studies were conducted in Nigeria (Mayston et al., 2017; Uwakwe et al., 2009), two from South Africa (Ibanez-Gonzalez & Tollman, 2015; Mthembu et al., 2016) and one was conducted in Tanzania (Dotchin et al., 2014). The included articles met three or four of the criteria of the MMAT and showed moderately high to high methodological quality (see Table 3.2). The qualitative designs of the included studies were exploratory or case study designs utilising semi-structured, in-depth or serial interviews as methods of data collection. The quantitative study was a single-phase cross-sectional catchment area survey. All studies focused on how informal care is enacted to support older adults with chronic life-limiting illness in Africa, taking the perspectives of either the older person, the caregivers or both portraying the unique characteristics of, or resources for, the African informal care. An overview of the selected articles is provided in Table 3.2.
Table 3.2

**Description of Primary Studies**

<table>
<thead>
<tr>
<th>Author (year)/ Country</th>
<th>Aim of study</th>
<th>Study design</th>
<th>Sample</th>
<th>Relevant findings</th>
<th>MMAT Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dotchin et al. (2014)/ Tanzania</td>
<td>To document the burden of caregiving for people with Parkinson Disease (PD) and dementia and to compare and contrast the difficulties associated with being a caregiver for two distinct conditions.</td>
<td>Exploratory qualitative design using in-depth semi-structured interviews.</td>
<td>Three groups of carers for: 20 people with PD 43 people with dementia 63 general older adults (controls) Age cut-off = 70 years Age range = 71.5 to 92 years.</td>
<td>Carers reported moderate to high level of burden. No formal resources or services exist to help carers provide care for persons with chronic and disabling diseases. In the African context, caregiving is a multigenerational activity, that is, more than one person contributes to providing care for older adults who are ill. More females than male (82:44) were family carers. Lack of understanding on the nature and cause of chronic and disabling diseases contributed to stigma and care burden. Loss of job opportunity as a result of caring for also accounted for caregiving burden.</td>
<td>****</td>
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<tr>
<td>Ibanez-Gonzalez &amp; Tollman (2015)/ Tanzania</td>
<td>To generate concepts of health care access and the management of non-communicable disease (NCD) in rural South Africa.</td>
<td>Qualitative methodology, using serial semi-structured interviews.</td>
<td>Older women with NCD living in rural South Africa N = 13 women Average age = 70 years.</td>
<td>Most participants lived with family. Children, grandchildren and spouses were the main carers. Family members helped with the psychosocial needs of participants and with household activities. The roles played by family carers helped to ease the burden of living with NCDs for participants,</td>
<td>****</td>
</tr>
<tr>
<td>Source</td>
<td>Study Objective</td>
<td>Research Design</td>
<td>Sample</td>
<td>Findings</td>
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<tr>
<td><strong>Mayston et al. (2017)</strong>/Peru, Mexico, China, Nigeria</td>
<td>To explore the socio-economic effects of caring for an older dependent person, including insight into pathways to economic vulnerability.</td>
<td>Case study design using in-depth interview methods.</td>
<td>Older person and their main carers, including spouses, children of older adults and grandchildren. N = 60 participants from 24 households.</td>
<td>Caring is in the form of meeting the activities of daily living and usually what the carer can afford and not what the recipient really needs. Care arrangements are those to keep body and soul together. When the bricolage approach to financial management failed, some families restricted health care use and food consumption. Even relatively small daily costs could tip the balance towards household insecurity. Women are mostly the carers and men pay for it. When women negotiated a different role, another (less socioeconomically positioned) man tended to fulfil the woman-as-carer role. In the African context, caring for an older person is a shared responsibility. Family caregivers struggled to balance their caregiver role with work and social life. The value of religion, religious obligations and vows made in relation to being a caregiver is demonstrated.</td>
<td></td>
</tr>
<tr>
<td><strong>Mthembu et al. (2016)</strong>/South Africa</td>
<td>To explore the perceptions and experiences of people who provide care for older adults with chronic diseases.</td>
<td>Qualitative exploratory-descriptor design using semi-structured interviews.</td>
<td>Caregivers of older adults Age range = 24-79 years</td>
<td>****</td>
<td></td>
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</tbody>
</table>
N = 6 participants; consisting of 5 women and 1 man. Less assistance from health care professionals and financial problems makes caregiving difficult.

Uwakwe et al. (2009)/Nigeria
To describe the prevalence and determinants of dependence in older adults and associations with informal care and health care utilisation.

A single-phase cross-sectional catchment area survey. Older adults living in a rural community
N = 914 participants
Male to female ratio is 432:482
Age range = 65-80 years
Mean age = 72.7 years.

Chronic disease is seen as a normal part of growing old and mainly managed by primary health care services (the least) and traditional healers (prevalent). Increase in dependency is a result of chronic disease directly related to ageing. Children, children in-laws and spouses are the main carers. However, with more women in formal education increased rural-urban migration, and decreased fertility, the informal care for older adults in African communities is on diminishing trends. In most cases, pension benefits are non-existent and there are no other available benefits, so the family is limited in their capacity to provide adequate social protection for older adults.
Findings of the review are presented in three themes, namely chronic illness management is a social as well as a clinical matter, burden of care can be relieved by connection with the church, and cultural obligations for informal care are contingent on the availability of people and resources.

**Chronic Life-Limiting Illness Management is a Socio-Cultural as well as a Clinical Matter**

The cause of a chronic life-limiting illness is attributed to two opposing views: cultural reasons and clinical or medical reasons. Those of the cultural view assumes that “spirits” inflict chronic illness on older adults as punishment for “wrongdoings” (Dotchin et al., 2014). Chronic illness is thus predominantly managed through traditional healers in the community (Uwakwe et al., 2009). From the clinical view, chronic illness is a normal part of growing old (Uwakwe et al., 2009) but, it is aggravated by poor health and lifestyle choices (Ibanez-Gonzalez & Tollman, 2015). Chronic illness in this context is managed through medical health care services (Ibanez-Gonzalez & Tollman, 2015). Nonetheless, managing chronic life-limiting illness is associated with high out-of-pocket expenditure (Uwakwe et al., 2009), and it is a source of a financial burden for family carers. Lack of pension benefits (Uwakwe et al., 2009) and inadequate formal health services providing financial, educational and emotional support (Dotchin et al., 2014; Mthembu et al., 2016) further impact the management of chronic life-limiting illness in Africa.
Cultural Obligations for Informal Care are Contingent on the Availability of People and Resources

In the African context, informal care is a multigenerational activity, with each member of the family contributing to providing care for older adults in the group (Dotchin et al., 2014). The review revealed that children, grandchildren and spouses, as well as children-in-law, are the primary family carers. The African concept of informal care is derived from cultural obligations or responsibilities and a sense of appreciation of the older person (Ibanez-Gonzalez & Tollman, 2015; Mayston et al., 2017). Family members are duty-bound to provide care for older adults living with a chronic life-limiting illness, sourcing the duty to care from the culture they subscribe to. Informal care is in the form of meeting the activities of daily living (ADLs) and instrumental activities of daily living (IADLs), as well as helping with the psychosocial needs of older adults living with chronic life-limiting illness (Mayston et al., 2017). Informal care takes a bricolage approach, which means it is contingent or dependent on the availability of people and resources (Mayston et al., 2017). Due to limited resources, informal care aims to keep body and soul of the older person together, and this may not necessarily be what the older person needs (Mayston et al., 2017). Usually, women provide active care and men pay for it (Mayston et al., 2017). However, with increasing social change, the female-male role dichotomy is increasingly contested. When women negotiate a different role (socioeconomically positioned), men tend to accomplish the woman-as-carer role (Lopes Ibanez-Gonzalez & Tollman, 2015; Mayston et al., 2017).
**Burden of Care can be Relieved by Connection with the Church**

The review indicated that informal care is a unique experience for each caregiver. It is acknowledged that different types of chronic life-limiting illness require different types of care requirements (Dotchin et al., 2014) and each of the requirements presents different caregiver burdens (Dotchin et al., 2014). The burden of care is also different and unique to each family carer’s circumstance. Also, the high strain between caregiving and the social life of caregivers results in caregivers struggling to balance caregiving and their socioeconomic life (Mthembu et al., 2016; Uwakwe et al., 2009). Also, a financial and emotional burden is experienced through actual caring and being with the care recipients. However, connections between caregivers and faith-based organisations, such as the church, provide emotional and financial support for caregivers (Ibanez-Gonzalez & Tollman, 2015; Mthembu et al., 2016).

**Discussion**

The purpose of this review was to describe the provision of informal care for older adults living with chronic life-limiting illness in Africa. The findings of the review show the understanding and management of chronic life-limiting illness at the community level, who provides the care and the resources used in the caring, as well and the burden of caring for older adults living with a chronic life-limiting illness.

The findings of this review suggest that providing formal support for people living with chronic life-limiting illness for symptoms management cannot be overemphasised, due to the physical and the psychosocial challenges associated with the illness. The finding that chronic life-limited illness management is a socio-cultural as well as clinical matter perhaps agrees
with the literature that in most African societies, health-seeking behaviour is pluralistic, mainly because of the differing views about the cause of illness, influencing management (Aikins et al., 2019; Dotchin et al., 2014). There have been some researchers reporting the importance of regularizing traditional medicine as effective in managing some chronic diseases in Africa (Barimah, 2013; Barimah & Akotia, 2015). Until now, the lack of consensus and policy backing this recognition perhaps necessitate the need to increase access to affordable formal health services for symptoms management, especially in communities, where a majority of older people reside and cannot access adequate health care due to low socioeconomic status.

To improve symptoms management, the WHO recommends the inclusion of palliative care in primary health care for people living with a chronic life-limiting illness. While a palliative approach can improve the quality of life for older people, a cheaper health care cost may reduce the financial burden on older people living with chronic illness and their families, and in this case, more can be achieved in terms of family involvement and engagement. More research is, however, required to determine how a culturally relevant palliative approach can be enacted in the African communities. With an increasing African older population also, other formal services, such as home support and hospice services, can be introduced. Evidence shows that Africa is lacking in terms of formal support for older people, especially aged care facilities, rehabilitation and recreational centres (Essuman et al., 2018).

Research on informal care for older people living with chronic life-limiting illness in Africa is very limited. Only five articles met the inclusion criteria and their findings were integrated to form the results of this review. Reason for limited research may be due to infectious disease epidemiology and maternal and child health challenges in Africa. Given a shift to
chronic illness and an increasing older population, there is a need to increase research on informal care to determine how it can be enhanced to support the growing needs of older people with progressive deteriorating health in Africa.

Based on the five studies, cultural obligations for informal care are contingent on the availability of people and resources, and findings suggest that informal care is a valuable resource used to support older adults living with chronic life-limiting illness in African society, consistent with studies in other societies (Chen, 2018). What is peculiar with Africa is that informal care provision extends beyond one’s immediate family, with each member of the extended family regarding it a responsibility to contribute to the care of older adults, the main form being of meeting their activities of daily living (ADLs) and instrumental activities of daily living (IADLs), as well as other psychosocial needs. Family members source the responsibility of care out of the African culture and rely on the availability of community or social interconnectedness in the provision of care. Adamson and Donovan (2005) suggest that caring is a norm, and the nature of Africans’ biography lends itself to caring.

For the older person, the presence and contributions of family members may reduce the burden of living with a chronic life-limiting illness. With increasing local and international migration, the proliferation of formal education and especially an increase in the number of women in formal education and employment disrupts the living arrangements of family members and de-emphasises the extended family system. Therefore, the multigenerational contribution to the care of older adults is gradually reducing, which means that there may be some older adults living with a chronic life-limiting illness who are being left to bear the burden alone, reinforcing the need for social and economic support for this group of people.
The review revealed that women’s increased participation in formal education and employment, as well as migration and reduced fertility among African population, are reducing the active care for older adults living with a chronic life-limiting illness in African communities (Mayston et al., 2017; Uwakwe et al., 2009). Just as Adamson and Donovan (2005) suggest, in as much as caring for older adults is standard in African culture, caring for older adults living with a chronic life-limiting illness appears to be on a different level of care which requires and presents different responsibilities and challenges. However, there is limited evidence on the nature of these responsibilities.

The review revealed that African informal care takes the bricolage approach, where what is available is what is used, with the focus being on the survival of the individual older person, and not necessarily what the older person needs. Limited resources reduce the ability of caregivers to provide for all the needs of the older person adequately, sometimes affecting the health and nutrition needs of the older person. It was revealed that when the bricolage approach to financial management failed, some families restricted health care use and food consumption, as even relatively small daily costs could tip the balance towards household insecurity (Mayston et al., 2017), further suggesting the need for long term and permanent social and economic support for older people living with chronic life-limiting illness in African communities.

A critical evaluation of how we can successfully develop and implement carer financial support will be a starting point to sustain informal care, amidst the changing family structure and financial difficulties, challenging the welfare system in Africa.

Although not the subject of this review, challenges caregivers face emerged as important findings. These challenges were socioemotional, financial and lack of information on chronic
life-limiting illness management. While impacting on the management of chronic life-limiting illness at the community level, these challenges are seen to be unique to each family carer’s circumstances, expressed in terms of age, gender, race and economic status (Holmes et al., 2017). The review also revealed that faith-based organisations, such as churches, serve as support for informal care in African communities, providing socioemotional and financial support for both older adults living with chronic life-limiting illness and their caregivers who are members of the organisations.

The connection of African communities with churches and churches’ support appear to be similar to those found among African Americans (Brown et al., 2015; Watkins et al., 2017). Africans and African Americans are also more likely to receive support from the church than whites (Mathews & Johnston, 2017; Watkins et al., 2017). The family find support from the church community as a means of coping with the stress associated with caregiving. This suggests that people who are not part of the church community may be missing out on this type of support. Therefore, there is a need to increase the connection between caregivers and the church for optimal support. Additionally, because support from social groups has been proven to help caregivers manage their caregiving experiences (Greenwood et al., 2019), similar support groups could be facilitated in African communities to provide social and emotional support for family carers.

The review showed limited experience with formal support for caregivers in Africa. It was reported that in Tanzania, no financial, educational and emotional resources or services exist to help family carers provide care. It was also reported that in Nigeria, pension benefits are non-existent, so the family is limited in their capacity to provide adequate social protection for older adults. Some communities in South Africa, however, experienced some financial
support from the health sector, and it was explained that the accessibility of community
clinics makes chronic illness management easier. Free health care services ease the financial
burden on family carers. The disparity in formal home service support has been found among
community-dwelling older adults with a chronic debilitating illness in rural Australia
(Henderson et al., 2017).

In as much as the search included all countries in Africa, it was limited to articles written in
English. This may have excluded potential articles written in other languages. Also, although
the process of this review was systematic, data emanating from the articles were subjected to
the authors’ interpretation.

**Conclusion and Recommendations**

As the older population of Africa will increase rapidly over the next few decades, and with
many of these older adults experiencing one or more chronic life-limiting illness, there is the
need to explore how we can provide adequate but affordable health and social services for
people living with a chronic life-limiting illness in African communities. Increasing life
expectancy and chronic illness also suggest that we need to explore how a palliative approach
can be included in the primary health care system to help both family members and older
adults in the management of psychosocial needs at the community level, especially at the
initial stages. Relationships and community engagements with social activities yield positive
outcomes for caregivers and older adults. To support family members caring for an older
person with life-limiting chronic illness, health and social policy should focus on
strengthening the ties between community social organisations and the family members in the
African community. Health and social work professionals can also engage in alleviating barriers that inhibit relationships between social organisations and families. Policy and structures that support the provision of education and information on chronic illness to boost both family carers and older adults’ confidence in disease management are required to support the creative, bricolage approach currently used.

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**Update of the Integrative Literature Review**

The integrative review was updated between the period of 8th of June to 17th of June 2020. The update used a similar search strategy initially developed and as reported in Adonteng-Kissi et al. (2020). The current searches produced a total of 192 references. Of these, 114 references were from PubMed Central, 64 from ProQuest, 8 from CINAHL, 4 from Scopus and 2 from PsychINFO (via OVID). As in the previous screening process, a similar process was followed to screen these references for their eligibility for inclusion. First, duplicates were removed, after which there were 158 references left. These references were further screened based on title and abstract for inclusion and exclusion. Preliminary screening based on the title and abstract showed that 143 references did not meet the inclusion criteria and they were thus removed. The 11 references left after the title and abstract screening
proceeded to full-text screening. Three articles out of the 11 references satisfied the inclusion criteria and they were included.

The description of the included references is given in Table 3.3. All the included articles were primary studies. Two of them were quantitative studies (Awuviry-Newton et al., 2020; Faronbi, 2018) and one was a qualitative study (Faronbi et al., 2019). Two of the included studies were conducted in Nigeria (Faronbi, 2018; Faronbi et al., 2019) and the remaining one was from Ghana (Awuviry-Newton et al., 2020). One of the quantitative studies, (Awuviry-Newton et al., 2020) was a cross-sectional correlational study and the other (Faronbi, 2018) was a hospital-based survey. The qualitative study used a phenomenological study design with in-depth interview method.

The provision of care from the perspective of care was highlighted in two of the studies (Faronbi, 2018; Faronbi et al., 2019). In both studies, burden of care was significantly high among family carers. Just as in previous results, the findings of Faronbi (2018) showed that relationships with religious societies were the major coping strategy for family carers. Also, aspects of African cultural values as an underlying factor to the provision of care were highlighted in Faronbi et al. (2019). Chronic illness advancement increases with need for care but availability of care was not directly related to chronic illness advancement (Awuviry-Newton et al., 2020; Faronbi, 2018). Where there was no adequate understanding between family carers and older people, care was challenged. Due to changes in the extended family support, migration, modernisation and a decrease in fertility among Ghanaian, there is an increase in the number of older people without family carers. However, no recorded social support services were found to assist vulnerable older people.
Table 3.3

Summary Description of Selected Studies (for the Updated Integrative Review)

<table>
<thead>
<tr>
<th>Author (year)/country</th>
<th>Aim of study</th>
<th>Study design</th>
<th>Sample</th>
<th>Relevant findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awuviry-Newton et.al., 2020/ Ghana</td>
<td>To investigate the relationship between WHO’s international classification of functioning, disability and health (WHO-ICF) and caregiver availability for older people living in Ghanaian communities.</td>
<td>Hospital-based survey.</td>
<td>Older people admitted to the hospital. N = 400. Male to female ratio was 49:51 Mean age = 71.3.</td>
<td>The findings of the survey showed that chronic illness and accidents like injuries and falls increased the need for carer availability, but where carers did not understand older people’s needs, the carers were less likely to be available for them. A call for the need to bridge the communication gap through the implementation of programmes targeting older people and their carers is made. There is an increasing level of older people with no carers available, due to the changes in the extended family support system, influenced by migration, modernisation and decreasing fertility. Older people also received limited support from their neighbours. Coupled with changes in extended family support, older people had unmet care and support needs. There were no recorded social welfare services to assist vulnerable older people in the municipality.</td>
</tr>
</tbody>
</table>
Feronbi, (2018)/Nigeria

To assess the experiences of burden of care and coping strategies among carers who provided care for older people living with chronic illness in Nigeria.

A cross-sectional correlational study using Katz index of independence in activities of daily living and the Zarit burden interview.

Carers of older people.
N = 325.
85.8% were females
Age range = 19 and 70
Mean age = 47.79.

The demand for caring increased with chronic illness. Caring for older people brought varying degrees of burden on carers, including physical, emotional, health and socio-economic. There are indications that carers coping strategies resulted in maladjustments, because these strategies did not necessarily alleviate the burden associated with care. The common coping strategy was religion, which belonged to the emotion-focus domain.

Faronbi et. al., (2019)/Nigeria

To explore the lived experiences of caregivers of older people living with chronic illness in Osun State, Nigeria.

A phenomenological qualitative study utilizing in-depth interview.

15 caregivers providing care for older people were sampled.
10 were females.

The culture of care increased carers perception that helping older people with their ADLs and IADLs were necessary for the preservation of life, yet helping with these activities were challenging, especially in transferring, bathing, providing hygiene and feeding. Burden of care included disruptions to family life and the physical and health effects of caring. Value in reciprocity, explained to include pride, karma and caring as a necessary social activity underpinned the cultural practice of care for carers.
In the next chapter, the philosophical underpinnings, methods, designs and techniques used to conduct this research are given and explained.
Chapter 4

Philosophy, Methodology and Methods

Introduction

The purpose of this research is to explore the experiences of older people and their family members with chronic life-limiting illness and informal care in rural Ghana. In Chapter 1, I reported that given the demographic and epidemiological changes in Ghana, the number of older people expected to suffer because chronic life-limiting illness is increasing, making informal care an important support structure for the management of chronic life-limiting illness. In Chapter 2, I used the literature to explain aspects of social change that have reduced the political, social, cultural and economic power of older people and affected the broader ability of family members to culturally, socially and economically provide informal care for older people in rural Ghana. Given that there is limited access to state sponsored support, as demonstrated in the policy analysis undertaken in Chapter 2, and the possibility of older people and their family members experiencing marginalisation when it comes to chronic life-limiting illness and informal care, there is a need for a transformative change. The idea of marginalisation and transformative change has informed the philosophies and methods used in the conduct of this research.

In this chapter (Chapter 4), I outline the philosophical underpinnings and give explanations to how, why and when the particular research process was undertaken. The first section of this chapter focuses on the philosophical paradigm for this research. Building on previous discussions, the ontological, epistemological and axiological ideologies of the transformative paradigm are used to explicate the experiences of older people living with chronic life-limiting illness and the support of informal care from study participants. In line with the
philosophical ideologies, the main features of the methodology and methods used and how they helped to achieve the aim of this research are outlined.

I then introduce critical ethnography, the design of the research, describing the logical structure of the research and how it impacts on the data collection, analysis and conclusions. I also provide an overview of the setting of the research and provide a justification for the choice of setting. The sampling procedure and recruitment process are explained, in addition to the techniques of data collection. Finally, how data was handled and analysed, and the ethical considerations of the research are discussed in the last three sections.

**Philosophical Paradigm**

A research paradigm is a set of metaphysical beliefs which a researcher holds and which serve as a guide in the process of acquiring knowledge (Mertens, 2013). The paradigm, together with distinct methods of data collection and analysis form the approach or methodology of every social inquiry (Creswell, 2013; Mertens, 2014; Schraw, 2013). Generally, social researchers’ choice of approach falls within a broad spectrum of post-positivist and constructivist philosophical traditions. The difference between these two philosophical traditions lies in the longstanding conflicting assumption of what constitutes truth and how knowledge about truth can be ascertained (Creswell, 2014; Stewart, 2011).

Post-positivists hold the empirical assumption that knowledge is gained through a causal relationship among elements in the social world, using methods that remove or separate the researcher from the subjects being investigated (Campanario & Yost, 2017). The post-positivists perceive that there is only one reality and that reality is a probabilistic
apprehension of an individual investigator (Campanario & Yost, 2017). This means that truth is probabilistically objective (Campanario & Yost, 2017; Mertens, 2014). Knowledge acquisition is a top-down process generated by conducting experiments to prove or disprove specified hypotheses (Phillips & Burbules, 2000).

Constructionists reject the view of objective truth and propose that truth is embedded in the social construction relative to a specific local setting (Campanario & Yost, 2017). From the constructionist view, the meaning of the world is multiple and subjective to those who live it. In other words, people who have interaction with the social world construct or interpret what it means to them (Robson & McCartan, 2016). Consequently, factors such as history, culture and experiences influence the constructions of people’s meaning of the social world (Creswell, 2014; Robson & McCartan, 2016). Unlike the post-positivists who develop theories and experiments to prove a theoretical hypothesis, the constructionists develop theory through induction or inference from the interpretation and construction of the people who provide their perspectives (Creswell, 2014; O'Reilly & Kiyimba, 2015).

Contemporary scholars have identified that real-world problems are complex, which means that the traditional singular means to solving problems are increasingly becoming inadequate. Rather, multi-faceted problem-solving processes are required (Andrew & Halcomb, 2009; Creswell, 2009; Lester et al., 2014; Steiner & Posch, 2006). Some scholars have argued that the philosophical debate for and against the post-positivist and constructivist dichotomy is increasingly becoming untenable (Asghar, 2013). This argument has given rise to other paradigms, which underlie contemporary health and social research. These paradigms include the pragmatic and the transformative paradigms (Creswell, 2014; Mertens, 2014).
The approach of inquiry for this research draws upon the transformative paradigm of knowledge production, critiquing the post-positivist perspective on objectivity and reality, discussed above. Thorpe (2020) explains that the post-positivist hierarchy of knowledge production may be narrow with no recourse to context-specification of occurring of experiences. This means that people from different backgrounds give different meanings to their experiences, and their experiences should be acknowledged within the specific background. For instance, in relation to chronic life-limiting illness and informal care, people from different backgrounds, such as those in the cities and those in the rural areas, would have different experiences. Also, because informal care can be considered as a cultural activity, I seek to understand the cultural practices involved in informal care and how they influence the lived experiences of older people living with chronic life-limiting illness, particularly in a rural district in Ghana. Building on the aim of the constructionist paradigm, I am guided by an awareness that research should address issues of marginalisation and change (Mertens, 2013; Thorpe, 2020).

The transformative paradigm forms the philosophical basis for critical social theorists, action participatory researchers, as well as Marxists and feminist researchers working with vulnerable populations, such as racial and ethnic minority groups and people living with disability (Canales, 2013). From the literature review presented in Chapter 2, older people living with chronic life-limiting illness in rural Ghana form the minority population group, and this means the politics of resource distribution benefitting the majority demographic group may relegate the needs of the minority group to the background, which may contribute to marginalisation.
The transformative paradigm assumes that society is beleaguered with injustices, but the many available theories developed by social science researchers have done little in alleviating the distress of the oppressed in society (Creswell, 2013). The transformative worldview proposes that research should be the blueprint for social and political actions which buttress the enhancement of social functioning of individuals and institutions who are experiencing injustice, giving recourse to human rights and respect for culture (Creswell, 2013; Romm, 2015). While the constructionists aim to describe people’s lived experiences, the transformative researchers go a step further by critically examining the political and social dimensions that contribute to the injustice (marginalisation) of lived experience and focus on ways to address (reduce) marginalisation (Mertens, 2013).

The justification for the use of the transformative paradigm in this research is that first, the scope of the research falls within the health and social domains. Moreover, many contemporary health and social research have proposed arguments in favour of the transformative philosophy as underpinning research (Hayes et al., 2015; Marsh et al., 2017). Furthermore, the transformative paradigm supports my aim to promote social justice by encouraging the implementation and access to social support services which may help improve the situation of older people and their family carers who are affected by ageing and chronic life-limiting illness and social change in rural Ghana. In this case, to advocate for social services for older people and their family carers who are first of all human beings and are affected by ageing, rurality, limited access to adequate health and social care, but have rights as stipulated in the Universal Declaration on Human Rights (UDHR 217, 1948) and the 1992 constitution of Ghana.
The transformative paradigm is discussed under four underlying philosophical assumptions. These assumptions are epistemology, ontology, axiology and methodology.

**Ontology**

Ontology is the study of the nature and the forms of the world (Coe et al., 2017). The ontological stance of the transformative paradigm assumes that although different people construct what the world means to them, there are consequences in accepting one version of reality over the other (Mertens, 2010; Romm, 2015). It suggests that factors such as power and privilege may influence the version of the accepted definition of reality (Mertens, 2010). Therefore, the transformative ontological perspective assumes that there is one version of what is real, but there are multiple opinions about the reality. According to Mertens (2010) and Thorpe (2020), people who are in oppressive situations, such as gender, race, ethnic and socioeconomic biased circumstances, tend to suffer if the definition of what is real is accepted from people who are from powerful and privileged background. Therefore, the voices of people in oppressed situation must be directly heard.

The transformative ontology assumes that what is real is the social construction of both the researcher and the study participants (Mertens, 2010), recognising my role as a researcher in the research process. My role as a researcher in this research involved designing the research process, identifying participants and establishing rapport and empathetic relationship with them, which eventually positively influenced participants’ willingness to participate and provide data for this research. In addition, I moderated the interview process to get rich data for the best analysis as well as analysing the data and writing the report.
Epistemology

Epistemology is the study of the sources of knowledge on reality or the world (Ormston et al., 2014). It is also concerned with the authenticity of the source or pathways to gaining knowledge about the world (Ormston et al., 2014). The transformative epistemology shares a similar philosophical assumption as the constructionists. It assumes that knowledge about the world is gained through the subjective experiences of individuals who live it (Creswell, 2013). In other words, the source of knowledge is multiple, and the authenticity of each knowledge is relevant to that particular source.

In terms of research, studying the population group with no prior knowledge or model of examination (a priori) using transformative epistemology allows for a prolonged unstructured relationship between the researcher and the participants, so that the researcher can learn as much from the population groups as possible (emic perspective) (Sacchetti, 2019). As the research progresses and the researcher has gathered enough information on the population under study, they can structure the research process in a specific way and develop constructs which will be relevant to achieving the research aim (etic perspective) (Sacchetti, 2019).

The transformative philosophy, therefore, makes an inference from the experience of the study participants as well as the relationship that exists between the researcher and the study participants to produce knowledge (Thorpe, 2020). For instance, multiple contacts with each participant in the field, so that each participant confirms what was previously discussed in each engagement means that the results presented in this thesis can represent experiences of chronic life-limiting illness and informal care agreed as true by the research participants. This means that the transformative epistemology in this research assisted in an etic-emic transition and influenced the data collection and analysis strategies (Rajack-Talley et al., 2017).
In addition, because the researcher-researched relationship influences the purpose, process and outcome as well as the implementation process of the research outcome (Mertens, 2010), a transformative epistemology emphasising rapport building and cultural sensitivity (Mertens, 2010) was followed in this research. For instance, living and participating in the locality of research participants for 6 months and building professional relationships with the local people, while conducting this research helped me to sharpen my cultural awareness of the local people. Cultural awareness increased my ethical responsibilities toward the research participants (Rajack-Talley et al., 2017). The ethical principles adhered to in this research are discussed further in the ethical consideration section, later in this chapter.

The difference between the transformative and the constructionist epistemology is that the former acknowledges that some people are of power and privileged background, others are of a marginalised background. Consequently, the researcher should be able to manage the different dimensions of diversities that are portrayed by the participants, while being aware of their own biases, values and influences at the same time (Mertens, 2010; Romm, 2015). Reflexivity is thus important for the transformative epistemology (Rajack-Talley et al., 2017). Throughout this research, I made sure to update my daily reflective journal, in which I reflected on the impacts of the research process on me and the research participants.

In addition, my positionality underscoring this research does not aim to further promote marginalisation, on the contrary, to encourage older people and their family carers to voice out their experiences. The process of conducting research can present a shared space where both the researcher and research participants can dialogue to contribute to the research output (Bourke, 2014). In such a position both the researcher and the research participants can play important roles in conducting the research and writing and disseminating the report. Because
of the contributory roles researchers and research participants play, each contributor can also contribute biases, in shaping the conduct, output and dissemination of the results. Being biased is a human tendency (Simeon, 2015), therefore in this PhD study I have made a conscious effort to reflect on my positionality as the primary researcher in every step, to prevent the possibility of invalidating the process and the results of this research.

Researchers’ positionality is recognised within several contexts, including, for example, personal experiences, educational background, nationality, age, and gender (Lu & Hodge, 2019). As I shared in the introduction of Chapter 1, shaped by my personal experiences and also having gained professional knowledge through two social work degrees, I developed an interest in ageing and older people.

I hold the belief that putting measures in place to ensure one’s successful and healthy ageing is existentially critical. Therefore, when I got the chance to do a PhD, I used the opportunity to apply science to study challenges faced by older people in Ghana, where my interest arose in the first place. I recognised that the best way to fully understand the challenges associated with ageing in Ghana was by understanding the realities of the people who have lived experiences of ageing, chronic illness and informal care. Therefore, I collaborated with older people, their family carers and other health care professionals to expand my subjective understanding of the phenomenon. Collaborating with research participants helped me to strengthen my emic/etic perspective of the phenomenon understudy, which formed the basis of the conclusions in this research.

Researching vulnerable groups in itself contributes to further vulnerability (Bourke, 2014), so my reflexivity and positionality emphasised building trust and rapport with the participants over time. Fieldwork was an essential component of the research, where I spent 6 months
establishing relationships with participants in the field. In recognising my positionality as a researcher this was shaped by my experience of the population under study. The fieldwork was guided by the expertise of a renowned Ghanaian social scientist (Professor Ama de-Graft Aikins) who was familiar with the cultural sensitivity of the people under study. Also, the participants who took part in this research willingly did so by expressing their understanding of the research process and giving their informed consent and verbal assent on each visit during data collection. By providing informed consent, each participant accepted the role of a research participant and my role as a primary researcher. Therefore, the primary data and its interpretation presented in this thesis represent a shared view of the subjective voices of participants who really wanted to be heard.

**Axiology**

Axiology is the study of values (O'Reilly & Kiyimba, 2015). O'Reilly and Kiyimba (2015) explain that axiology is applied in relation to the values of the researcher and how these values influence the conduct and outcome of the research. Values are very important in all research processes, irrespective of the philosophical paradigm a researcher subscribes to (Menapace, 2019). The transformative axiology demands that researchers should maximise good, and the good of any research should advance from the individual level to the community or societal level (Mertens, 2017). My personal values coincide with the transformative axiology. One of my personal values in life is that fairness and equity is important because given fair treatment, everyone can achieve their full potentials. As a woman and from a continent of historical oppression (Batist, 2019; Bawa, 2019), the opportunity to attain higher education gives me the power to develop conditions which will
perpetually liberate me from any historical oppression. With this research, I believe that given the needed support, ageing, chronic illness or social change should not marginalise older people or their family carers in Ghana.

The transformative axiology requires researchers to adhere to ethical principles when conducting research (Stewart, 2011; Widianingsih & Mertens, 2019). So, not only was a study protocol for this research approved by experienced professors, but as part of the research protocol, both formal and informal permissions were sought from recognised authorities, as will be described in the data collection section in this chapter. Through effective communication (Rajack-Talley et al., 2017) and good recruitment strategy, such as information meetings (Mertens, 2017), members of the research locations got to understand the purpose and benefits of the research, leading to their willingness to participate by signing the informed consent sheet.

According to Lincoln and Guba (2013), researchers’ own values, those of the research participants as well as those of stakeholders who may be directly involved in the research process must be acknowledged. The axiology of the transformative paradigm is operationalised by involving research participants in the identification and solving of a research problem (Mertens, 2012). The transformative axiology form the base for the epistemological, ontological and the methodological positions of every research. Mertens (2012) explains that researchers must ensure that study participants reflect the complex cultural diversities which are related to the phenomenon under study.
Methodology

There are many and diverse research methodologies, and each of these methodologies has its own merits and demerits. However, the choice of a research methodology is fundamentally dependent on the social phenomenon being studied and whether the considered methods will yield the desired outcome (Daniel et al., 2018). Based on this assumption, this research adopted an exploratory qualitative research methodology to address the aim of exploring the experiences of older people and their family carers in relation to chronic life-limiting illness and informal care in rural Ghana.

This is the first research of its kind to explore marginalisation among older people living with chronic life-limiting illness and their family carers in rural Ghana. Exploratory research offers new clarifications for existing narratives, which previous researchers may have overlooked (Reiter, 2017). Through an exploratory methodology, I expand my perception using research tools to create an in-depth understanding on the social phenomenon (Reiter, 2017).

Generally, qualitative research is a social enquiry of empirical information, and from the health point of view, it revolves around an understanding of the health of people in society, their health behaviour, practices and services to meet health needs (Green & Thorogood, 2018). A common characteristic of qualitative research is the word-form data it generates, contrary to quantitative research, which basically collects and analyses numerical data. The qualitative methodology used in this research acknowledged the context-specific lived experiences of older people and their family carers in relation to chronic life-limiting illness and informal care in a specific rural district of Ghana. The reason for choosing that specific rural district is given in a later section on setting of the research in this chapter.
According to Stierer and Antoniou (2004), methodology has to do with “selecting methods which consist of frameworks and concepts and providing critical reasoning (intellectual, epistemology and ethical) for the choices and why they have been used in the ways specified” (p. 278). In this research, methodology is operationalised as the scientific use of design, methods and instruments which supported the data collection and analysis (Daniel et al., 2018). In relation to the transformative philosophy, methodology puts into consideration the various issues of power that may be at play in the conduct of research.

The transformative methodology focuses on the interaction between the researcher and the participants, such that the interactions between the researcher and participants lead to a better understanding of the lived experiences of older people and their family carers and the creation of ideas (Holloway & Galvin, 2016). This methodology assumes that power influences both the process of the research and the intervention, which the researcher may or may not have control over (Mertens, 2012). Either way, the methodological belief of the transformative paradigm is that the process and the outcome of acquiring knowledge on any social phenomenon must take social justice and emancipatory pathways (Mertens, 2010).

By observing, listening and asking questions, a rich data was generated and analysed. This analysis led to determining how informal care can be strengthened to improve the quality of life of older people living with chronic life-limiting diseases in rural Ghana.

**Research Design - Critical Ethnography**

As already indicated in Chapter 2, this research adopts a critical ethnographic research design. According to Ross et al. (2016), “critical ethnography is a qualitative research design
that endeavours to explore and understand dominant discourses that are seen as being the ‘right’ way to think, see, talk about or enact a particular ‘action’ or situation in society and recommend ways to re-dress social power inequities” (p. 4). Critical ethnographers aim to describe culture and advocate for cultural change, and in line with the philosophies underlying this research, by promoting cultural change; it means that those whose voice cannot be heard can be heard and those who cannot be seen can be seen (Sharp et al., 2018).

In relation to health, vulnerable people who are experiencing health challenges and live at the influence of other people are more suitable to be studied using critical ethnographic research design (Ross et al., 2016).

The methods of critical ethnography are like that of traditional ethnographic studies, such as interviews, observations and fieldnote taking (Stiles et al., 2019). Traditional ethnography is the study of human groups in order to understand their formation and maintenance of culture (Marshall & Rossman, 2014). Traditional ethnographic methods are used to describe the behavioural patterns of a group of people, their values and belief systems (Ribeiro, 2017; Sorrell & Redmond, 1995). In addition to playing the role of traditional ethnography, critical ethnography identifies the macro-social factors which contribute to social disequilibrium (Madison, 2011). Therefore, the critical path taken in this ethnographic study not only describes “what is”, it advocates for older people living with chronic life-limiting illness and their family carers by determining what can be done to improve the situation (Cook, 2005).

In other words, critical ethnographic research speaks on behalf of the research participants, because of the notion that research participants are reliable informants due to the fact that they are social actors who know their own culture (Goodson & Vassar, 2011; Sharp et al., 2018; Sorrell & Redmond, 1995). For this reason, fieldwork was very important in this
research. As a researcher, I actively took part in the cultural activities of the people in the fieldwork location and my interaction with the people and their culture helped me to generate understandings and ideas peculiar to them, as reported in this thesis.

In this case, critical ethnography became the doing, or the performance, of critical theory or the critical social theory (Oudshoorn et al., 2013). Critical ethnography demonstrates the referral pattern of older people receiving informal care in the community, the missing link and how to bridge the gap. One basic way of identifying oppressive situations is through problem identification (Freeman & Vasconcelos, 2010), facilitated by the critical ethnographic process and critical social theory engaged in the conduct of this research. In this study, problem identification was used as an empowerment tool to help the research participants engage in critical evaluation of current situations. This study focused on how the findings ‘fit’ within the various social discourses in a way that promotes the well-being of older people living with chronic life-limiting illness in a rural district in Ghana, ways of supplementing informal care and supporting family carers due to the challenges of providing direct care.

**Method**

Methods refer to the means by which data is collected and analysed (O'Reilly & Kiyimba, 2015). Usually, the choice of the methodology and design influences the methods to be used. For the transformative, what is important is the expected outcome of the research, in this case, it is understanding of the experiences of older people and their family carers in relation to chronic life-limiting illness and informal care and determining whether these experiences
constitute marginalisation, and how social inclusiveness can be achieved in a rural district in Ghana. To achieve this outcome, qualitative methods were used. Specifically, I used ethnographic interviews as a method of data collection, in line with the research design for this research. Broadly, interviews are seen as a craft or design a researcher uses to ascertain explanation of the various experiences people have in a social world (Bevan, 2014). Sorrell and Redmond (1995) explain that the purpose of ethnographic interview is to expound on the cultural meanings of a group of people’s social construction of their lived experiences, an example is understanding the lived experiences of older people and their family carers on chronic life-limiting illness and informal care, the purpose of this research. Details of how ethnographic interview method was used in this research is provided in data collection section, to be discussed later in this chapter.

Although, observations and photography were part of the methods utilised in this research, the agreement among the supervisory team led to the exclusion of the resulting data from this thesis output. This agreement was made to adequately manage the volume of data generated from the 70 interviews within the doctoral program timeframe, while maintaining the richness of the story intended to be told. The data emanating from observation and photography will be used in postdoctoral publications.

In summary, based on the assumption that older people living with chronic life-limiting illness and their family carers who use informal care to support them may be experiencing an existential crisis of marginalisation, the transformative paradigm, which seeks to promote social justice for marginalised groups was justified to be the philosophical underpinning for this research. In line with this paradigm, the transformative epistemology and ontology which acknowledges multiple sources of knowledge and the meaning of reality were used to explain
the specific circumstances of older people living with chronic life-limiting illness and their family carers in a rural district in Ghana. The transformative axiology portends researchers to comply with values during the conduct of the research. For the transformative methodology, the focus is on the rapport between the researcher and the participants to lead to in-depth understanding of the lifeworld of the participants, so the exploratory qualitative methodology was adopted and justified. The ethnographic interview was used as the method of data collection.

Research Location

The main location of this research is the Gomoa West District, Ghana. The research was conducted in three sites: the Palliative Care Clinic of the Korle Bu Teaching Hospital, located in the city of Accra; the St. Luke Catholic Hospital in Apam; and the homes of participants in the Gomoa West District. The Palliative Care Clinic of the Korle Bu Teaching Hospital in Accra was included because it is the only national referral centre for chronic disease related to management and palliative care. The St. Luke Catholic Hospital was chosen because it is the main and closest hospital in the Gomoa West District providing primary health care for the population under study, the Gomoa West District in the Central Region of Ghana. Apam is the District capital and it is where the St. Luke Catholic Hospital is situated. The ethnographic fieldwork was conducted in the homes of participants selected from towns/villages (which were easily commutable from the district capital) in the district.
Community Profile of Gomoa West District

The Gomoa West district is one of 17 districts in the central region of Ghana. It shares boundaries to the north with the Agona East District, to the east with the Effutu Municipal, to the west with Ekumfi District and to the south with the Atlantic Ocean (GSS, 2014). A pictorial map of Gomoa West is given in Figure 4.1 below. It is about 69 kilometres away from the capital city of Accra. The total population of the district is 153,570 with the male to female ratio being 44.7%: 55.3% (Ayin & Ayetey, 2017). Just like the national demographic description, older people (those 60 years and older) represent 7.5% of the Gomoa West District population (GSS, 2014). 57.4% of the total population in Gomoa West District is considered rural (GSS, 2014). There are about 20 towns/villages that make up the Gomoa West district, and participants were selected from seven of the towns/villages: Apam, Ankamu, Kyere Nkwanta, Mumford, Dago, Eshiem and Mozano.

The people of the Gomoa West District are mainly Fantes. Fante people are part of the dominant Akan ethnic group in the south-western part of Ghana and they are the main settlers along the coast of the Atlantic ocean and the Gulf of Guinea (Nolan, 2019). The dominant religion in the Gomoa West District is Christianity (82.6% of the population). More than half of the population have some form of formal education. Of the 69.9% working population, 91% are employed in the informal sector (GSS, 2014). The main occupations are fishing and farming. Most people live in compound houses and are more likely to be in a single room with at least five other people sharing the room. A compound house is typical West African housing with several single rooms built on an open court with shared amenities like toilets and kitchens (Eduful & Hooper, 2019). The district has one mission hospital, the St. Luke Catholic Hospital, one reproductive and child health centre, two community clinics, one child
nutrition and rehabilitation centre and seven Community Based Health Planning and Services (CHIPS) compounds (Ayin & Ayetey, 2017; GSS, 2014).
Figure 4.1

*Map of Gomoa West: Sourced from Ghana Statistical Service, 2014*
The Palliative Care Clinic of the Korle Bu Teaching Hospital, Accra

The Palliative Care Clinic is one of four special clinics run by the Korle Bu Polyclinic, and the polyclinic is one of the centres under the Korle Bu Teaching Hospital. The Korle Bu Polyclinic is a 42-bed facility that serves as a training centre for the teaching hospital. The Palliative Care Clinic was established at the polyclinic due to an increase in presentation of non-communicable disease, increased life expectancy and a high prevalence of acute and chronic infections (Yennurajalingam et al., 2019). The clinic serves as both an inpatient and outpatient consult, as well as offering home care visits for some patients. The Palliative Care Clinic serves as a referral point for other institutions, mainly the oncology departments.

St. Luke Catholic Hospital, Apam

The St. Luke Catholic Hospital (SLCH) is one of the primary health care facilities within the Catholic Archdiocese of Cape Coast, Ghana. The hospital is located in Apam, the administrative capital of the Gomoa West District. SLCH is under the National Catholic Health Services and a member of the Christian Health Association of Ghana (CHAG). As a CHAG facility, the hospital collaborates with the Ghana Health Service at different levels to deliver primary health care services. It serves as a referral facility and offers dependable around the clock health care services to communities within Gomoa West District as well as others in Gomoa East, Gomoa Central and beyond. Although the census data indicates a district population of 153,570 (GSS, 2014), the catchment population of SLCH is only 33,645, providing inpatient, outpatient and other surgical services to this population.
Study Population

Because of the theoretical assumption of critical social theory, which holds that people’s experiences of social phenomena are understood within society’s structural frameworks within which they occur, multiple views were sought in this research. Thus, the focus population of the study included older people living with chronic life-limiting illness and those involved in their care, such as family members and health care professionals from the Palliative Care Clinic (i.e., doctors, nurses) of the Korle Bu Teaching Hospital as well as health care professionals (including doctors and nurses) from the St. Luke Catholic Hospital in Apam who helped older people manage their symptoms in the district. Inclusion and exclusion criteria for sample selection is outlined in Table 4.1.

Older people who did not meet the inclusion criteria, such as those living in urban areas or living with communicable diseases were excluded. Older people with advanced mental illness were excluded due to possible negative reactions to the interview, and the limited community support available for them following the interview.

Table 4.1

Inclusion and Exclusion Criteria for Study Sample

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
<th>Exclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older People:</td>
<td>Older People:</td>
</tr>
<tr>
<td>• Aged 60 years or older</td>
<td>• Living in urban areas</td>
</tr>
<tr>
<td>• Living in a Gomoa West</td>
<td>• Advanced mental health problems</td>
</tr>
<tr>
<td>• Diagnosed with at least one chronic life-limiting disease, confirmed by word of mouth by the older person or the family carer</td>
<td>• Living with communicable disease</td>
</tr>
</tbody>
</table>
• Identified by the palliative clinic as being frail, socially or medically dependent due to that chronic disease
• Receiving some form of informal care from family
• Sufficiently healthy to be involved in the study
• Speaks English or Akan

Family Carers:
• A relative or a friend who lives with the older person or in a nearby community
• 18 years or above and capable of making his/her own decisions
• Spends at least one hour a day with care recipient
• Assists with ADLs and IADLs
• Assists with other psychosocial needs, for example, financial, emotional, spiritual
• Sufficiently healthy to be involved in the study
• Speaks English or Akan

Health care professionals from the Palliative Care Clinic of the Korle Bu Teaching Hospital:
• A professional palliative care worker
• Involved in matters of palliative care for people with chronic diseases in Ghana
• Speaks English or Akan

Health care professionals from St. Luke Catholic Hospital:
• A GP or clinician
• Familiar with the local people
• Helps older people manage their chronic conditions
• Speaks English or Akan

Sampling Technique

Non-probability sampling techniques were used to sample participants to participate in this research. Non-probability sampling is the technique of sampling participants into research where members of the population do not have equal chances of being selected (Etikan et al., 2016). In other words, non-probability sampling means that the chance of a participant to be selected is not known, but the participant possesses specific features from which the most can be learnt, as a rich data source. With non-probability sampling, generalisation to the entire
population is not the aim; however, each of the samples selected have some unique characteristics which are of interest to the research, such as living with chronic illness, 60 years or older, family or significant other, and health worker. The non-probability sampling technique is useful when time and resources are factors to be considered in the conduct of research (Etikan et al., 2016). Ritchie et al. (2013) suggest that the nature and purpose of qualitative study and analysis demand the use of non-probability sampling. Purposive sampling is an example of non-probability sampling techniques utilised in this research.

The process of identifying people who participated in this research is discussed in detail later in the recruitment process and strategies (p. 111-116). After potential participants were identified, purposive sampling technique was adopted to recruit participants in this research by subjecting the potential participants to screening. Screening of participants was conducted against the inclusion and exclusion criteria for this research, as outlined in Table 4.1. Crossman (2015) explains that purposive sampling is a type of sampling based on the knowledge the researcher has about the population on the subject under study. As already stated, a purposive sampling technique requires or encourages researchers to pick participants who provide rich information for the best quality of data (Ritchie et al., 2013). Older people and their family carers who took part in this research were purposively selected because they met the inclusion criteria and they were able to give their perspective to the circumstances of living with chronic life-limiting illness, and their rich data has been analysed to form part of this thesis.

The Palliative Care Clinic of the Korle Bu Teaching Hospital is the major referral centre in Ghana, and they provide specialist services and symptom management to Ghanaians who seek them, and thus they understood the nature of chronic illness experienced by people in
Ghana. Each health care professional sampled was a qualified physician or palliative nurse and they gave a unique but insightful perspective based on their relationship and experiences with older people with chronic life-limiting illness. While the health care professionals from the Palliative Care Clinic of the Korle Bu Teaching Hospital provided a perspective on symptom management at the national level and a focus on palliation, the health care professionals from SLCH provided a perspective on chronic life-limiting illness management at the district level.

The health care professionals from the St. Luke Catholic Hospital (SLCH) in Apam whose data has been included in this research were purposively selected to be part of this research, because the SLCH is the main and closest hospital in the study location, and they offer services for primary health care and some chronic illness management services, such as hypertension and diabetes clinics. Also, it is the closest hospital in the district where older people seek periodic health care services for their symptom management.

**Sample Size**

Forty participants were sampled to be part of this critical ethnographic study. The breakdown is as follows:

- 15 older people
- 15 family carers
- 5 health care professionals from the Palliative Care Clinic of the Korle Bu Teaching Hospital
- 5 health care professionals from the St. Luke Catholic Hospital in Apam
As regards sample size, many qualitative researchers rely on purposive sampling technique and data saturation as the yardstick to determine the number of participants for data collection and analysis (Guest et al., 2006; Nelson, 2017). In this research, data saturation was used to determine the number of participants for data collection and analysis. How data saturation was reached is described in the findings chapter.

**Introductory Phase**

Just like any ethnographic study, and as already mentioned, fieldwork was an important aspect of this critical ethnographic research. In this research, I used ethnography as a novice to explore the experiences of older people living with chronic life-limiting illness and the support of informal care in the Gomoa West District. With this goal, it was important for me to gain access and acceptance into the district. I spent 6 months between August 2018 and January 2019 in the field conducting this research. During this period, I visited seven out of the 20 communities in the Gomoa West District.

The fieldwork began with 2 months of introductory rites where I established trust and community partnership with participants. I moved between Accra and the Gomoa West District during this period to complete the introductory phase. I established professional relationships with health care professionals from the Palliative Care Clinic of the Korle Bu Teaching hospital in Accra through telephone calls, emails, and in-person discussions. Concurrently, I introduced myself to the St. Luke Catholic Hospital’s administrator and other health care professionals at the hospital. Likewise, I established relationships with all other
key people who in one way or the other had influence in the district. These people included the Chief and his elders, health care professionals, church leaders and other opinion leaders.

The Apam chief is the highest traditional authority (not political) in the district. As part of ethical requirements which guided this fieldwork, it was important that I obtain his verbal permission to interact with the people in the district, which I did. In addition, it was easy to identify other opinion leaders in the district through schools, churches and the hospital. In the district, I participated in some of the community activities, such as festivals, church services, funeral rites, naming ceremonies, and weddings. This helped me gain acceptance, consistent with a role balancing researcher and community member (Tickle & Tickle, 2017). Through my participation, I identified with community culture and customs by adhering to the rules and regulations of the community.

**The Recruitment Process and Strategies**

Recruitment of participants begun during the introductory phase of the fieldwork. Four groups of participants were identified and invited to participate in this research: older people with at least one chronic life-limiting illness, family carers, health care professionals from St. Luke Catholic Hospital and the Palliative Care Clinic of the Korle Bu Teaching Hospital. The specific processes and strategies used to recruit the sample are outlined for each participant group in the next three sections.
**Older People**

Two strategies were used to identify older people. The first strategy was through an information meeting, held in the Chief’s palace in Apam. Before arriving in Ghana, I had contacted the Chief by telephone to arrange the meeting. When I arrived in Ghana, I personally visited the Chief in his palace and formally introduced myself, explaining the study and how I intended to recruit participants from Apam through the information meetings. A date and time were confirmed.

The Chief’s palace is usually a place where local disputes are settled. On the day of my presentation, there were people waiting to address the Chief, so it was a good opportunity for me to meet the people. There were about 25 people (mostly men) present, and all of them contributed to our discussion in the meeting. We discussed topics such as “older people and chronic disease”, “what palliative care is”, “how older people with chronic disease and their families can be helped”, and “the role of government and family in providing care”. The people gave their opinion on the challenges older people face in the community and the role of family, community and government in alleviating the distress of older people. After the discussion, I invited people to participate in the research. Those who expressed interest in participating or knowing more about the study were invited to provide their contact details. And the participant information sheet handed to them. Later, I contacted them on telephone, and also I went to their homes to screen them for eligibility.

In addition, I went into the community with the permission of the Chief, and identified some key informants, mainly health workers, teachers and church leaders. After I interacted with them and explained to them my purpose for being in the community, they readily directed me to the houses of older people they personally knew or whom they think could fit with my
inclusion criteria. I went to these houses and interacted with the people and screened them against the inclusion and exclusion criteria. Additionally, with the permission of the church leaders, I had the opportunity to attend and introduce myself and my research to two churches in Apam and Dago. After I invited the congregation to contact me following church service if they were interested to participate in the research. Some older people approached me, I took their address and visited them and the older people in their houses. Then after the introduction, I screened people against the inclusion and exclusion criteria. Those who met the inclusion criteria were selected, and a date was set for data collection. On the day, we went through the information sheet again. After all their questions were answered, informed consent forms were signed and delivered to me. Please refer to details of participant information sheet and informed consent forms in Appendices 1 and 2, respectively.

The selection process was intensive. I had more than 50 people who showed interest to participate in the research. However, due to circumstances such as people not meeting the inclusion criteria or either the older person or the family carer not showing interest, only 15 pairs of older people and family carers were recruited into the study. In three instances, an older person lived alone, which means there was no family carers and based on the inclusion criteria, such people could not be included.

**Family Carers**

As part of the inclusion criteria, older people had to have family carers with them because both of them must be recruited together. Both the older person and the carer must agree and be eligible to participate. Therefore, if it was the carer who expressed interest first, the older
person they cared for had to agree to participate and they had to be screened for eligibility as well. The two strategies used to select, screen and recruit older people were repeated for their family carers. Those who met the inclusion criteria were given the participant information sheet to go through. Details of the participant information sheet and informed consent forms for family carers are included in Appendices 3 and 4, respectively. Those who accepted the terms in the information sheet were recruited, and a date was set for data collection. On the day of the first interview, the details of the information sheet were discussed again before the informed consent sheets were signed and delivered to me.

*Health Care Professionals from the Palliative Care Clinic of the Korle Bu Teaching Hospital, Accra*

At the Korle Bu Teaching Hospital, there was a pre-existing institutional review board that required further ethical review and approval for my study. Once the study was approved and a certificate issued to the effect (KBTH-STC/IRB/00093/2018, details in Appendix 5), I met the administrator of the Palliative Care Clinic and established rapport with her. She provided a list of names and emails of palliative care professionals who were likely to fit into the inclusion criteria. She also included the geriatrician. I distributed the email to professionals to invite them to participate in the study. The participants’ information sheet and consent forms were attached to the email (refer to Appendices 6, 7 and 8 for email script, information sheet and consent forms). The email directed interested health care professionals to make direct contact with me for further information about the study and interested health care professionals contacted me and invited me to their offices.
In their offices, I personally introduced myself to them and we went through the information sheets together. Then a date was set for the interviews. On the day of the interviews, participants signed and delivered the consent form to me.

Health Care Professionals from the St Luke Catholic Hospital, Apam

Before I arrived in Ghana, I had already established rapport with the hospital administrator through five telephone calls and several WhatsApp messages. I also sent him copies of my research proposal and ethical approval in an email, so he was aware of the research expectation. When I arrived in Ghana, I booked an appointment to see him personally for further discussion related to the research and recruitment.

He advised that he speaks directly to health care professionals in a meeting after which he would introduce me to the health care professionals. Then each of health care professionals would decide whether they would participate or not, after they had gone through the participant information sheet. After the introduction, I screened people against the inclusion and exclusion criteria. I left a printed copy of the participant information sheets and informed consent forms with those who met the inclusion criteria: mainly doctors and nurses. Details of the participant information sheet and informed consent forms for health care professionals are included in Appendices 9 and 10. Each of the potential participants had the opportunity to decide whether they would participate or not. Those who accepted to participate contacted me by telephone, and they were invited to complete the consent form, after which a date was set for an interview. On the day of interview, the signed consent form was delivered to me.
Data Collection

I engaged in ethnographic data generation. Designing the ethnographic interview was guided by the Sorrell and Redmond (1995) approach of using the ethnographic interview method in nursing research. According to Sorrell and Redmond (1995), three distinctive structures characterise the ethnographic interview method: purpose, style and sequencing of questioning. Sorrell and Redmond (1995) also explain that the style of questioning should adopt both a descriptive and structural approach.

The descriptive style of developing ethnographic interview questions uses open-ended questions, allowing the informant to be free in providing the answers. Hence, the descriptive ethnographic interviews allowed the research participants who took part in this research to reflect on their own responses and what their experiences meant to them. Examples of descriptive questions older people answered included “Please tell me about your experiences of living with the illness?”, “What kinds of symptoms do you experience?” and “How do the symptoms affect your activity?”.

The structural style incorporates knowledge of the participant on specific cultural knowledge. For example, the following questions were asked: “Sometimes when people have lived with chronic illness for a long time, the palliative care team will become involved to help with symptom management. Has your GP discussed a palliative clinic for symptom management? Can you tell me more about your management decisions?”, “How does the government support you in your illness?” and “In what ways do you think government can support your family carer to help you?”. Please refer to Appendix 11 for more of the ethnographic interview questions utilised in this research.
Lastly, Sorrell and Redmond (1995) suggest that drafting an ethnographic interview schedule should adopt a sequenced style, that is the questions should start from a descriptive point and move to a structural point. This will allow the presentation of results moving from a subjective to a more structural level. Because questions arise after data collection, Sorrell and Redmond (1995) postulate that researchers should maintain contacts with participants so they can go back to seek further answers to the new questions. In line with this assumption, this research utilised the double ethnographic methods, where another set of questions were developed and administered based on the emerging issues analysed in the first round of data collection.

The ethnographic interview method was complemented by field notes. The ethnographic data generation took approximately 3 months to complete. The techniques utilised to collect data from each of the participant groups are explained below.

**Double Interviews with Older People and Family Carers**

The ethnographic interviews with older people were in-depth, which means they were extensive and semi-structured, following a set of prepared questions developed based on the objectives of the study (Corbin & Strauss, 2008; Westby et al., 2003) and with the help of my co-principal supervisors (WM and LG). In addition to using the Sorrell and Redmond (1995) approach to develop the interview guide, I adopted the techniques and strategies used in ethnographic interviewing suggested by Westby et al. (2003) in the conduct of the interviews. Westby et al. (2003) recommend that the interviewer should ask questions which will connote elaborative answers, such as, “What are the things you used to do at home that you are no
longer able to do? The interview questions were developed in such a way to generate participants’ general understanding of the benefits, needs and challenges in order to explore their experiences related to chronic life-limiting illness and informal care. Older people and their family carers were interviewed separately in line with the transformative epistemology underlying data collection and analysis. I had two interview sessions with each paired older person and their family carer; the initial interview was held after consent was gained and a subsequent one took place after the first data was transcribed and initial analysis made. Based on the emerging data, a new set of interview questions were developed with the help of my co-principal supervisors for the second interviews with older people and their family carers. These are also outlined in Appendix 12 and 13. Each ethnographic interview lasted for about an hour. With the permission of participants, all interviews were recorded on a digital voice recorder for transcription purpose.

At the beginning of the first interview, participants read and signed the informed consent form. Where participants could not read or write, I read the informed consent letter out aloud and explained the letter in the Akan language, to get their verbal consent to participate. Verbal consent was digitally recorded. The ethnographic interviews were conducted in both English and the Fante (Akan) language. All interviews with older people and their family carers were conducted face-to-face and individually. Interviewing older people and family carers individually ensured that issues of power and balance, which are key concepts in the transformative epistemology, are addressed and dealt with (Mertens, 2010; Romm, 2015).

During the interviews, I adopted a restating and summarising style of interviewing to help the participant know that I was listening, and also to give them the opportunity to confirm what they said (Westby et al., 2003). Data collection took place in the homes of the participants.
However, as participants were allowed to choose where data collection took place one older person and her carer agreed for their data to be collected in their place of work. The most important thing was they were comfortable and felt free to participate in the interviews. At the end of each encounter, I entered my observations in the fieldnotes.

**Single Interview with Health Care Professionals from the Palliative Care Clinic of the Korle Bu Teaching Hospital in Accra and the St. Luke Catholic Hospital in Apam**

Semi-structured interview questions were used to collect data from all health care professionals (see Appendix 14). The interview questions were prepared based on the objectives of the research, and with the support of my co-principal supervisors. Health care professionals from both institutions were interviewed once. Each interview with health care professionals was conducted face-to-face and in the offices of the health care professional. The interviews with health care professionals from the St. Luke Catholic Hospital were approximately thirty minutes, whereas it was up to an hour with the health care professionals from the Palliative Care Clinic. All interviews were conducted in English and during working time (between 9am and 5pm). With the permission of all health care professionals, interviews were digitally recorded for transcription purposes.
Data Handling

Interview recordings were stored on a computer and secured with a password. At this stage, I was the only one with access to the data, for confidentiality purposes. I transcribed English digitally recorded interviews verbatim. I translated one of the Akan audiotapes during transcription. Then I sought the service of a local Akan-English translator for confirmation of language equivalence. There were no major edits required, because the Akan language was easy to transcribe. The translator provided advice only on excerpts of the audio recording/transcripts (instead of the full tape or transcript) to protect the anonymity of participants. Then, the rest of the audio recordings were transcribed. Translation occurred during transcription. Occasionally, I called on the professional Akan English translator to assist in translating some words I came across that I did not understand.

Review of my translations by a professional translator helped maximise the opportunity for language equivalence and validity of data (He & van de Vijver, 2012). The word format was also stored and secured on a computer with a password. In total, and as already indicated in the sample size section, there were 70 transcripts: 30 each from older people and their family carers and five each from health care professionals from the Palliative Care Clinic of the Korle Bu Teaching Hospital in Accra and the St. Luke Catholic Hospital in Apam.

Data Analysis

The following procedures of data analysis were undertaken. Data analysis was inductive and commenced during data collection (Farrell et al., 2017). The analysis was guided by the thematic analytic procedure (Braun & Clarke, 2013). Braun and Clarke (2013) suggest six
steps in analysing qualitative data: familiarisation with the data, coding, searching for themes, reviewing themes, defining and renaming themes and writing up. The process of analysis begins with familiarisation with the data. I did this by carrying the responsibility for transcription of all 70 interviews. Other research team members (supervisors) also familiarised themselves with the data by reading the transcripts to understand the content and intention of each of the responses.

The next step was coding, which is the process of assigning names to interesting aspects of the data across the entire data set (Braun & Clarke, 2013). ATLAS.ti (version 7.1) qualitative research analytic software was used to manage the coding process. At the initial stage, coding was inductive. The emphasis was to give codes names that were a representative of the quotation. After initial codes were developed from each of the transcripts, the codes output with the quotation were generated from ATLAS.ti and sent to the supervisory team (WM, LG, ND) for review. After a series of discussions, and where applicable, codes were renamed to show better representations of the data.

When a consensus of code names was reached, the codes were grouped under code families in ATLAS.ti, which was the beginning of searching for themes at step three of the analysis. The purpose of the groupings was to facilitate the development of themes; thus, codes that represented the similar ideas were grouped together under a representative name. In total, there were 106 code families developed from all the four participants groups representing more than 1,000 code lists. Names of code families were also discussed in a series of meetings among the analysis team (supervisors) until a consensus was reached.

The code families were further condensed to form super-code families. Likewise, names of super-code families were discussed until consensus was reached. The groupings of the data
into code families and super-code families were based on patterns from the responses. After this step, when the volume of data became more manageable, both list names of code families and super-code families were transferred to a Microsoft Word Table. Then initial themes and subthemes were generated. What counted for a theme or subtheme were code families and super-code families which captured the experiences of older people living with chronic life-limiting illness and structures and processes which impacted the experiences. The themes and subthemes were developed to answer the research questions. The process of themes generation was also inductive, which means the themes emanated from the data. An example of the analysis process is included in Table 4.2 below.
### Table 4.2

*An Example of the Analysis Process*

<table>
<thead>
<tr>
<th>Exemplar quotations</th>
<th>Example of code names</th>
<th>Code families</th>
<th>Super-code family</th>
<th>Theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. “I feel the pain under my skin. It is the same feeling you have when an insect stings you. I feel the pain in my toes, then it goes up, through to my ribs. It is very painful. b. “Due to the illness, I cannot do any hard work like I used to. The little I do these days; I feel very tired like I have done a difficult job. I am always worn-out these days. I cannot even go out to meet people. I am at home every time”</td>
<td>a. Body pain; pains in the skin, toes and ribs b. Feeling tired; cannot go out.</td>
<td>a. Physical evidence of illness. b. Older people’s interpretation of how illness affects the self.</td>
<td>Awareness of physical limitations related to disease and treatment.</td>
<td>Increasing awareness of illness in the body.</td>
</tr>
</tbody>
</table>
After initial themes and subthemes were generated, the names were discussed in a series of meetings, until a consensus was reached. This was the reviewing of themes step. The reviewing of themes involved checking whether the initial themes fittingly described the quotations. To this end, I reflected on the meaning of each of the themes and subthemes, and whether they were adequate to tell the story intended, as suggested by Clarke and Braun (2013). Where applicable, themes and subthemes were revised or renamed for better representation.

Defining themes and subthemes are presented in the finding’s chapters (Chapter 5 and 6) of this thesis, where I give detailed description of each of the themes and subthemes. In Chapter 5, I tell the story of how the subjective experiences of chronic life-limiting illness and support are exacerbated by existing social role expectations and community understanding on chronic life-limiting illness and ageing. In Chapter 6, I present an analysis of the specific structures and processes of informal care and how they influence the subjective experiences of chronic life-limiting illness and informal care. The step defining the themes and the subthemes is where the essence of each of the themes and subthemes is displayed (Braun & Clarke, 2006). Finally, Clarke and Braun (2013) explain that writing up is the important step of the analysis. This is where existing literature is used to support the data in the discussion. This discussion is presented in Chapter 7 of this thesis, where data is analysed within a transformative ontological frame to draw conclusions about the transformation of structures and processes of care.

**Experiences from the Field**

As a first-time student ethnographer, the process of this research and the outcome have been remarkable for me. My experience in the field was very positive, and both strongly
interesting and educative. The people in the district, as is a common characteristic of most Ghanaians, were very receptive, friendly and willing to help in the best possible way they could, because I identified with their culture and they considered me as one of them. I usually hear or see in books about the proceedings in the Chief’s palace, and it was interesting for me to experience it in person.

I built a good rapport with the people I came across through self-introduction and communication. As much as possible, I maintained a professional relationship with all the people I interacted with. I experienced how participants and I built trust, in a way which made them open to talk about their experiences with me. At some point, I needed to repeat to participants my role and the purpose of the research. Some of them perceived me to be a doctor who can cure their pain. For instance, there was an old woman I visited. In my next visit to her, she showed me all the medications her daughter bought for her from the city and she asked me what I thought about them. I felt as if a heavy weight was put on me, because she wanted me to confirm that the medications were good. I told her that I was not a medical doctor and that she should report any discomfort to her doctor, but at the same time I felt mandated to assure her that everything was going to be fine.

Another highlight of the fieldwork was when I advocated for health care professionals from the St. Luke Catholic Hospital to be trained in how to treat pain. During the fieldwork, I had the opportunity to attend a 3-day workshop organised by the African Palliative care Association in connection with World Health Organisation (WHO) and American Cancer Society in Accra. After the seminar, I thought it would be appropriate for the health care professionals from the St. Luke Catholic Hospital to be trained to enable them to adequately manage the pain of their patients, as it was one of the main chronic life-limiting illness older people who participated in the research reported.
After a long conversation, the hospital agreed to host the training. Although I will not be there to see how the older people will directly benefit from the training, I am content that through this research, an attempt has been made to deal with some of the problems of older people living with chronic life-limiting illness in Gomoa West District, in line with the transformative philosophical underpinning of this research.

Good communication skills and adequate information sharing with participants ensured that ending the professional relationship was not problematic. In the second interview with each participant, I reminded them it was the end of the research and that our professional relationship had come to an end. Before that, I explained to them in the participant information sheet what their role was as participants in the research and when their role was going to end. I left my contact details on the information sheet for participants to contact me if the need arises. I spent one more month in the field, and during this time, no participant contacted me to complain of a negative impact as a result of participating in the research.

**Ensuring Rigour**

As already explained, in this critical ethnographic research, I spent 6 months in the field conducting the fieldwork. During this time, I built professional relationships, rapport and trust with the people. I used ethnographic interview methods to ascertain a verbal account of the experiences of older people living with chronic life-limiting illness and how their family carers supported informal care. Older people and their family carers were interviewed twice. The reason for the second interview was that it enhanced prolonged interaction with participants, which promotes the credibility and trustworthiness of the findings (Lal et al., 2017). Also, data collected utilising this strategy was rich and touched on topics which did
not emerge in the first interview, helping to achieve data saturation and adequate exploration of themes (Lal et al., 2017).

With the double encounter with each participant, trust was established, and they were more open to freely express themselves than in just one instance. This method was supported by making daily entries in my field notes, in which I noted and acknowledged my experiences in the field in the conduct of this research. My reflexivity guided my preconceptions and opinions about the subject under study. The support and guidance of my supervisors helped me to adhere to the ethical conduct of this research. More so, their experienced contributions in the analysis ensured the democratic process of themes generation and dependability of results presented are a true representation of the participants accounts.

Although the findings of this research relate to the experience of people in context-specific settings, the process and methods used in the conduct of this research have been adequately outlined and justified. An adequate description of the qualitative research process ensures that the results are reliable. As regards transferability, this research used recognised research methods and strategies which have been used in different contexts, but with people with similar characteristics. Also, purposive sampling techniques used ensured that only participants from whom the most could be obtained were selected, leading to in-depth information. Interviewing health care professionals who were knowledgeable on the subject increased the scope and relevance of the results.

Finally, I used exemplar quotes in the presentation of results as a way of aiding methodological rigour and credibility.
Ethical Considerations

This research gained ethical approval from Griffith University’s Human Research Ethics Committee with reference number (GU Ref No: 2018/423) and the institutional review board of the Korle Bu Teaching Hospital (KBTH-STC/IRB/00093/2018), before fieldwork took place. Audio and text data were stored in a filing cabinet on the Griffith University research storage site and made accessible to my thesis supervisors (LG, WM and ND) for analysis. The data is stored with Griffith University and will be retained for 5 years post publication of the findings. Ethical principles adhered to in this research are based on the National Statement on Ethical Conduct in Human Research. These ethical principles included the principles of respect, justice, informed consent and autonomy, beneficence, privacy and confidentiality, discussed in detail below.

Principle of Respect

All participants who took part in the study were accorded with due respect for human dignity and self-worth. Their welfare, beliefs and cultural practices as well as individual perceptions about the topics under discussion were respected. For instance, in the Ghanaian cultural settings, older people are referred to as “maame” or “paapa” instead of their first names as a sign of respect. So, older participants are referred by these titles to show respect, as indicated in the presentation of results. Also, the privacy of participants was not invaded, except with invitation. For instance, participants chose to sit outside of their room for the interview, instead of in their rooms, and I respected their decision. Also, the decisions of potential people who were approached but declined to participate in the research were respected.
Principle of Justice

The process and scope of the research was adequately explained to all participants, verbally and in writing. In addition, only participants who met the inclusion criteria clearly stated above and willingly consented to participate were recruited into the research. Likewise, the benefits of the research, including the possible risks, were adequately explained to all participants. I worked to reduce the possible risks associated with the research. Although participants were given the opportunity to nominate a person to consult with in the case of any risks directly as a result of the research, the situation did not arise for participants to use this option. Each participant was accorded the same benefits which was a morning or afternoon tea chosen by the community as a way to say thank you for their participation. Members who requested a copy of the lay summary of the research received it appropriately.

Principles of Informed Consent and Autonomy

Consent was sought from all study participants for their participation. Consent was gained in two forms: in writing and verbally. Participants who could read and write English were invited to append their signature to the informed consent form after the purpose, risks and benefits of the research were adequately explained to them. Verbal consent from participants who could not read or write English were sought after participants confirmed their understanding of the purpose of the research as explained to them by me in their homes. Digital verbal consents were captured. Informed consent was sought to give access to the home to have the two interview sessions. Informed consent was also required from participants for their data to be used in conference presentations and publications. The informed consent form was signed at the beginning of the first interview. Subsequently, assent was required from participants in the following interview.
Principle of Beneficence

I ensured that all benefits and risks in relation to the conduct of the research were adequately explained to all participants. In the informed consent, measures were put in place to ensure that any participants who experienced emotional distress would be provided for. All study participants were shown appreciation for their time in participation by offering them morning tea.

Principles of Privacy and Confidentiality

I respected the extent to which participants wanted their personal information to be made public. Pseudonyms were used in place of participants’ names to prevent identification. No part of the data will be made available to any third party without the prior consent of study participants.

Summary of Chapter 4

This chapter has outlined the methods used in the conduct of the research. The chapter begun with a description of the transformative paradigm, the philosophical underpinning of this research. The critical ethnographic research design and the exploratory qualitative methodological ideology informed the double and single ethnographic interview methods used to collect data from participants purposively selected. In addition to the interview data, data collected through observation and photography will be used in postdoctoral publications. The setting and selection procedure have also been explained. How data was analysed and the
ethical principles guiding the research have been explained. In the next chapter, I present the results of the first research question.
Chapter 5

Findings I

Introduction

In this chapter, I present the findings related to the first objective of this research, which was to explore the experiences of older people living with chronic life-limiting illness in rural Ghana. The research question associated with this objective was, “What are the experiences of older people with chronic life-limiting illness in rural Ghana?” Critically understanding the experiences may help to identify the needs of this group and to explore how Ghana’s public health and social policies can be transformed to correspond to the emerging needs of this rural population group. The findings related to this research question and emanating from the data are presented in three themes. The findings are preceded with the demographic description of participants. The chapter ends with a summary of the findings.

Demographics of Older People

Fifteen older people participated in this research. Fourteen of the older people were females. Thirteen out of the 15 participants were widows; two were still married and living with their partners at the time of data collection. One of the two married older people was a male. The youngest older person to participate in this research was 62 years and the oldest was 90 years, and the average age of participants was almost 75 years (\( \bar{x} = 74.93 \) years). Each participant had lived with a chronic disease for almost 5 years (\( \bar{x} = 4.8 \) years), with the range being from 1 to 17 years. In this research, chronic illness was self-identified by participants and the most recorded chronic illness was hypertension. Pseudonyms were used to represent older people
and their voices in this thesis as a way of removing identifiers and maintaining their confidentiality, as shown in Table 5.1.

Table 5.1

Demographics of Older People

<table>
<thead>
<tr>
<th>Name (pseudonym)</th>
<th>Age (yr)</th>
<th>Gender</th>
<th>Occupation</th>
<th>Number of children</th>
<th>Marital status</th>
<th>Known chronic illness</th>
</tr>
</thead>
<tbody>
<tr>
<td>Maame Araba</td>
<td>78</td>
<td>female</td>
<td>retired farmer</td>
<td>2 of 8 alive</td>
<td>widow</td>
<td>hypertension</td>
</tr>
<tr>
<td>Auntie Esi</td>
<td>70</td>
<td>female</td>
<td>retired farmer</td>
<td>0 of 8 alive</td>
<td>widow</td>
<td>hypertension</td>
</tr>
<tr>
<td>Obaa Grace</td>
<td>80</td>
<td>female</td>
<td>fishmonger</td>
<td>6 of 10 alive</td>
<td>widow</td>
<td>hypertension</td>
</tr>
<tr>
<td>Maame Akua</td>
<td>81</td>
<td>female</td>
<td>retired nurse</td>
<td>3 of 4 alive</td>
<td>widow</td>
<td>mild stroke</td>
</tr>
<tr>
<td>Obaa Yaa Akoto</td>
<td>66</td>
<td>female</td>
<td>trader</td>
<td>3</td>
<td>widow</td>
<td>hypertension</td>
</tr>
<tr>
<td>Maame Afua</td>
<td>70</td>
<td>female</td>
<td>trader</td>
<td>3 of 4 alive</td>
<td>widow</td>
<td>hypertension, diabetes, hypertension</td>
</tr>
<tr>
<td>Obapanyin Abokomah</td>
<td>88</td>
<td>female</td>
<td>retired baker</td>
<td>6 of 10 alive</td>
<td>widow</td>
<td>hypertension</td>
</tr>
<tr>
<td>Maame Ama Serwaa</td>
<td>90</td>
<td>female</td>
<td>retired trader</td>
<td>7</td>
<td>widow</td>
<td>hypertension</td>
</tr>
<tr>
<td>Opanyin Kojo</td>
<td>75</td>
<td>male</td>
<td>retired security officer trader</td>
<td>3 of 5 alive</td>
<td>married</td>
<td>hypertension</td>
</tr>
<tr>
<td>Auntie Mansa</td>
<td>68</td>
<td>female</td>
<td>trader</td>
<td>7</td>
<td>married</td>
<td>hypertension</td>
</tr>
<tr>
<td>Auntie Serah</td>
<td>62</td>
<td>female</td>
<td>trader</td>
<td>5</td>
<td>widow</td>
<td>hypertension</td>
</tr>
<tr>
<td>Maame Mercy</td>
<td>73</td>
<td>female</td>
<td>trader</td>
<td>0 of 1 alive</td>
<td>widow</td>
<td>hypertension</td>
</tr>
<tr>
<td>Obapanyin Philo</td>
<td>83</td>
<td>female</td>
<td>trader</td>
<td>6 of 10 alive</td>
<td>widow</td>
<td>hypertension, diabetes</td>
</tr>
<tr>
<td>Maame Abena Manu</td>
<td>70</td>
<td>female</td>
<td>retired caterer</td>
<td>4 of 7 alive</td>
<td>widow</td>
<td>hypertension</td>
</tr>
<tr>
<td>Auntie Attaa</td>
<td>70</td>
<td>female</td>
<td>retired caterer</td>
<td>4 of 9 alive</td>
<td>widow</td>
<td>stroke</td>
</tr>
</tbody>
</table>
Presentation of Findings

As indicated in the introduction of this chapter, the findings of the first study objective are presented in four themes and four subthemes. Data saturation was reached during the data collection. There were 70 interviews, but the last five pairs of interviews with older people and their family carers did not add any new information to what had already been revealed. Using the ATLAS.ti software, the total number of codes which emanated from the data was more than 2,000. In as much as each of the quotations were coded differently, there were some codes in the code families that presented the same idea. This indicated a further confirmation of data saturation after coding and during analysis. Table 5.2 presents the themes below.

Table 5.2

Findings I

<table>
<thead>
<tr>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Increasing awareness of illness in the body</td>
</tr>
<tr>
<td>2. Limitations in meaningful activities being experienced as loss of independence</td>
</tr>
<tr>
<td>3. Dependency relationships being experienced as vulnerable</td>
</tr>
</tbody>
</table>

The following sections discuss each of the themes and subthemes. Exemplar quotations are provided.
Theme 1: Increasing Awareness of Illness in the Body

This theme explicates participants’ perceptions of feelings and reactions that accompanied the physical changes, particularly changes in the body’s biological systems and in the body’s physical appearance as illness progressed. The feelings regarding the awareness of illness were descriptively expressed as a range of undesirable physical and emotional experiences, including apprehensiveness, pain, fatigue, weakness, distress, anxiety, frailty and “old”. The reactions to these negative physical and emotional experiences of illness were the negative living adjustments of disengagement and withdrawal from society that led to self-isolation.

The perception of how the body’s biological systems functioning had declined was a contributing factor to the awareness of illness. The body’s functions were explained in relation to the functioning of the basic biological systems necessary for day-to-day living, such as the urinary, circadian and digestive systems. Changes in the urinary and circadian systems, for example, an increase in night-time urinary frequency, caused some older people to experience changes in their sleep behaviour that resulted in sleep deprivation. Experiences of consistent tiredness or fatigue were a result of lack of adequate sleep. These physical experiences were expressed as distressing, as expressed by Maame Ama Serwaa in the following exemplar quotation:

Another experience is that due to these sicknesses I cannot do anything. I cannot sleep. I will just turn in my bed until day breaks. I urinate a lot in the night. I must wake up on several occasions to go to the toilet before day breaks. I sleep short intervals because I need to go to the toilet frequently. Sometimes I urinate eight times before morning. This makes me tired. All these are uncomfortable.

Consistent fatigue affected participants’ perceptions of strength. The perception of not having strength influenced the ability to feel useful. Feelings of usefulness were evident in
participants’ unwillingness to continually sustain their meaningful activities, which continued to compound their limitations and disabilities in these meaningful activities. There was a perception that feelings of usefulness also influenced the number of times interactions occurred between older people and members of their community, because there was a downplay of inner abilities to do so. Some participants indicated that not participating in activities was easier. Maame Mercy perceived that the fatigue in sustaining her social networks was related to her medical condition. She said,

Due to the illness, I cannot do any hard work like I used to. The little I do these days; I feel tired like I have done a difficult job. I am always worn-out these days. I don’t do anything. I can’t go out and meet people, I am at home every time. The sickness is not good for my body.

In addition, some older people revealed that due to the decline in the function of their digestive system, they may not be consuming an acceptable amount of food. Pains in the tummy, bloated tummy or loss of sense of taste for food were some of the physical changes experienced in connection to changes in the digestive system. These experiences increased feelings of apprehensiveness over the emerging nutritional deficiencies as illness progressed. This is illustrated by Obaapanin Abokomah, who raised concern over her restricted food consumption pattern as,

Now, for instance, I cannot eat much. I feel bloated with the little food I eat and a small amount of water I drink. I cannot even finish less than 1 Ghana cedi (GHS1) worth of Mbor [maize meal]. My tummy is now very big and hard. It causes me lots of troubles … It has been very difficult for me these past few years.

Decreased ability to consume an expected amount of food influenced the perception of strength to undertake some physical activities. There was an indication that inadequate
nutrition resulted in experiences of weight loss as illness progressed. Concomitant to weight loss was changes in the skin that led to the appearance of wrinkles. For older people, weakness, weight loss and the appearance of wrinkles in their bodies meant that beauty was diminished, constructed as “old”, and old meant a body not beautiful. These changes were cognitively perceived as frailty.

The interpretation of reduced beauty as frailty suggested that beauty was an integral part of the participants’ social identity and that frailty may indicate an identity change. A poor judgement on social identity with increasing awareness of weight loss and appearance of wrinkles were closely linked to the decision to self-isolate from the community. In other words, as they seemed to have lost their preferred youthful, strong and beautiful body with the progress of illness, some older people inhibited themselves from not only physical activities, but also being seen in the social environment. Maame Ama Serwaa shared her experiences on frailty, identity loss and self-isolation as,

See, look at my face, my face is frailer. My whole body is wrinkled. Hmmm, I never used to be like this oo [sic, expressing shock], like, I was a big person [heavy person] … The body is finished. Sickness will not leave me alone … Now I don’t have strength like I used to … I don’t go anywhere.

Loss of identity contributed to some older people’s feelings of low self-worth. Grieving loss of identity and experiencing low self-worth influenced some people’s decisions to self-isolate from the wider community. Auntie Serah explained she could not go and visit her family because she tried to avoid people in her community. She felt that avoiding people by refusing to walk through the community will prevent her from answering people’s questions about her weight loss and deteriorating health. She said,
For some time now, I have stopped going out because people ask unnecessary questions, such as, “What is wrong with you? Are you sick?”. I am tired of answering those questions, so I don’t walk through town anymore. For instance, I have a niece who just had a baby, and I was asked to go and see the baby, I had to hire a taxi to the place and back. I just wanted to avoid people seeing me and answering their questions about my health.

Changes in the biological functioning of the body increased participants’ personal decision to isolate from meaningful activities. In the next examples an awareness of illness and problems with pain contributed to experiences of self-isolation.

Pain was most commonly identified as the physical evidence of illness, and this was expressed by all participants. Pain presented in different parts of the body, and it manifested itself differently for each older person. Pain and changes in the biological systems increased feelings of disability and frailty and compounded vulnerability associated with self-isolation.

As indicated in Table 5.1 (p. 133), the most physically painful of the chronic life-limiting illness among this sample was cardiovascular disease. Changes in the functioning of the cardiovascular system were perceived to be the cause of pain in the head, eyes, legs, ears, waist, stomach, ribs, knee, thighs, neck and heart. In some situations, experience of dizziness was associated with the experience of pain. Older people attributed their increased propensity to fall to pain and dizziness, and falls were also the reason for older people’s deteriorating health. For Maame Ama Manu, her deteriorating health increased her perceptions of limited ability (disability) and increased dependency on family for support. She said,

Often, I feel pain in my stomach, the pain gets severe quickly, then it moves to my eyes, affecting my sight. Then I feel dizzy. It comes unexpectedly. When it happens like that and if there is no one around to lean onto, I fall … When I fall, I cannot get
up. The last time I called my granddaughter to help me up. And she put me in bed. I remained in bed for the rest of the day because my hip was very sore.

Cardiovascular diseases were experienced as more painful or agonising and increased perceptions of disability, such as the following:

- Body shakes, as experienced by Maame Araba, “But now I cannot go anywhere. So now, my life has been reduced to pains in my legs, thighs and knees. The knee is very shaky [shaking her hands to demonstrate how her knees shake]”.

- Numbness, as experienced by Maame Akua, “The sicknesses are a lot, I feel them in my legs and knees, mostly they are very sore, like they are very numb [uses an expression to mean motionless]”.

- Irrepressible heart palpitations and oedema, as experienced by Opanyin Kojo, “My heart beats faster during an episode. And most especially, I cannot walk because my legs are very sore. Sometimes I experience swelling of my feet. You see? [shows the researcher his legs]”.

Depending on the time of day, perceptions of pain disability reduced activity and engagement with the social environment. For example, pain in the night increased sleeplessness, and caused fatigue that reduced strength to mobilise and socialise during the day. The presence of pain and its influence on meaningful activities caused some older people to take the decision to self-isolate from the society, although there was a desire to the contrary. When older people say, “I can’t do anything”, they mean the decision to self-isolate is imperative. For Obaa Grace, who was totally immobile, she indicated that it was too painful to walk without an assistive devise, such as a walking stick, because she did not have one. Gradually, her walking disability resulted in her withdrawing from society. She said,
I need to take short distance walk very often during the day, but I would need a walking stick to walk. If I walk without a stick, it is too painful, and I will fall. I don’t have a walking stick, so I can’t go anywhere.

Although awareness of changes in the functioning of the body’s biological systems and the presence of pain contributed to a nuanced decision process to self-isolate from meaningful activities, the underlying factors of suffering and vulnerability in self-isolation emerged in association with such awareness. In the next theme, how the experiences of limitations in physical activities were perceived by participants are explored.

**Theme 2: Limitations in Meaningful Activities Being Experienced as Loss of Independence**

As already stated in Theme 1 of this chapter, as people living with a chronic illness aged, they experienced disabilities and limitations in meaningful activities. Theme 2 focuses on the meaning of disabilities and limitations in meaningful activities for older people. Being active in meaningful activities seemed to be the same as living a healthy life. Also, being physically able to manage these activities by themselves seemed to be necessary to maintain their independence, such that physical limitations were counted as loss of independence.

Two areas of loss in limitations were identified: (1) losing independence through limitations in physical activities and (2) missing pleasurable activities. These are discussed as subthemes with exemplar quotes below.
Theme 2.1: Losing Independence Through Limitations in Physical Activities

I begin the explanation of this subtheme with some observations from the field and then clarification of perceived loss of independence follows. It was observed that two older people were totally immobile. Of the two older people who were immobile, one had a cane which she used to support herself when she was being transferred or mobilised by her family carer. The other did not have a cane; she was totally dependent on her family carer for transferring and mobilising her from one position to the other. Eight older people were partially mobile, but only one of these had a cane to move around. The remaining five were mobile.

There were no other observed assistive devices, such as wheelchairs, to help older people move around. Lack of assistive devices contributed to a loss of independence and, therefore, restricted life and limited engagement in meaningful activities. Limitations in meaningful interactions and engagements induced further isolation from society. Losing independence was evident in relation to physical limitations in activities of daily living (ADLs) and limitations in instrumental activities of daily living (IADLs). ADLs encompassed walking, transferring, toileting and bathing. IADLs also encompassed maintaining finances, managing the home, grocery shopping, meals preparation and laundry making.

In terms of ADLs, for older people in this sample, walking was explained as moving from one place to the other, such as moving from the house to a local construction site to observe building activities, to the market or seashore to pursue petty trading activities, and to the church to pray or to sing. While walking was perceived as a basic independent activity, it was also viewed as the precursor to the engagement in other physical and social activities necessary for self-care. It appeared that the centres for the accessibility of essential goods and services for self-care, such as the market, hospital, and so forth, were walking distance away, but people with restricted mobility could not access them. Therefore, disabilities that led to
losing independence in walking restricted functionality in other physical, economic and social activities as well as limitations in self-care. For example, Maame Araba explained that previously she could easily walk to the hospital by herself to seek medical care when necessary, but now she could not walk. Not only had she lost her independence to walk, the need to access medical care, especially when she was sick was thwarted. She said,

I had severe pains in my legs and pains in my ribs. I kept rolling on the bed and I felt like cobwebs on my eyes. So, my granddaughter came to me to find out what was wrong with me. That was the day she asked me to prepare for us to see the doctor at the hospital. But we couldn’t go because I couldn’t walk.

While the inaccessibility of essential services may aggravate loss of independence in walking and challenge self-care abilities, participants who were completely immobile expressed extra loss in the inability to transfer their body from one position to the other, indicating significant disability and loss. Transferring was explained as physically moving the body from one position, such as lying on a bed to sitting on the bed or sitting on a bed to standing position. Sometimes an attempt to independently transfer resulted in a fall. When a fall occurred, health deteriorated quickly, compromising strength to remain independent. Auntie Attaa’s case is a typical example. Apart from the stroke, she had a fall when she attempted to transfer from the bed by herself, that further injured the paralysed side of her body and made her completely dependent on her family to both transfer and mobilise. She said,

During the night, I had the urge to pass urine, I tried to wake up from the bed, but I couldn’t. When I tried to get up, I fell down on the floor. It was too dark or just my sight went blank, so I didn’t see anyone in the room. I remained on the floor till I heard a cock crowing [until morning]. So, I called me grandson and told him that I cannot get up from the floor. So, he came and helped me up. That was when I
realised one side of me is completely paralysed. Since then, I haven’t been able to move by myself. Since my paralysis, I haven’t been outside my house. I have remained in the house.

These examples of disabilities and limitations in walking and transferring indicate a loss of independence. These examples suggest that the severity of disabilities in ADLs may implicate self-care activities alongside the trajectory of illness and cause further loss of independence. Losing independence due to severe disabilities in ADLs led to other psychological challenges that decreased social identity and self-worth.

The severity of disability in ADLs was perceived to be distressing because of an increase in feelings of burden and loss of independence, in particular in walking and transferring and in using the toilet and taking a shower. Obaa Grace, for example, pointed out that she required extra help to mobilise and transfer since she had an accident where a church building collapsed on her. She revealed that her disabilities and loss of independence were particularly challenging because she constantly had diarrhoea and continuously needed to use the toilet. In addition to being overweight, she explained that her walking restrictions meant that she needed extra support to use the toilet. She said,

I have not been able to walk since then. Someone has to carry me to the bathroom, toilet, everywhere … It is very difficult for me, because of my situation [I can’t walk], I cannot go and use our toilet, I usually use a chamber pot [bed pan] and she [family carer] clean after me and empties the pot.

Independence in ADLs appeared to be rooted in the personal expectations of an older person in the local environment, thus dependency challenged their perception of social identity and self-worth. Auntie Attaa insinuated that at 70 years old, it is not worth her living, if she had to rely on other people for toileting. She expressed her agonising experience as,
At my age, I don’t have to rely on people to use the toilet. I should be able to do those things by myself. Those older people who have gone before me, they didn’t suffer due to diseases for long. At most, within a month, they were dead and gone. I feel I have been sick for a very long time. I am living with pain uncontrollable pain, yet I feel my people [family] sometimes give up on me because they do everything for me. In my old age, I feel miserable.

These examples suggest that physical disabilities, self-care behaviour, dependency and social identity and self-worth are important structural considerations in re-abling efforts for transformative change. From the data, there was an indication to the development of a compensatory approach as an informal tool used by some participants to maintain independence and to protect social identity and self-worth. When it comes to independence in taking a shower for example, it was revealed that (severe) disability did not necessarily become a limitation. Some older people managed to independently take a shower, although they required support in fetching water to the bathroom, as in the case of Auntie Serah, who explained that she tried to bathe herself, but she had no strength to carry a bucket full of water to the bathroom to bathe herself. She said, “Well, I can take a shower by myself, but I need someone to help me put water at the bathroom for me. I cannot carry a bucket full of water to the bathroom”.

The perception of social identity and self-worth may create an internal tension between disabilities and independence, making older people more vulnerable. While losing independence in ADLs increased perception of low social identity and self-worth as dependents, losing independence in IADLs increased perception of low social identity and self-worth due to loss of social position. I demonstrate loss of social position due to limitations in IADLs in the next section.
As already stated in the introduction of this theme, losing independence in IADLs were recounted in the inability to maintain finances, manage the home, shop for groceries, prepare meals, and undertake the laundry. Just as in ADLs, the severity of disability determined the level of loss in independence in IALDs. Again, just as with ADLs, older people’s perception of social roles in the community were related to IADLs, and they felt it was their personal duty to perform IADLs to meet these social role expectations. Fulfilling these social roles were necessary to maintain their social position as older people in the family and the community at large. However, disability reduced the ability to fulfil these roles and challenged the individual expectations for social position. The inability to continually be active in expected social roles made some older people grieve the loss of their social position necessary for their identity, and this was expressed differently for men and women.

The first IADL, which all older people expressed difficulty in maintaining, was finances. An inability to maintain finances was constructed as losing financial independence, and it emanated from cessation of economic activities due to disabilities and frailty perceptions as changes in the functioning of the body’s systems and pain progressed (as already discussed in Theme 1 and in earlier section on ADLs). In the local setting, the commonest form of economic activity was selling of goods and services in small quantities, commonly known as petty trading. Petty trading belongs to the informal economic sector of Ghana. As indicated in Table 5.1, most of the older people had previously engaged in petty trading. Petty trading, already explained under social change and poverty in Ghana in Chapter 2, is a business activity of purchase and sale of agricultural and general consumables in small quantities, providing small services or farming, often by women and in small market spaces (Yendaw, 2019).
Losing financial independence reduced the ability to independently meet basic needs. From the data, income generated from petty trading was used to meet nutrition, medication and other basic needs. With the onset of pain, and despite the expressed desire to remain economically active, older people abandoned their primary economic activity, petty trading, which meant that their ability to maintain their financial independence and to continually meet their basic needs was eroded, and dependence on family to meet these basic needs increased. For example, Auntie Esi, who provided funeral services, explained that she depended on that income for buying foodstuffs for cooking, but “These days I cannot do that anymore, meaning my source of income is gone, and I don’t have money to buy foodstuffs anymore”, she explained.

In addition, it was explained that it was a normal expectation for a person advanced in age to have some savings to rely on in old age. However, most participants did not have any saved credit to rely on for trading, feeding or for medication needs in their old age. This raised questions about their personal expectations for their social role and self-worth in the community. For example, Obaapanyin Philo seemed sad and apprehensive because she has no savings to reawaken her petty trading activities. The sadness made her question the worth of her age. She used a popular Ghanaian adage to metaphorically express her sadness and apprehensiveness. She said,

There is a popular adage that, ‘the beginning of life is not as painful as the end’. In the beginning, I was up and about my own business, I used to sell cloth, bake bread and other pastries. Today, I have retired from all these activities. Even there is no money to continue working, even if I want to. Look, at my age, I haven’t eaten anything since morning. I don’t have money to buy food.
Losing financial independence led to the loss of valued social positions due to an inability to fulfil the role expectations associated with the social positions. Some participants shared stories of being the breadwinners and financiers of their family members’ education and businesses through their petty trading activities. Others shared stories of being active grandparents through their petty trading activities. The combination of losses raised concerns for wellbeing. For example, Auntie Attaa used to be the primary family carer of her grandchildren. The important position she held as a grandmother enabled her daughter to migrate to the city for work. Her daughter remitted money to her regularly, which Auntie Attaa used to augment her personal income from selling food by the roadside (petty trading), and she was able to take care of herself and her grandchildren. However, because she had a stroke, her petty trading activities ceased, and she could no longer fulfil her role as a grandmother. Subsequently, her social identity and self-worth as an independent woman and a grandmother were diminished. This made her unhappy and distressed, and she felt she is failing both herself and her daughter, who now has become her family carer. She said,

Anyone who is sick will not be happy, that person will be depressed. That is the state I find myself in, now. I don’t know where this illness came from and I don’t know why it came to me. I want to take care of my grandchildren, so my daughter can go back to her business in Kumasi [the capital city of Ashanti region].

Men expressed more challenges with low identity and self-worth because of their perceived expectation of having a high-performing economic role. Opanyin Kojo indicated that being a man means he has to do hard work, and hence his inability to work made him sad. He expressed low self-worth because he had lost his physical and economic independence and as such could not be identified as a protector of his family. He said,
What makes me sad is that, you know, as a man, I need to make movement every morning. I need to be seen working every day. All these people you see around know how I used to work before, but now, I am just at home. I feel very sad because of my current situation. What worries me is that I have children and grandchildren, they are very young, and they need security and protection. I pray to God every morning to give me strength to be able to protect them and give them security. Till now, I have not been able to do that. I think about them all the time. I want God to heal me, so I can provide them with protection and security.

From these illustrations, petty trading can be seen to be a valued IADL for financial independence, such that this inability in this area eroded not only financial independence, but the perceived value of older people and the important positions they occupied in society as well, increasing the number of losses older people experienced. Again, from these illustrations, some social positions were gendered, yet loss of social position as family breadwinners or financiers was not expressed exclusively by older men. Some older women expressed more distress about their loss of independence to maintain their homes as part of their valued gender related positions, raising structural concern for the significant losses in older women’s position in Ghanaian rural society.

As older women, some had the added role of supervising the younger family members in performing their roles, such as cooking, grocery shopping, making laundry, cleaning the house, and head-portering water. With increasing chronic illness, older women experienced additional loss in their ability to maintain and supervise their home activities, leading to dependence on others and low identity and self-worth. For example, Obaa Grace expressed some sort of personal devastation for not being able to perform a task as simple as head-portering water because she was completely immobile. She said, “I have become dependent
on other people for my daily activities. Even, I have to depend on my grandchildren to fetch water for me”.

Just as in maintaining independence in some ADLs to feel worthy, some older people considered some IADLs as a less complex way to compensate for other losses and to salvage their independence, social position and identity and self-worth in the community. Maame Araba explained that she did her best not to further deteriorate her diminishing independence. She said, “The little food I need, I manage to cook because I am not that frail and bedridden; I do my best”. Despite the compensatory efforts, some IADLs were found to be more complex, and an expressed inability to perform these complex activities increased dependency on family for support. These complex tasks included preparing certain types of meals, such as the traditional maize meal, doing the laundry, sweeping and or cleaning the home.

From the responses, all older people who took part in this research expressed value in the presence of family and their support in compensating for their losses in ADLs and IADLs. For example, Auntie Serah said, “I am lucky to have good children. They are always willing to help me with anything I ask them”. Not all participants had consistent family support, but the evidence of feeling like a burden and an inconvenience to an (in)consistent family was consistent throughout participants’ accounts, thus the preference to remain as independent as possible was embedded in all participants’ accounts:

What I wish to continue doing is that when I wake up in the morning, I should be able to sweep and clean the house and fetch water for the use at home. I believe at my age, I should be able to run some errands at home, but the contrary is the case. My granddaughter has to do them.
Loss of independence in IADLs increased vulnerabilities to economic and social dependence. Losing independence in both ADLs and IADLs limited potential self-care activities increased dependence on family support, caused low social identity and self-worth and threatened the social position. These social conditions may have more complex health and social implications (details in the next theme). The specific physical limitations in ADLs and IADLs gives clues as to what health and welfare services are required for transformative change. In the next subtheme, I present additional experiences of loss of independence in pleasurable activities and their implications on self-isolation, social identity and self-worth for older people living with chronic life-limiting illness.

**Theme 2.2: Missing Pleasurable Activities**

The second area of limitations in meaningful activities expressed as losses were missing pleasurable activities. Pleasurable activities were the ones that emphasised participants’ relationships with other members of their family and their community at large. The pleasure in relationships included a sense of belonging, fulfilling and intimacy. Missing pleasurable activities seem to have stemmed from older people’s perception of themselves, specifically, their perceptions about changes in the biological functioning of the body, changes in physical appearance (weight loss, frailty), problems with pain and loss of independence in ADLs and IADLs.

As already mentioned in awareness of illness in the body in Theme 1, changes in the biological functioning of the body were experienced as one of the reasons for self-isolating from wider community engagements. Self-isolation compounds loss in the pleasure and sense of belonging in community activities. Obaapanyin Abokomah, for instance, explained that she enjoyed getting involved in her church choir. But since she lost her voice as a result of a
persistent cough, she could no longer get involved, grieving both her loss of ability to sing (i.e., the biological change) and of her sense of enjoyment in church community engagement. Her self-isolation caused more challenges in self-worth. She reported,

I cannot talk louder because I have been coughing for a long time. I have even lost my voice. At first, I used to sing in church but since I became sick and the cough never went away, I have stopped singing in church.

In addition, the activity of dressing was considered more meaningful than just the act of selecting an attire and putting them on without help. It included wearing the appropriate costume for an occasion. Dressing meaningfully was considered an important aspect of finding pleasure and of being engaged in community activities. “Slit and kaba” is a traditional women’s wear for both formal and informal social occasions. From the responses, a combination of factors, such as problems with pain and walking disabilities, appeared to reduce some older people’s ability to dress in a “slit and kaba”. Those who could not dress to an occasion, indicated that they were not able to attend the occasion. Disengagement and missing pleasure affected social identity and self-worth and compounded older people’s vulnerability in self-isolation. Maame Afua expressed her inability to dress up as painful and blamed it on ageing. She said, “Growing old is very painful, because I cannot even dress up by myself and go places like I used to. I cannot wear slit”.

As indicated in limitations in economic activities in the previous subtheme, loss of financial independence reduced the ability of older people to purchase new clothes. Although some older people thought it was important to maintain a connection with the church, when they could not afford new clothes, they chose not to go to church, thereby missing the pleasure they derived from engaging with church activities. Obaa Yaa Akoto explained that to maintain her identity and self-worth, she stopped going to church and she avoided church and
personal anniversaries because she does not want to take chances on people gossiping behind her due to her impoverished clothes. She said,

I have stopped going to church in a long while. My younger sister pleaded with me to start attending church, but I haven’t started because I don’t have new dresses. People will gossip at my back when they see me in worn-out clothes.

Again, as already described in the previous subtheme on losing valued social positions, disabilities and limitations in ADLs and IADLs made older people lose the joy of being engaged in social activities, such as church, funerals or other social gatherings in the community. In those social activities, older people had previously held vital ceremonial positions, such as funeral consultants, traditional naming ceremony leaders, and festival organisers, etc. However, disabilities and limitations prevented continuous participation, leading to loss of pleasure in participation and valued positions, causing more challenges in social identity and self-worth, as identified in the previous subtheme.

For example, Obaapanyin Philo explained that she used to be a respected organiser of funerals, weddings and other occasions in her community. However, she could no longer maintain that position because of her worsening oedema. She explained that playing the role of an organiser was pleasurable and fulfilling; however, it was shameful for people to see her without footwear. Therefore, she stopped organising occasions or attending them as a way of hiding her shame; she perceived herself as unable to fulfil her expectations for the role. She said,

I cannot wear any footwear. When I wear any footwear, they come off by themselves. Due to that I cannot attend any social gathering like funerals or church or weddings because people look at me and ask me too much questions. Usually, I need to wake up at dawn and walk to the shop, at that time, people are still sleeping.
In the evenings when I am going home, I avoid the main streets with the intention that many people will not see me.

The aforementioned examples represent missing pleasure in participating and engaging in local community activities. Missing pleasure in engaging in community activities also had implication on social identity, self-worth and isolation. For the older people who were married, it was revealed that being intimate with their partners brought them joy and happiness, but also that partner intimacy was a cultural responsibility. Problems with pain and limitations in ADLs meant an inability to be intimate with partners. Older people felt that they were missing out on enjoyment in intimacy and failing in their cultural duty to satisfy their partners at the same time. Auntie Mansa was more regretful and sadder on the loss of both her sensuality and physical strength to fulfil her sexual duty to her husband. She said,

And more importantly, I cannot be intimate with my husband. Sometimes when we reminisce on some of the happy times we shared together, we feel very sad that we cannot do those things again. You know, men have the strength all times, but I don’t have that strength anymore … When I think about it, I feel sad because I am married yet I cannot satisfy my husband.

Similar sentiment was shared by Opanyin Kojo, who disclosed that he lost his sexual pleasure and duty to sexually satisfy his wife because of pains in his legs.

I have a wife and like every married couple, it gets to a time I should be able to have some sort of sexual relationship with my wife, but I cannot do that. I always have pains in my legs–how can I have that relationship with my wife?

From these examples, missing pleasurable activities contributed to the feeling of low identity and self-worth. Feeling of low identity and self-worth may increase vulnerabilities that have
more complex health and social challenges. In the next theme, I will show how vulnerabilities lead to more complex challenges health and social challenges.

**Theme 3: Dependency Relationships Being Experienced as Vulnerable**

This theme explicates the experiences on dependency relationships with community-based health and social support resources as well as family and community support. Experiences with these care structures and processes exposed some level of vulnerability. As already presented under losing independence in the second theme of this chapter, disabilities and limitations in ADLs and IADLs increased the need for community-based health and social support resources, but experiences on formal care were not common from the data. It appeared that formal care to meet required emerging needs increased dependence on informal care.

However, family and community support were experienced differently by the older people in this study. Some older people perceived that they were lucky, with family support readily available and accompanied with love. For this group of older people, their experiences with self-worth in dependency appeared stable. For other older people, family support was not readily available nor accompanied with love. This group of older people experienced challenges with their self-worth in dependency.

With regards to formal care, vulnerability expressed was related to inaccessible and unaffordable health and social services in the rural district. As already discussed, the emerging needs associated with the chronic life-limiting illness trajectory evolved around disabilities and frailty perceptions on biological dysfunction of the body, weight loss, frailty, pain, body shakes, numbness, heart palpitation, oedema as well limitations in ADLs, IADLs
and pleasurable activities. From the data, when it came to managing these health care required needs, high cost and inaccessible health care services in the rural community exposed older people to physical and mental health vulnerability. Health vulnerability related to cost and access was particularly highlighted, because older people’s loss of financial independence due to cessation in economic activities (as discussed in the previous theme) served as a barrier to adequate health care. Obaa Yaa Akoto explained that because she did not have money, she could not undertake the required medical tests to determine the cause of her chronic stomach pain:

The last time I went to the hospital, the doctor prescribes some tests to be conducted on me, because I was experiencing pain in one half of my stomach. Although the pain in my stomach was usual, I didn’t go for those tests. I didn’t have money to do those tests. That is the reason why I didn’t go to the hospital.

Sometimes, inadequate access to health care services due to cost cause an increase in uncontrolled use of cheaper traditional or alternative medicine with no known knowledge on scientific efficiency for specific symptoms management, reemphasising health vulnerability, as expressed by Obaa Grace:

When I don’t have money to go to the hospital, I rely on medicine from the earth [traditional or alternative medicine] … Just any of the herbal medicines being sold nowadays. I grind some herbs and use the liquid as purgative with an enema bulb syringe. So, if I purge myself, I feel a little bit better.

In acknowledging the potential health risks in using alternative medication, Maame Mercy explained that
In recent times, herbal medicines are all over the place, one cannot trust the source of these medicines. It is possible some of these medicines could complicate issues if we rely on them, but people continue to use them anyway.

While the suffering associated with chronic life-limiting illness persists, the government health scheme exists for older people who could access medical health care. It helped to cover part of the cost of health care. However, not all benefited from the scheme for chronic life-limiting illness management, mainly because some older people could not afford to be registered on the scheme. Also, some medications for chronic life-limiting illness management, which were prescribed by the doctor, were not covered under the scheme and required direct payment. As demonstrated in the following examples, for older people living in rural Ghana, the existence of these structural limitations increased health vulnerability.

It was revealed that older people who were in extreme financial difficulty could not afford to register to acquire a health care card and/or to pay for the part of health care cost not covered under the health scheme. Maame Araba explained that the need to pay part of the health care cost out of pocket at the hospital prevented her from subsequent health reviews: “I took it [the health card] with me [to the hospital], but I still had to pay. So, when they [doctors] asked me to go for review, I couldn’t go because I didn’t get money”.

Apart from the direct cost, some medication for pain or any other symptom management were not covered under the health scheme’s medication list, and doctors’ prescriptions outside the health scheme’s medication list were an added cost that some older people in extreme financial difficulty could not afford. Maame Mercy indicated that she had forgone her medications on several occasions due to affordability problems. She said,

On several occasions I have skipped my medications because I didn’t have money to buy. Sometimes, some of the medication is giving at the hospital, and those that are
not available at the hospital, they are written for you. So, if I don’t have money to buy what is written for me, I use the ones given at the hospital alone.

The current health scheme exempts older people who are 70 years and above from paying to be registered or to remain on the scheme; however, people who are not yet 70 and in extreme financial difficulty are still vulnerable. Auntie Serah was 62 years. She explained that most older people in her age range in the rural community could not afford to be registered under the scheme. She said,

For us older people in this community, health care is very important to us. The government can register older people’s health insurance for free. Older people do not have to pay any premium. Currently only those who are 70 years do not pay for the premium, but what about those of us who are not yet 70 years but can’t afford?

Sometimes, personal circumstances, such as immobility and inconsistent home support to transport older people to the health care centre, intersected with physical inaccessibility (such as rural location limiting proximity to health care centres) and high cost for chronic life-limiting illness management, even with the health scheme’s support. For example, Maame Abena Manu explained that, “The clinic is far from here. If I feel worse, my children bring a taxi to take me to the clinic but not all the time”.

Apart from the financial difficulty, distance and family circumstances in accessing medical health care discussed above, a sense of increasing despair among older people when it comes to using orthodox medicine for chronic life-limiting illness management was a factor to consider in accessing medical health care in the local setting. Some older people who went to the hospital for prescriptions indicated that they were “given the same prescriptions”. Over time, some older people stopped using the prescriptions, because they believed the prescriptions did not alleviate their symptoms. For example, Maame Ama Serwaa indicated
that when the hospital drugs did not alleviate her pain, she got rid of them: “I got tired of them. I put all of them in the bin. I was having the same feeling in my stomach. The pain never went away”.

Unrelenting pain and adequate nutrition were the major concerns expressed by most older people in this study. When older people’s perception of community-based social support resources was probed, some explained that they believed the needs of older people were not adequately prioritised by people in authority (government). For example, Opanyin Kojo explained that

The government could have built an old age facility for those of us who are frail and sick to stay, and we will receive the health and personal care we need. In this country, nothing of the sort exists here us in this village, not even in other parts of the country. The government will not do that for us. Older people are not the government’s priority.

There was a belief that government support could make a difference if there was adequate prioritisation of aged and chronic illness needs. Lack of prioritisation of need increased economic and mental health vulnerability. Opanyin Kojo’s explanation suggested that health vulnerability is common among the older people in his village. He said,

I am very stressed because of my [health] situation. If government can take care of our feeding needs and our hospital bills, it would ease the stress on my life. There are a lot of old people like me in this village. I have heard that elsewhere (in other countries), their governments give some stipends to the older people every month, but that system is not available in Ghana.
Health (both physical and mental) and economic vulnerabilities that reinforced persistence of suffering increased dependence on family and community support. Family and community relationships also raised concerns for other forms of vulnerability because of challenges associated with self-worth in dependency; these issues are presented next.

Older people who described challenges with family support and self-worth appeared to experience a higher sense of physical, social and emotional vulnerability, expressed in two ways: either the presence of people increased vulnerability, or the absence of people increased vulnerability. For the former, vulnerability in dependency expressed in the presence of family members was the susceptibility to physical abuse and neglect of needs by family members. A common perception among older people, as discussed on losing social positions in Theme 2 was that active care was a gendered activity: females were supposed to support in home physical activities and males provided money. Mostly, older people perceived female family carers as more empathetic to their needs, suggesting dependence on males was challenging. For example, Maame Efua had limited vision. She indicated that her son did not understand her, because her son often thought she was suffering from “old age” when she complained about care: “My son, the eldest one, he took care of me for a while. After some time, he said I am suffering from old age. He left, so now I don’t have a helper”.

In addition to feeling “old age” was derogatory, Maame Efua said that since she lost her source of livelihood and depended on her son for support, she was fearful of her life because her son was capable of abuse under the influence of alcohol. She said,

Yes, he did, but now his behaviour towards me has changed. He is not talking to me. Yesterday, he threatened me with a knife. I didn’t do anything bad to him. When he drinks alcohol, his behaviour changes towards me.
She added that she was miserable. She often has unmet nutrition needs because her family carer sometimes neglects his responsibility of meeting her nutrition needs.

When he is angry with me, he refuses to give me money for my upkeep. He doesn’t always have [money] anyway, perhaps that is [why] he fights with me, so I don’t ask him for money. When he goes out to work and gets back in the evening, he knows that I haven’t had anything to eat, but will not give me just GHS2 [2 Ghana Cedis] to buy food. I live a miserable life.

In addition, she explained that the only way to get her son to give her some money for food or medication was by begging, causing more challenges with her identity and self-worth: “Even with money, I have to beg for it before they give me something”.

Vulnerability was expressed in another way as well: an apparent or anticipated absence of supportive family members. The culture of the local people indicates that adult children have shared responsibility to take care of their ageing parents. The more adult children, the bigger the availability, capacity or consistency of shared responsibility to provide support. In Table 5.1, the demographics of older people showed that most older people had some, and in one case, up to eight of their children who were deceased. This means that there will be limited availability, capacity or consistent support for older people. The data showed that in some cases, when family carers were outside of town on work reasons, older people were left alone at home. Increasing experiences of limitations in physical and social activities, combined with inconsistent family support increased older people’s exposure to feelings of loneliness and isolation, further implicating the self-worth of older people. Maame Ama Serwaa said,

My children, there are only two of them left [alive] … They [my children] are not in this town. When there is bountiful harvest during the fish season, they go and work at the seashore. I wish I could be having a conversation with them every day … I
feel lonely sometimes. I don’t have any person to help me at home. Until they visit, there is no one to chat with.

For Auntie Attaa, an anticipation that the amount of family support will reduce in the future, when she needed it most, made her more fearful of loneliness and she questioned how she will live her life. She said,

If I could get up, and not depend on people for daily needs, such as toileting, bathing and cooking … Even my grandchildren, one of them is in a boarding school … What will happen to me if I have to urinate at dawn?

To add to that, although older people expressed gratitude in the support of the general community, when it comes to managing chronic life-limiting illness, older people’s vulnerability was pronounced when sustaining their physical and medication needs were dependent on random acts of kindness from members of the community for their upkeep and medication needs. Maame Araba explained that she only lived on inconsistent acts of generosity from other people in the village. She said,

For now, I’m waiting for someone from the city or even abroad to show me kindness since I am old and cannot work to take care of myself. If this person can give me a pound [the old Ghana currency, as if to say some small amount of money as a gift], I can buy all the medication prescribed to me by the doctor … I can go and buy cassava, if the money is enough, I could buy palm fruits and some fish … or clothes.

From these examples, dependency on inconsistent community-based health and social resources as well as family and community support increased an exposure to health (physical, mental, emotional), social and economic vulnerabilities. I discuss what these mean in terms
of Ghana’s aged care, health and social welfare policies in Chapter 7. In the next chapter, I present the findings related to the second research objective.

**Summary of Findings 1**

The presentation of findings in this chapter are related to the first research question, “What are the experiences of older people with chronic life-limiting illness in rural Ghana?” The findings for this research question were presented under three main themes depicting the older person’s experiences of living with chronic life-limiting illness in rural Ghana. In the first theme, awareness of illness in the body was experienced as a range of negative feelings descriptively expressed as suffering as illness progressed. Suffering due to sleep deprivation, emerging nutritional deficiencies, weight loss, pain, dizziness, numbness, body shake, oedema and heart palpitations associated increased disability and frailty perceptions. Disability and frailty perceptions influenced personal decision processes to feel useful for meaningful activities and community engagements, and they were associated with vulnerability in self-isolation from immediate family and community.

The second theme presented an indication that older people were not living a healthy life due to limitations in meaningful activities, experienced as loss of independence. Two significant categories of meaningful activities experienced as loss of independence, physical activities (in ADLs and IADLs) and pleasurable activities (in community activities and intimacy), were identified. Limitations in ADLs were connected to the experiences of loss of ability to sustain self-care activities as the disabilities and illness trajectory progressed. Inability to sustain self-care increased dependence on family and community support, but the perception of being a burden on dependents decreased social identity and self-worth. Limitations in IADLs were experienced as loss of independence in maintaining valued social positions due to an inability
to sustain the role expectations associated with the social positions. Disabilities increased limitations in petty trading and led to the experiences of loss of financial independence. Loss of financial independence caused loss of grandparenting, family financier and other social roles. These multiple losses were expressed differently for men and women and give an indication that structural responses to the emerging needs in limitations in meaningful activities that led to loss of independence should take into consideration the different dimensions of meanings expressed by the different demographic groups in the rural setting.

The experiences of suffering and loss discussed in the first and second theme were explained as being associated with complex health, psycho-emotional and social challenges, emerged as vulnerability, and were presented in the third theme. The data indicated these needs have not been adequately prioritised to translate into action plans or resources in the community. The government health scheme served to increase access and affordability of health care, but there were some limitations identified with the scheme. In addition, the existence of socio-economic and personal circumstance often worked together to exclude older people living in rural areas from adequate health care and social services.

Suffering, loss and vulnerability in inadequate access to community-based health and social support resources increased dependence on family and other members of the community for support. Although not in all cases, and also already stated in the previous paragraph, older people perceived their dependence on family support as being vulnerable, which increased when support was inconsistent and unavailable. Dependency challenges further affected older people’s self-worth and also caused more challenges and limitations in meaningful activities. Highlighting these emerging needs associated with the experiences of chronic life-limiting illness, I discuss how they constitute marginalisation and the need for transformative change in Chapter 7 of this thesis.
In Chapter 6, the findings of the second research question, related to the perspective of family members on chronic life-limiting illness and family and community support are presented.
Chapter 6

Findings II

Introduction

The purpose of this critical ethnographic research was to investigate the experiences of older people and their family carers on chronic life-limiting illness and informal care in rural Ghana, using the Goma West District in Ghana as a research location. In the previous chapter, I presented the findings of the first objective of this thesis, describing older people’s subjective experiences with chronic life-limiting illness and care. The findings on the subjective experiences with chronic life-limiting illness were the awareness of illness in the body, losing independence through limitations in physical activities and dependency relationships being perceived as vulnerable.

In this chapter, I present the findings on the second objective of this research, that is to assess informal care for older people living with chronic life-limiting illness in rural Ghana, from the perspective of family carers and health care professionals working in the St. Luke Catholic Hospital (SLCH) and the Palliative Care Clinic of the Korle Bu Teaching Hospital (KBTH). The research question which was answered to achieve this objective was, “What are the structures and processes of informal care for older people living with chronic life-limiting illness in rural Ghana?”. The findings presented in this chapter illustrate how informal care for older people living with chronic life-limiting illness is enacted as specific care processes, delivered in the context of distinctive structures of support in the local setting. The findings are preceded with the demographic description of family carers and health care professional who participated in this research. The chapter ends with a summary of the findings.
Demographics of Research Participants

In the following sections, the demographics of family members and health care professionals who took part in this research are presented.

Family Carers

There were 15 family carers who participated in this research. Each family carer was associated with one of the older people described in Chapter 5, Table 5.1. The average age of participants was 45.47 years, with the youngest 25 years of age and the oldest 72 years. Further demographic details of family carer participants are included in Table 6.1. Although all participants stated their occupation or trade, most of them stated they were not actively employed at the time of data collection. All the family carers except one cohabited with the older person in the same house. One of the family carers lived within walking distance to the older person’s house. Those who were not actively working spent up to 24 hours a day with the older person. Those who worked, made their caring arrangement before and after working hours. Also, depending on the health needs of the older person at any particular time, family carers increased or decreased the number of hours they spent with older people. Pseudonyms are used to represent each family carer who took part in this research for confidentiality purpose and are shown in the table below.
Table 6. 1

Demographics of Family Carers

<table>
<thead>
<tr>
<th>Name (pseudonym)</th>
<th>Age</th>
<th>Gender</th>
<th>Occupation</th>
<th>Relationship with older person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gyasiwaa</td>
<td>40</td>
<td>female</td>
<td>fishmonger</td>
<td>daughter</td>
</tr>
<tr>
<td>Donkor</td>
<td>68</td>
<td>male</td>
<td>retired welder</td>
<td>brother</td>
</tr>
<tr>
<td>Ama</td>
<td>25</td>
<td>female</td>
<td>fishmonger</td>
<td>daughter-in-law</td>
</tr>
<tr>
<td>Ewurabena</td>
<td>51</td>
<td>female</td>
<td>former dietician</td>
<td>daughter</td>
</tr>
<tr>
<td>Mintaa</td>
<td>36</td>
<td>female</td>
<td>teacher</td>
<td>daughter</td>
</tr>
<tr>
<td>Ebo</td>
<td>33</td>
<td>male</td>
<td>fisherman</td>
<td>son</td>
</tr>
<tr>
<td>Agyeiwaa</td>
<td>28</td>
<td>female</td>
<td>trader</td>
<td>granddaughter</td>
</tr>
<tr>
<td>Adwoa</td>
<td>72</td>
<td>female</td>
<td>farmer</td>
<td>daughter</td>
</tr>
<tr>
<td>Gifty</td>
<td>75</td>
<td>female</td>
<td>farmer</td>
<td>wife</td>
</tr>
<tr>
<td>Antobam</td>
<td>70</td>
<td>male</td>
<td>block manufacturer</td>
<td>husband</td>
</tr>
<tr>
<td>Sika</td>
<td>32</td>
<td>female</td>
<td>teacher</td>
<td>daughter</td>
</tr>
<tr>
<td>Maame Kukua</td>
<td>58</td>
<td>female</td>
<td>trader</td>
<td>sister</td>
</tr>
<tr>
<td>Kwame Oboh</td>
<td>54</td>
<td>male</td>
<td>refrigerator repairer</td>
<td>son</td>
</tr>
<tr>
<td>Maame Kakra</td>
<td>56</td>
<td>female</td>
<td>trader</td>
<td>daughter</td>
</tr>
<tr>
<td>Kumwaa</td>
<td>32</td>
<td>female</td>
<td>fishmonger</td>
<td>daughter</td>
</tr>
</tbody>
</table>

Health Care Professionals

In all, 10 health care professionals were included in the study, five from the St. Luke Catholic Hospital in the Gomoa West District and five from the Palliative Care Clinic of the Korle Bu Teaching Hospital in Accra. Two of the five health care professionals from the St. Luke Catholic Hospital were females. Two of the participants were physicians, one was a physician assistant, one was a nurse matron, and one was a psychiatric nurse. Voices of health care professionals from the St. Luke Catholic Hospital are represented as SLCH in this chapter to protect their identity.
Correspondingly, three of the five health care professionals from the Palliative Care Clinic of the Korle Bu Teaching Hospital were females. Three of the participants were family and palliative care physicians, one was a geriatrician, and one was a palliative care nurse matron. Voices of health care professionals from the Palliative Care Clinic are represented as KBTH in this chapter to protect their identity.

**Presentation of Findings**

There are four themes presented in this chapter. The first theme characterises the structures within which informal care occurred in the local setting, and the next three themes characterise the processes of providing informal care for older people living with chronic life-limiting illness. The themes are presented in Table 6.2.

**Table 6.2**

*Findings II*

<table>
<thead>
<tr>
<th>Themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Sustaining family and social networks for care and support</td>
</tr>
<tr>
<td>2. Multiple roles of being a family carer</td>
</tr>
<tr>
<td>3. Enablers to informal care</td>
</tr>
<tr>
<td>4. Burden, resilience and barriers to informal care</td>
</tr>
</tbody>
</table>
In the following sections each of the themes is described, with exemplar quotations provided for each of the themes.

**Theme 1: Sustaining Family and Social Networks for Care and Support**

This theme explores the broader societal structures within which the processes of support occurred, that is, the support system of older people and what sustained the support system in the Gomoa West District. It appeared that normal (traditional) care and support for older people in the local district was garnered from specific groups in the locality who had some form of relationship with the older people. Some common values and principles were revealed to act as a bond, and sustained the relationship existing between group members and older people for care and support. These basic values and principles are elaborated by participants from each of the groups.

There were four main groups which formed the traditional care system: the immediate family, extended family, neighbourhood acquaintances and religious or philanthropic groups. The type of relationship determined the level or amount of care and support sourced. From the data, traditional care and support to older people consisted of different activities, such as providing money, assisting home activities, and assuring a safe, healthy and happy environment.

The first and most common social group supporting care was the immediate family, with an emphasis of provision of care from the nuclear family. The immediate family variably comprised adult children, spouses, in-laws, as well as sisters and brothers. This group was the most common support group because of the common compound house cohabitation practice existing in this specific community. Also, because of the cohabitation practice, grandchildren
were considered as part of older people’s immediate family. All forms of care (providing
money, home activities, and safe environment) were presented in immediate family care.

The immediate family relationship, for example parent-child or husband-wife relationship,
etc. was sustained by the notion of responsibility. Adult children were duty bound to provide
care. As already explained about dependency in the previous chapter, from family carers
responses, the immediate family responsibility to provide care and support was accompanied
with the duty to reciprocate care with love and respect to the older person. It appeared that the
duty to reciprocate care with love and respect alluded to an intergenerational purpose that
structured traditional care as the mainstay of long-term care for the local people. Most adult
children revealed that they chose to honour the social role expectation to provide care and
support for their chronically ill ageing parents. It was explained that since their parents took
care of them when they were born, it was now their responsibility to take care of them in
older age. Kwame Oboh said,

Oh, your mother who has given birth to you and she has gotten to a stage that she
can't do some things, you have to help her do those things. You can't leave all on
her, because it's something that people used to ask that if you go and meet your mum
and your wife in a river drowning, which one will you rescue first, is it your mum or
your wife? Ha. So, your mum, if you go and meet her even if she's insane, that's your
only mum so you have to help her.

It was within the capacity of intergenerational purpose and social role expectation that the
notion of shared responsibility emerged from the data. As already indicated in the previous
chapter, the more adult children, the bigger the perceived support available for the older
person. For instance, Ebo explained that any time his mother was sick, his brothers
contributed money to provide medical care for their mother: “Some of my brothers do help in
the care of my mother”. Also, in relation to shared responsibility, the compound house cohabitation system ensured greater capacity and flexibility to care. For instance, Agyeiwaa lived together with her own children, her mother and her grandmother in the same house. She explained that her mother was responsible for taking care of her grandmother, but since they all lived together, she took over the care when her mother was out of town. She said,

> Usually, my mother does all these things, because I also have my own children to care for in the mornings, but if my mother is not around. I complete her chores for her. You see, today she is not around, so I will do everything for her.

As identified in the previous chapter on gender role expectations, physical care in immediate family care was gendered work. Care and support in house chores, specifically were supposed to be provided by females, and most of the immediate family members who spent more time with the older people and supported them with their home activities were more likely to be adult daughters, granddaughters, sisters or daughters-in-law of the older person. Again, as already discussed about dependency in the previous chapter, despite the underlining value in social role expectation, the success of shared responsibility was dependent on availability and willingness of an immediate family member. Kumwaa, for instance, had a peculiar unfavourable gender role expectation experience. She explained her brothers were unwilling to participate in the shared responsibility to care for their mother, who was suffering from paralysis associated with stroke. Since she was the only female among the siblings, her brothers insisted that it was her gender responsibility to care for their mother. “They don’t help me. They say I’m the woman so I should do everything”, she said.

There were other indications that some sons or other male immediate family members were not necessarily willing to contribute to the physical care of the older person. They reported work-related or migration reasons for their unavailability for shared responsibility in physical
care. To compensate for their unavailability, some male family members contributed more money, and others delegated their part of the physical responsibility to their wives (daughters-in-law to the older person), as in the case of Ama. Her husband brought her from her village to live with his mother while he worked. She said, “When my husband married me, there was no one staying with her [mother-in-law] so he asked me to pack my things to come and stay with her, so I can help her”.

Also, in the case where family members migrated, the novel electronic means of sending money, such as the mobile money transfer (which was not common in the past) helped siblings and other family members who could not be physically present but are willing to contribute money to the care of the older person to do so. In that way these immediate families were appropriately disposed to honour their social role expectation and shared responsibility to care, as Ebo explained, “I have an elderly brother; he is out of town now. When I call, he sends something through the mobile money transfer”.

From the responses, where there seemed to be an agreement on the specific contributions each immediate family should make and there was a good effort to honour this agreement, usually, providing home support for the older person was easier for that family. Some family carers supposed that their immediate family prioritised their contribution: “Oh, they do their best. Some cook for her, others bring money … They [family] sometimes take her to the hospital when I am not around. They pay for the medical bills too”.

Where there was no specific agreement, and a willingness among immediate family or other members was not available to contribute to the care of the older person, one person bore all the responsibilities, as in Kumwaa’s case (narrated in previous paragraph) whose brothers expressed an unwillingness to contribute. “They [my brothers] don't bring anything, I do everything by myself”, she explained. Kumwaa’s case seemed not to be an isolated one,
because health care professionals observed that where one person single-handedly acquires all these responsibilities it became a burden on that person. Health care professionals explained that it was very frustrating for the family carer when they were the only person who shouldered all the responsibilities. In some instance, when the family carer could not bear the burden anymore, there was the likelihood that they left the needs of the older person unattended (explained as experiences of neglect of needs in previous chapter). SLCH said,

They [family] do desert them because they [older people] become … I think the care become a sort of burden for them at home. Maybe they [family] can’t … you know you have to feed them; you have to turn them in beds, so they [older people] don’t develop sores, you have cleaned their diapers, yeah … Sometimes it is quite frustrating when the rest of the family washes their hands of the patient and the whole burden falls on just one person. Sometimes they come and desert them when there is nobody around to help.

A detailed discussion on burden of care is presented in a later theme of this chapter. From these examples, the structure of intergenerational long-term care is enabled by cohabitation, which increased capacity and flexibility, as well as honouring social role expectations in shared responsibility, contribution and gender roles. Regardless, the immediate family care system may not necessarily signify a consistent source of support for a rural Ghanaian older person because of the underlying dependency on availability and willingness of individual immediate family as well as the exposure to family carer vulnerability in isolation. In the next examples a description of the structure of extended family care is provided.

The second social support group was the extended family, including distant relatives, such as cousins, aunties and uncles, and children and grandchildren of their distant relatives who were related by blood to the older person. Support from this social group did not exist
exclusive of the support from the immediate family; they occurred alongside each other.

Extended family support was mostly related to physical and socio-emotional care. As already identified in the immediate family care, emphasis of support expectations was placed on the nuclear family because of the perception of eroding extended family support. Socio-cultural and economic factors were cited as the reasons for the eroding of extended family care, including poverty and migration. The most common perception shared by participants in this research was a growing indifference to suffering in old age among extended family members. It was explained that the existing extended family support did not take into consideration the suffering of the living when it is needed most. Agyeiwaa said,

> For now, it's just the nuclear family—the person's children and grandchildren. Just like it happens abroad. Your children and your grandchildren are those who take care of you when you're old. In the past, family members choose a young person to go and live with older people. Some would cook and send it to the older person to eat. These systems are no more. If your family members will help them it's when you're dead and being laid to rest. When you are alive and in hardship they will never help.

That notwithstanding, the values which sustained the immediate family support also sustained the extended family support. It appeared that based on the factors for the eroding of the extended family as a system of care, the values underlying the extended family care were not as binding on the extended family members as they were on the immediate family. In the instance where the older person’s children were not available, as in migration or death, the older person informally adopted one available and willing extended family member who then became the primary person to provide home support in time of need.
These were extended families who willingly kept in touch with the older person and family carers out of love. Some also offered some form of advice on how to manage older people’s chronic illness. Some offered to pay for medication bills, provided money for food or just engaged in visitation as a way of showing love when the older person was sick. Again, through electronic means, extended family away kept in touch with the older person, as explained by Kwame Oboh, who believed that in addition to physical support, periodic communication and interaction were also very important:

My cousins are in Accra [capital city]. Some of them help, others are not supporting at all. Those who want to help, even though they don’t come here until something happens, like funerals, they often call. The communication is there.

The aforementioned discussion on existing extended family support also indicates another reason for an inconsistent structure of support for rural Ghanaian older people. The next support system to be discussed is neighbourhood acquaintances.

Neighbourhood acquaintances supported older people with money and household chores. It appeared that neighbourhood care and support was based on the concept of generosity. Also, the local community valued interaction and engagement, and older people would ask for money from their neighbours based on such interaction. Some older people revealed that they intentionally made themselves visible in their neighbourhood to stimulate more interaction, engagement, respect and love, which they capitalised on to seek support, although they recognised that support from neighbours was also inconsistent. Obaa Grace revealed that she sat at a particular position in her house so a lot of people could see her when passing, then she capitalised on that and asked for financial help for her nutrition needs: “I sit here, and when someone sees me, I can ask him to give me GHS1 [1 Ghana Cedis] for food. If I am lucky the person can give me GHS5 or GHS10”.

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Some neighbours of older people helped with household chores, such as head portering of water for daily use at home, running errands, and cooking meals. Kwame Oboh indicated that home support from neighbours was quite common. “So those little helps, occasionally, they happen. So, they [neighbours] offer that help because they know her [my mother]”, he explained. Family carers revealed that they may also receive money and social support from their friends in their community. For instance, Gyasiwaa, who travelled often for work, revealed that she asked her neighbours to lend her mother some money for her upkeep and she repaid this when she returned from her trip. She said, “If maybe I am not around and she [my mother] needs something [money], I just call one of my friends to give it to her, I’ll give it back when I return”. She added that when she was away, she communicated to her mother through her neighbours’ mobile phone: “When I am away, and she wants to speak with me, she asks one of my friends to call me on her mobile phone”.

Neighbourhood support occurred through sporadic interaction and engagement. The fourth and final social group which made up the care and support system of older people were members of the church community that the older person was a member of or other philanthropic groups. Although most of the older people and family carers revealed that they were part of a church community, they professed that not enough support was sourced from the church as expected. For those who received some support, it was revealed that church members were a source of encouragement or consolation for both the older person and the family carer, especially during difficult times, like funerals. It was also revealed that the church occasionally provided spiritual care, money or food items to older people at home, like Ebo explained, “When they come, they bring something small. Maybe some money, they bring GHS50, and they motivate or console you when you are sick or experiencing any difficulty”.
It appeared that participants who were not appreciative of the amount of support from the church expected more financial support. Ama was disappointed that members of her mother-in-law’s church did not bring her money to take care of herself even though the accident leading to her chronic illness happened in the church premise. “When the building collapsed on her, they didn’t come and help in any way. They only came to check up on her. They ask, ‘Aunty, how are you?’ and she respond, ‘by God’s grace’”, she explained. Gyasiwaa also disclosed that most churches used to have a well organised welfare system for its members, but this system was no more: “[Name of church removed] church members, my grandmother told me that the church used to give older people gifts but now they’ve stopped”.

In addition to the church community, there were some individual philanthropists or non-identified or non-organised social groups in the community who occasionally provided some form of support for older people. It was revealed that some social organisations occasionally came for conversations with older people in the community or brought them food stuff. Kumwaa said,

Recently, some people brought some maize. I wasn’t around when they came. I think the group is called Compassion … There is a man from this community, he is a customs officer and a philanthropist, he usually comes to help older people, financially and talk to them. To encourage them.

All four social groups presented an inconsistent structure of support for older people, based on variable personal, socio-cultural and economic reasons. An inconsistent structure of care and support highlights the emerging care-requirement gaps underlying ageing experiences in Ghanaian communities. Further, a dependence on an inconsistent system of long-term care may be problematic for chronic illness management. In the next chapter, I discuss what this may mean in terms of policy for transformative change. In the next theme, a presentation on
the processes adopted for the everyday care activities for chronic life-limiting illness is presented.

**Theme 2: Multiple Roles of Being a Family Carer**

The multiple roles of being a family carer theme describes the day-to-day processes that family carers adopted through the roles they played to provide informal care specific for older people living with chronic life-limiting illness in rural Ghana. In the previous theme, the systems of care and support available to older people were examined. Also, as demonstrated in the previous theme, one of the underlying values of the immediate family as a system of long-term support was the notion of shared responsibility, but often one person became the primary person to provide day-to-day care. As part of the sampling inclusion criteria for this research, all family carer participants were the primary people who were responsible for meeting the day-to-day care requirements of older people who participated in this research. The multiple roles of being a family carer theme highlights the extent to which these care requirements were met through the performance of specific roles.

The overarching role as a family carer was as a care manager, responsible for making decisions and managing the processes of care over time. As care managers, family carers undertook practical tasks or personal care and provided social and emotional support for chronic life-limiting illness. The practical tasks or personal care activities involved, but were not limited to, the care requirements in disabilities and limitations in ADLs and IADLs, as introduced in Chapter 5.

By helping with the completion of ADLs, family carers were perceived to be performing the role of a nurse in the home environment. ADLs requiring carer support coincided with older
people’s disabilities and limitations in walking, transferring, toileting and bathing, and these were discussed as losing independence in the previous chapter. Depending on the severity of disability and health needs of older people, family carers performed activities in support for these ADLs, mostly without assistive devises. For example, and as already observed in the previous chapter on losing independence, two older people with severe disability and limitations in walking and transferring received support from their family carers. Family carers, like Kumwaa described the process of mobilising as difficult based on their care recipients’ disabilities and the lack of assistive devises. She said,

I just have to help her get to the room. She is very heavy, you know, but she supports with her walking stick sometimes. There is no one here with me so I always find myself doing everything all by myself … So, when I sit her down in the chair in the morning, she will be here until I take her inside the room to sleep.

Kumwaa added that her mother cannot take baths by herself, so she literally carries her to the bathroom, showers her and brings her back to the room to dress her up.

From these examples, the perception of role of a nurse demonstrated in family carers’ ADLs participation was difficult because of a lack of assistive tools for maximum care. In terms of IADLs, there were two major activities family carers performed in their care manager roles. The first was related to managing the chronic illness and the second was managing the home. In relation to managing the chronic illness and especially during a crisis, family carers described their role as a nurse. They adopted a locally developed medical process to manage the illness in the home setting, some family carers described their medical care process as “treating”, simulating the role of professional nurses in medical centres. Kumwaa described her treatment process as involving, and it was aimed to improving her mother’s health. “It's
treatment. I'm treating her. I'm trying my best to get her treatment, so she gets better”, she explained.

Depending on the obvious symptoms, the first therapy was any medication available. It could be a previous medication from the hospital, drugstore or herbal concoction. If the symptoms didn’t improve, family carers went to the drug store to buy more medication for the older person. When things were worse, family carers took the older person to the hospital to see a doctor. Gyasiwaa explained the process of managing her mother’s pain through the night and how they ended up in the hospital in the morning. She said,

At dawn, maybe it [pain] starts from her knees so if there's any pill, I give her some. When I ask in the morning and she tells me she's well, then I give her another dose, if I find out there's no improvement, I let her go and see her Doctor.

In addition to playing the role of a nurse, there were other roles in relation to managing a chronic illness in the home environment. First, most family carers accompanied older people to see the doctor when it was necessary, especially during a crisis. Mintaa explained how she stayed the night with her mother in the hospital when her mother was sick. She said, “One evening she told me she couldn't breathe so we went to the hospital. She was admitted for treatment overnight”. It was explained that family carers accompanied older people on their regular doctors’ appointments, sometimes in the doctors’ office, as Gifty explained, “I even have to take him to the hospital tomorrow because these BP [blood pressure] patients have specific days they go for treatment”.

Sometimes, family carers’ nursing role included the role of coach, coaxing the older person who was reluctant to attend their reviews. For example, Kwame Oboh confirmed that his mother was not happy with the long waits at the hospital any time she goes, and she always hid under the impression that her health was doing well: “After she finished with her drugs, I
expected her to go for another medication, but she thinks her BP [blood pressure] is normal now, so when I tell her to go, she doesn’t want to go again”.

In addition, family carers included the role of teacher to their nursing role. They established local medication routines to assist the older person. The activities included reminding older people to take their medication, teaching them how to take medications and also providing the medication at the appropriate times. Mintaa said,

> When she [my mother] brings them [the medicine], maybe what they have written it she might not know how to go about it so she will call me to explain to her … She makes me look at how she will take them, and I teach her how to take them. She can serve herself. I just have to tell her how she should take them, so that when I am not around, she can take them by herself.

In addition to prescribed medication, home remedies were included, such as localised therapy, regular massages and some form of exercises to aid the rapid improvement of health during a health crisis. For instance, in terms of giving massage, family carers revealed they played the role of a masseuse as part of treating older people’s pain. They used local ointments in the massage, as explained by Kwame Oboh:

> I stay with her in the same house, so most at times when she complains that she’s feeling body pains or back pains and she has some ointment and she needs a massage, I am the one who uses the ointment to massage her.

Family carers also played the role of a therapist during the treatment process. It was perceived that local resources, such as water from the Atlantic Ocean, had pain healing properties. Therefore, some family carers encouraged older people to have regular baths in the ocean for treating pain. Also, it was believed that walking barefoot increased blood
circulation, with family carers encouraging their older relative to frequently walk barefoot. Donkor seemed very sure of the healing properties of the ocean and his therapeutic ideas. He said,

I’ve even told her [Auntie Esi] that it’s not every day that she will need to wear slippers, she can walk barefooted around, it massages her somehow … I’ve told my sister to wash her face with sea water. I use some to wash my face. Sometimes I even swim in it to my satisfaction. The sea water is medicinal. If you bath in it, you feel good and when you use the sea sand to bath well, you’ll not feel body pains when you come home.

In relation to therapy, some family carers also encouraged older people to undertake routine physical exercises, such as short distance walking, to improve their health. Ewurabena made sure she monitored her mother’s walking and blood pressure during her daily exercises. She said, “She takes a walk with the walking stick and walks around for about 20 times. She goes up and down on the veranda, yeah, then she goes to take her bath. After, I check her blood pressure”.

These examples represent the idea of care requirements in treating chronic life-limiting illness in the home setting. Related roles in performing care required IADLs exposed the support strategies that need to be implemented to transformatively enhance the localised processes of treating chronic life-limiting illness in rural communities. In the next example, the care manager role performed at home is explained.

In relation to managing the home, it was revealed that family carers managed the home duties of older people, and they did that to the best of their ability, with limited resources. In doing home activities, family carers performed the duty of a cleaner when they helped with cleaning the house or the room of the older person. Other home activities included head
portering of water for bathing, washing and drinking at home, doing the laundry and running other errands. In some cases, and as already described on cohabitation practice in the previous theme, the involvement of other families, such as family carers’ own children or other people in the house, increased the capacity and flexibility in the engaging home care requirements. Maame Kakra said,

> By the time she wakes up from bed, I'm done sweeping the compound…When I'm washing and she has dirty clothes, I wash them for her too. So, I do all this, after she's bathed, I lay her bed for her then she goes and sleep. I just have to help her get to the room. Then my job is done for the day … My children, her grandchildren, they really help her.

In addition, family carers performed the role of a cook when they cooked older people’s food. It appeared that following the required nutritional pattern was important for managing chronic life-limiting illness. For example, it was revealed that there were specific foods family carers cooked for the older person to meet their perceived nutrition needs. Family carers were responsible for going to the market for grocery shopping. They bought the right ingredients they needed to prepare older people’s food. Mintaa indicated that because of her mother’s diabetes, she made sure she followed all the dietary instructions given to them by the doctor. She said,

> She's diabetic so there are certain foods she doesn't take. So, I have to cook for her. Like plantain, she has been told at the hospital that if she will eat fufu, it must be plantain alone without cassava, so with that I'll have to prepare for her, maybe don't eat too much pepper, too much salt. All these, I take note of them and ensure she does just that.
Family carers also played the role of a companion who provided social and emotional support for the older person. Specific activities such as keeping them company, talking to them, visiting them regularly and creating humour made older people happy and provided emotional stability for the older person. This role was particularly important for Gifty, who explained she did that to reduce distress. She said,

I have to create humour for him to laugh because if I don’t, he’ll worry and think more, you see? You have to be with them [older people] always and chat with them so that they cannot think much.

The care manager role in home activities also signifies the extent of care requirement for chronic life-limiting illness management in rural communities. Furthermore, and with a greater importance, the role family carers played to support older people included that of breadwinner. As already demonstrated in Chapter 5, loss of financial independence due to limitations in economic activities reduced older people’s ability to meet their daily health and nutrition needs. This challenge increased reliance on the family for support. One of the ways family carers helped older people financially was supporting them in their petty trade, as a way of maintaining older people’s cash flow to support daily needs. For instance, Agyeiwaa sold firewood with her grandmother so they can raise money for their upkeep. She said,

Oh, in the farm, we cut firewood, but she can’t cut them, so she tells me to cut some for her. Sometimes I get one heap. By the time I finish cutting mine and hers isn’t up to a one heap, I help her to cut more firewood to get the required heap. I carry mine home and help carry her too because she can’t carry it. So, when we come, and I sell it, we use the money to take care of ourselves.

Another way family carers contributed was to provide cash for basic needs. Managing chronic life-limiting illness was a challenging and expensive activity, mainly because of the
associated progressive health demands and the different roles family carers were required to execute. When financial contribution from family members was not adequate, family carers had to add their own money to manage chronic illness, adding to the physical challenge of providing informal care. The physical and financial challenges of providing care will be explored further later in this chapter.

The examples presented in this theme help to identify the processes in the care requirements for chronic illness management. The underlying perspectives on care processes were difficult and complex. Currently, there is no national policy or strategies supporting the roles families play in chronic illness management. As demonstrated in the previous theme, reliance on an inconsistent long-term system of support may be problematic for the processes of informal care for chronic life-limiting illness. I explore how transformative action in the structure of support can promote consistency in informal care to accommodate the emerging care requirements of older people living with chronic life-limiting illness in the next chapter. In the next theme, the social conditions that served as enablers to informal care are explored.

**Theme 3: Enablers to Informal Care**

In this theme, the factors that served as enablers to informal care for older people living with chronic life-limiting illness are presented. Four major enablers were identified: information and education, planning ahead, delegation and carer benefits.

Information and education were particularly evident in the account of family carers who used medical care regularly. It was revealed that information and education from the doctors helped family carers to manage older people’s chronic illness in the home environment. Family conferencing and encouragement from health care professionals made information
and education more effective for informal care. Health care professionals (KBTH) explained that making information and education available through family conferencing addressed the needs of family carers, improved their understanding on the needs of their care recipients and encouraged availability, willingness and contribution among family. For example,

Sometimes, they [family] are understanding this [chronic illness] for the first time. That is one of the things we do for them, family conferences, where we get everybody caught up and explain to them what we do and how we are going to manage the illness.

Education and information provided by health care professionals included the need to accompany older people to doctors’ appointment, how to use nasogastric (NG) tubes, provide appropriate food, hygiene, give insulin, and regularly turn older people in bed to prevent pressure sores. In acknowledging the challenges of informal care for older people (as discussed in sustaining family and social networks for care and support), some health care professionals from SLCH noted that information and education made a big difference for family carers:

We try to encourage them because taking care of the aged is not easy. Then we educate them especially those who bring them here and when we discharge them, we tell them they should keep eyes on them, they should feed them, they should take care of their hygiene needs, so that at least even if they will die, they will live a bit longer before they die. So, we try to educate them and educate them also on the medication that we give to them.

Availability of information and education led to some family carers learning the importance of maintaining the right nutritional regime for older people living with chronic illness. When family carers accompanied older people to doctors’ appointments, they asked the doctor
nutritional questions to assist them to manage the chronic life-limiting illness at home. For example, Mintaa said that since the doctor educated her about the cause of her mother’s diabetes, she knew exactly what meals to prepare at home:

So, when we went to the hospital, I ask what is wrong and they said it is diabetes and her blood sugar is high and then I ask what caused that and they tell me maybe she took some food … so, when the doctor explained to me like that, I also learn how to prepare her meals.

In addition, it was also revealed that information from other medical contacts on medication and use enabled family carers to manage the medication needs for older people with efficiency. Ewurabena was happy that she could check on Google for information and that she had doctor and pharmacist friends she could count on for medication advise. She said,

Thanks to Google, I can Google and search. Yes. And I know few doctors so maybe I'll take one or two of the opinions, call a few pharmacists and tell them, hey this is what they [doctors] said to me, what do you think?

A second enabler to informal care was carer planning and coordination of activities. When family carers put a lot of effort into planning and coordinating the activities, the actual caring became efficient. Planning ahead was an important factor because family carers had other personal responsibilities, such as work or school; they often put in efforts to plan and coordinate their caring activities so that they could be able to meet their multiple responsibilities. Cooking in bulk was one of the locally utilised planning and coordinating skills family carers engaged in to successfully and timely meet the nutritional requirements of older people, without compromising on their own work duties. For instance, Gyasiwaa worked at the fishing harbour every day of the week. She indicated that she cooked in bulk to save time and to ensure that nutritious food was readily available for the period when she was
away. She said, “I go to the market to buy all the things I need and cook. Mostly I cook in bulk and keep in the room. Anytime she is hungry, she can serve herself”.

The third enabler to informal care was the ability of the family carers to delegate some of their roles to other members of their family or even other members of the community. Delegation was enabled by the cohabitation system, noted earlier in sustaining family and social networks for care and support and multiple roles of being a family carer. Appropriate delegation improved the capacity and flexibility in caring roles and ensured the wellbeing of family carers, so that family carers were not overburdened, or their personal responsibilities did not become a barrier to providing informal care for older people. Mintaa for instance supervised the younger children at home to perform some of the activities: “My brothers’ kids are here, and my younger sister is also here, so I make sure they do anything my mother asks them to do. For the important ones, I always try my best to do for her”.

Delegation was also possible, because, again as described earlier, traditional care and support for older people in the rural community is sustained by generosity and willingness of social networks. Mintaa added that she involved her neighbours in the care of her mother to make it easier for her to go to work while the other children in the house were in school. Before she went to work every day, she told people around the house to check on her mother and to inform her on her mobile phone, if the need arose. She said, “She [my mother] has a phone, but she always says she cannot dial my number. I’ve told some carpenters near our house to call me in case she needs something”.

The fourth enabler was a perception of benefits derived from caring. Perceived socio-emotional and physical benefits in caring, despite the challenges encouraged family carers in their day to day caring activities, was frequently reported. In terms of the psycho-emotional benefits, some family carers explained that they were able make a difference in the older
person’s life or when they were able to meet older people’s need, they felt good about themselves and it brought them peace. As Mintaa said, caring for her mother incurred blessings on her and blessings made her feel good:

Sometimes she'll call in the night that she's feeling pains. When I rush her to the hospital and she later gets well, she blesses me, I feel good … In the morning, when I see she she's feeling better and smiling, at least I have some inner peace.

Sometimes I wonder what would have happened if I were not in the house. The worst perhaps.

Likewise, verbally expressing appreciation for caring by older people was also deemed as a psycho-emotional enabler to informal care. Maame Kakra explained that she was happy to share the little she had because her mother appreciated the effort by verbally expressing it. She said,

I become happy when she appreciates the little contribution I make in her present life. For instance, when she calls me that she doesn’t have money and I come to give her with something, she says thank you.

In addition, family carers benefited from the social relationship which was built between family carers and older people over time. Some family carers revealed that they enjoyed having adult conversations with the older person, as in this response from Donkor, who was a widower and lived alone in his house. He said in caring for his sister, “I feel very happy when I come here. I would not come all the way from my house. When I meet her, and we have a chat, it makes me happy”.

The benefit of value in reciprocity was also revealed to enable informal care. Some family carers indicated that the older person shared their food or money with them or gave them
some money to invest in their business. In this case, the older person served as a source of support for the family carer too. Maame Kukua said, “She also helps me when I need something. Sometimes, when I’m going to purchase my goods and I tell her I don’t have money, she gives [it to] me if she has [it].”

Some family carers indicated that they received gifts, such as money and clothing from other family members, as a way of showing appreciation for their daily efforts:

Her children give me money when they come here to buy things for her grandchildren. Like her daughter, when she comes, she gives me rice and soap and sometimes clothes for my children. One of her children has even promised me that I should take care of her Mum so when she comes, we’ll know what do… One of our family members visited from abroad. She gave me GHS100. I was very grateful. I appreciated it a lot.

From these examples, it appeared that those family carers who did not have access to these resources or benefits may not only be burdened with the enormity of challenges associated with informal care, they may also experience isolation in the caring processes. I discuss how Ghana’s health and social policies can ensure inclusion by increasing access to these resources in rural communities in the next chapter.

**Theme 4: Burden, Resilience and Barriers to Informal Care**

Regardless of identified enablers discussed earlier, there were some indications that providing informal care was a burden. The burden of care influenced family carers’ health and wellbeing and posed recognisable threats in sustaining informal care in the future, due to the exposure to physical, financial and emotional vulnerability. The vulnerability in burden of
care did not necessarily discontinue informal care, as the data indicated. Some family carers were resilient, and others became creative in their care activities. However, in some cases, the burden of care became a barrier to providing informal care.

In terms of physical vulnerability, family carers expressed an exposure to poor health and wellbeing because of the multiple roles in sustaining informal care. In addition to informal care being involving, difficult and complex (as described in multiple roles of being a family carer), it was revealed that the processes in informal care were exhaustive and time consuming. Family carers explained that the processes of caring for a sick older person was twice as exhaustive as the processes of caring for just an older person because the former were involving and difficult. They explained these processes required prolonged engagement and attention with no extra time for personal relaxation or adequate sleep. Maame Kukau said,

For the one who is not sick, he would not require you to be with him every time, because he can do things for himself, then you the family carer can also have time to do whatever you want to do. For the one who's sick, you have to be closer to her anytime all the time … It [caring] makes me tired because I don't get enough sleep. I couldn’t rest even in the afternoon because I have to prepare for lunch and dinner.

So, I'm never free. Every time, I am busy.

Prolonged engagement and inadequate sleep increased anxiety and anxiety worsened family carers’ chronic conditions. For example, Gyasiwaa had heart disease. She revealed that anytime her mother had a health crisis, her heart palpitations increased, and increased the need to access health care. She said,
Sometimes my heart beats faster (heart palpitations), especially when my mother is sick. I discussed with a friend and she suggested that I should go and see a doctor. I have to go so I know exactly what is wrong with my heart.

Those who had personal responsibilities in other areas, for example caring for children, expressed that caring for the older person was an additional physical burden. Ama indicated that juggling the care of her mother-in-law with her own children’s caring was difficult and time consuming. She said,

\[\text{It can be time consuming and exhaustive … When both my mother-in-law and my child is sick at the same time, I make arrangements to care for them in turns. My attention is split between the two of them.}\]

The abovementioned examples represent different conditions that the burden of care increased physical vulnerability in informal care. The socio-economic burden of care, which increases financial vulnerability in informal care, is explained in the next examples.

As already discussed in the previous theme on family carers’ economic roles in informal care, although all family carers who took part in this research specified their trade or occupation (refer to Table 6.1), most of them stated they were financially vulnerable because they were not actively employed, or they did not have a regular job, at the time of data collection. It was acknowledged that informal care for chronic life-limiting illness was expensive, due to the changing needs of older people and the different activities family carers were required to engage in, to sustain their needs. Inactive employment caused insufficient income and insufficient income affected the ability of family carers to prioritise their informal care activities appropriately.
Family carers who were engaged in some form of petty trading revealed informal care disrupted their trading activities, either in full or partly and disruptions meant financial vulnerability. Family carers who were presently unemployed expressed that it was the caring which brought full curtailment to their work. For example, some had migrated and worked as full-time traders in other regional capitals in Ghana. They abandoned their trading activities and returned to the village to care, risking their personal business income, as explained by Kumwaa:

I used to go [travel to work] and come but now because of the sickness I don’t go anywhere … I operate a business in the city, but anytime I come here, I have to stop. Usually when I think I have been able to revive it; I get called back to the village to help out with my mum. By the time I go back, everything has collapsed.

Family carers explained that the most substantial financial risk of taking care of a chronically ill older person was constant visits to the doctor, suggesting that they had to miss their jobs for some days to take the older person to the doctor and to care for them, which reduced their income. Mintaa was a teacher, and she explained that she missed class anytime she accompanied her mum to see the doctor. “The hospital appointment coincides with my shift at school, so I cannot go to school if she has to go to the hospital. I go with her, so she doesn’t miss her appointment”, she explained.

Most family carers revealed they had to risk reducing their work hours to spend more time with the older person during crisis. The frequency of reducing their work hours increased financial vulnerability, as expressed by Kwame Oboh, who said,

I travel frequently to work in other places, but I have reduced my working days to spend more time with my mother these days. Now we are facing financial challenges … I used to go to work at 7:30 but because of her I'd go at 10am. The day I waste
time in the house I miss some customers and the money that I'll get … I’m the only one who stays with her throughout the day. Sometimes when I go to the beach [to work], I have to be back very early in the afternoon to stay with her. Sometimes I lose money because of that.

Family carers’ work disruptions that increase financial vulnerability may suggest that sustained informal care could not be established. Health care professionals (SLCH) explained that the family’s financial vulnerability could underlie older people’s experiences of neglect (described in dependency relationships are perceived as vulnerable in Chapter 5): “I think it’s [the neglect is because of] finance, so, sometimes they [family] do desert them [older people] because they [older people] become … I think they become a sort of burden for them [family] at home”.

As shown in the data, in most cases the value of shared responsibility or using family conferencing and encouragement as tools (as discussed in earlier themes) did not necessarily encourage a consistent system of financial contribution from families; there was evidence of an inconsistent financial contribution from siblings or other family members from family carers responses. Family carers were then totally responsible for informal care with little or no support. In addition to the financial burden of personal responsibilities, an inconsistent system of financial contribution or other external financial support was a potential threat to the consistency of informal care, increasing family carers’ exposure to vulnerability in isolation. Maame Kukua lamented, “I buy her water for bathing and drinking and water to wash her things, all other things are on me. No one helps me. I have my own children to cater for too”.

In addition to family carers’ exposure to physical and financial vulnerability, it was revealed that informal care was emotionally intense since family carers became responsible for the
emotional wellbeing of older people, with limited external emotional support. In view of the physical and financial vulnerabilities and the emotional instability of older people, it was indicated that the emotional wellbeing of family carers was affected, and poor emotional wellbeing affected their caring activities. Family carers explained that it was particularly difficult because older people experienced emotional fluctuations, in relation to their experiences of living with chronic life-limiting illness in ageing. Ewurabena explained she experienced her mother’s emotional instability in the form of excessive complaints about biological changes in her body. She said,

Yesterday she called me and said she just realised now she hasn't got any more tears with her eyes. And they're days she'll say that oh I'm wee-weening [urinating] too much and sometimes within two or three hours she'll call that it looked like the whole day she hadn’t urinated, you know. So, I do get that kind of stuff every time, but ….

Kumwaa described her mother’s needs were not simple to manage. She was overwhelmed by the amount of physical and emotional resources she had to use especially without extra support. She was worried her efforts may not be enough to care for her mother. She said, “The sickness is big. It's not a simple illness and no one comes to support, only me. There's no good work there for me to do so sometimes I think [I am worried]”. When the emotions were managed inadequately, it sometimes put a strain in the carer-recipient relationships, and strained relationships limited family carers’ involvement in informal care. Agyeiwaa thought that the more her grandmother’s illness increased, the more it became difficult to cohabit with her, because she got angry quickly and she exchanged words with her:

When the sickness comes, it is very difficult to live with them, if you put this thing here, she won’t understand, even if you are doing it the right way, you know … She
will go and misquote me somewhere and bring me troubles all the time. So, old women can worry me … I make sure to shut her up.

From the responses, it appeared that family carer’s physical, financial or emotional burden of care that increased vulnerabilities did not necessarily curtail informal care. Some family carers were resilient, and others were creative in resilience, suggesting that the enablers to informal care presented above also included resilience and creativity.

From the responses, family carers’ poor health and wellbeing did not curtail informal care. Despite that some family carers were living with debilitating health, they showed resilience in sustaining care required activities. For example, Maame Kakra complained about her failing eyesight. She lived in fear of anticipated failed eyesight, yet she continued to care. She said, “I have problems with my eyes so I can’t see someone from far. I am scared that with time I cannot read her medications”. Gifty also lived with a heart disease which made it difficult to cook for her husband sometimes; “But I try and cook”, she explained.

It appeared that experience in caring was an important factor in informal care. Some family carers revealed that they did not have previous experience in caring for an older person with a chronic life-limiting illness, as such performing the multiple roles presented challenges to them, yet inadequate caring experience did not inevitably render informal care a burden. The focus on care made them resilient. For instance, based on Ewurabena’s response, her resilience in care was sourced from a desire to honour her social role expectation and responsibility in her mother’s care. She indicated that she specifically did not want to adopt the nurse role. However, the responsibility to care for her mother made her accept the role of care manager to her mother. She said, “For me, to be honest, I’m not too good with patients so I didn’t want to be a nurse. But when it happened to me, I just assumed the post”.

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Likewise, financial burden of care was acknowledged, but it did not discontinue informal care. Family carers revealed that they spend their limited finances to care for the older person, in terms of meeting their basic needs, such as food, water, clothing, paying for their utility bills, mostly denying their own comfort. Gyasiwaa said,

I am forced to share with her the little that I have, forgoing my own comfort, sometimes. The little I share with her, I just explain to her to manage it, because I don't have much … Life is really hard for us here especially in our work. There is no work here so if you don't travel and you stay here, you don't get any money to help your Mum if she's alive.

For those who were creative in resilience, resilient creativity came at a cost. In some instances, family carers borrowed money or food from people to supplement their effort, but there was a high risk of using credit. For instance, Agyeiwaa explained that sometimes when there was no money at home, she had to buy food on credit for her grandmother and when she was not able to pay on time, the debtors disrespected them, verbally. She said,

We go and buy on credit and when we're not able to pay, they'll be insulting us. Sometimes when the woman we bought the thing on credit comes home to collect her money and we're not able to pay, she starts insulting us and when she (mother) also hears of it then she starts crying.

Based on family carers’ responses, some form of support could enhance the resilience of family carers in informal care provision. In view of the physical, financial and emotional burden of providing informal care, some family carers suggested that it would be good to have support from the government to assist them in their care duties in the form of finance, education, training and health care. As at the time of data collection, there was no report on the availability of formal support services for informal care in the rural district. Health care
professionals (KBTH) indicated that there had been an inclusion of family carers health in the primary health care for older people, but it was geographically disproportionate to rural dwellers. At the same time resources limitations in the provision of geriatric services in the country had necessitated the rationing of geriatric services to older people who are 65 years or older and their family carers:

Because the back log is so many we can’t handle. We only have one specialised clinic a week. We cannot take the back log if we reduce the age to 60 years. So, we have criteria … 65 years with evidence of chronic disease.

Some family carers revealed that they had knowledge of government financial support for other groups of people, but not older people. Agyeiwaa did not understand why government should be selective in support. She said,

I am hoping that the government will bring us some money to help us because sometimes we hear the government is helping people. I don’t know why the government is not helping older people. I also believe that these government officials should come and help her [grandmother].

Family carers revealed support services will help relieve some of the challenges which made caring a burden and carers more vulnerable. For instance, it was revealed that family carers would prefer a day care centre where they could leave older people, so they could take a break from the physical demands of care. For instance, Ewurabena said,

Ideally it will be a good idea to have some kind of caring home. If even it’s not a home, like a day care centre, where the aged can go and relax like you know once in a while it would also give the family carers a break, you know, that is if it’s possible. It'll be a very good idea like I'm saying not like living per say but. You know that
you can take your mother to the centre maybe from morning to about half day, till about 2 o’clock, so you can also have a little time for yourself.

Despite the resilience, financial and health burden of providing care sometimes served as a barrier to providing care. Family carers’ poor health did not only reduce caring activities, poor health served as potential barriers to informal care. The major cause of poor health of family carers was the influence of pain. It appeared that pain influenced family carers’ physical activities the same way it influenced older people’s physical activities; pain reduced the ability of family carers to perform their multiple roles in ADLs and IADLs. For example, Antobam said,

My waist has been paining me … I feel back pain … Recently the pain got worse, so I went to the clinic. For few days she had to manage [to walk and carry things] without my help because I couldn’t. If both of us are sick at the same time, I cannot take care of her.

Family carers’ financial limitations served as a barrier to accessing health care for chronic illness management in the local setting, expressed by both family carers and health care professionals. For instance, Ama indicated that her mother in-law was in urgent need of medical attention, but due to her financial circumstances, she could not accompany her to the hospital. She said, “People are suggesting that I take her to the hospital; however, there is no money to do that … it’s financial problem. If I had money, I would have sent her for treatment”. In acknowledging family’s financial problem as a potential barrier in accessing medical care, health care professionals (SLCH) explained, “You know when they [family] bring them [older people], sometimes because of money issues even though the person is not well, they [the family] would like to send the person home”.

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While caring was a disruption to family carers’ work life, it was revealed that in some instances, family carers’ work or other personal responsibilities became a barrier to informal care. The few family carers who were employed indicated that their personal work life was a barrier to active care, often exposing older people to loneliness and unmet needs (as discussed earlier on older people’s vulnerability in dependency in the previous chapter). In explaining the implication of their absence on the availability of care, Maame Kukua said,

Sometimes I go to other places to work … Sometimes I travel to city to purchase some goods. Sometimes too there might be a funeral … I spend a lot of time outside home. It is my greatest trouble. When I leave, there’s no one here to take care of her. She is left with nobody to assist her.

As described earlier on emotional instability and tension, family carers revealed that when there was a tension, they were reluctant to provide care. Some older people were described as perfectionists, thus they expected things to be done in a specific manner or timeframe. Refusal to do things their way resulted in altercations, that increased emotional vulnerability in caring. Kwame Oboh said,

My mother is very troublesome. When I wash her things and I don’t soak the clothes in blue solution [potassium permanganate], she’ll be talking that I didn’t wash them well, so I tell her to wash her own things [clothes] … She is a perfectionist so nothing, I mean nothing that you’ll do will make it right for her … Some days, she refuses to take her lunch. When I see there is a problem, I just pick my shirt and go out and sit somewhere for some hours to cool things off. Yes, she is quick tempered. She often gets angry and speaks to me in a disrespectful manner, but I think it is part of ageing.
These examples on how physical, financial and emotional burden can serve as potential barriers to informal care reemphasise the need for support as a transformative action to enhance resilience in informal care for chronic life-limiting illness. I discuss the implication on Ghana’s social policy in the next chapter.

Summary of Findings II

Older people’s available care and support was provided by family and other social networks, and the system of support was sustained by socio-cultural values considered important to the local people. The traditional system of care appeared to be a cooperated, shared activity, and it was structured on gender roles, responsibility, flexibility, contribution, availability and willingness of people. Yet, the underlying perception of an inconsistent family structure of support suggests a problematic system of support for chronic life-limiting illness management at the community level. There were significant differences expressed between traditional care and support, and informal care for chronic life-limiting illness management. When it comes to the day-to-day management of chronic life-limiting illness, one person usually becomes the primary family carer.

The primary family carer assumes different roles in the overarching care manager role, including nurse, teacher, therapist, masseuse and home caretaker. These roles, executed with little or no support, were experienced as being difficult and complex. However, availability of education and information, ability of the family carer to plan and coordinate caring activities, the ability to delegate caring roles to other people and the perceived personal benefit from the social relationship built with the older person over time served as enablers to informal care. Despite the enablers, family members who acted as primary carers expressed varying financial, physical and socio-emotional vulnerabilities that suggested that informal care for
older people living with chronic life-limiting illness was a burden on family carers. Burden of care included disruptions to their personal, work and family lives, the physical consequences of providing care, inexperience and lack of external economic, physical and socio-emotional support in the rural district. In effect, the management of chronic life-limiting illness was based on local knowledge and resources. When the burden of care was seemingly becoming overwhelming, family carers became resilient based on the structures which sustained and enabled care. When family carers were not able to maximise resilience, the burden of care acted as barriers to providing informal care. I discuss how burden of care contributes to marginalisation of older people and their family carers and identify the need for transformative change in Chapter 8 of this thesis.
Chapter 7

Transformative Discussion of the Findings

Introduction

In this chapter, I present a discussion of the findings from this study. The discussion focuses on the third research objective: investigating ways of strengthening social structures to enhance the quality of lives of older people living with chronic life-limiting illness in rural Ghana. The related research question was, “In what ways could social structures be strengthened to enhance the quality of life for older people with chronic life-limiting illness in rural Ghana?” Drawing on the theoretical framework of critical social theory (CST), and operationalising oppression as marginalisation as presented on the relevance of CST in Chapter 2 (p. 50), I show how the findings from Chapters 5 and 6 may constitute marginalisation of older people and their family carers. Then, based on the transformative paradigm presented in Chapter 4, I discuss how inclusivity on the basis of social justice can be achieved through national policy reorganisation or restructuring.

There are four main sections in this chapter. Section 1 focuses on the experiences of informal care for older people living with chronic life-limiting illness and their family carers. In section two, I use critical social theory to argue that these experiences constitute marginalisation. Then I show how family carers’ resilience contributes to sustaining informal care for marginalised older people living with chronic life-limiting illness. In the third section, I use the conclusions about marginalisation of older people living with chronic life-limiting illness and their carers to show how Ghana’s social policies can be transformed to include the concerns of older people and their family carers. The fourth section summarises the recommendations from this transformative analysis.
Informal Care for Older People Living with Chronic Life-Limiting Illness in Rural Ghana: Experience, Structure and Process

The findings presented in Chapter 5 suggested that older people’s subjective experiences with chronic life-limiting illness were interpretively disadvantageous. Based on the findings, the answer to the first research question, “What are the experiences of older people with chronic life-limiting illness in rural Ghana,” is that older people living with chronic life-limiting illness experienced inadequate accessibility to community-based health and social support services to manage the limitations associated with chronic life-limiting illness, and these experiences increased vulnerability to self-isolation, challenging social identity and self-worth.

Older people living with chronic life-limiting illness experienced suffering as a result of the emerging changes in the biological functioning of the body. Suffering associated with the changes in the biological functioning of the body has also been descriptively reported, for example, by Klindtworth et al. (2015), who found that older people living with chronic heart failure experienced shortness of breath, fatigue, dizziness, fear and anxiety. Klindtworth et al. (2015) further explain that due to the suffering, the participants did not ascertain their chronic illness as progressive, but as an acute life-limiting illness. Although this current study was not related to heart failure, the chronic nature of heart failure cause similar suffering to those in this study, indicating the prevalence of suffering associated with changes in the functioning of the biological system as the human body ages with chronic life-limiting illness.

Pain emerged as a common description of suffering for older people living with chronic life-limiting illness. In Ghana, available studies on pain and suffering mostly focus on people living with cancer, such as Bonsu et al. (2014), who found in their study that pain was the most listed reason for suffering associated with breast cancer among women from the Ashanti
Region of Ghana. Although the population of this study was younger, women between the ages of 32 and 65 years, the phenomenon of pain as an expression of suffering related to chronic life-limiting illness requires more research in Ghana.

Chapter 5’s findings indicate that changes in the biological functioning of the body and the presence of pain subsequently induced disability and perceptions of frailty. Disability and negative frailty perceptions influenced the decision of many older people to self-isolate from meaningful activities (i.e., activities of daily living (ADLs), instrumental activities of daily living (IADL) and pleasurable activities). Disability and perceptions of frailty associated with chronic life-limiting illness and the reaction of self-isolation may also be more widely expected in African societies. In a systematic review of people living with diabetes in African societies, social isolation was considered normal (Suglo & Evans, 2020). On the contrary, outside of Africa, in an international study of over 8,000 people living with diabetes, researchers found that while social isolation may be expected, the availability of social support built resilience and coping mechanisms necessary for social participation among older people living with diabetes in advanced countries (Stuckey et al., 2014). Hence, it is possible, that given the necessary social support, chronic life-limiting illness may not be an isolating factor for older people living with chronic life-limiting illness in African communities.

In addition, in African, and for that matter Ghanaian, rural societies, the living arrangements reflect a communal, or family, participatory and social support culture (Gyasi et al., 2018; Gyasi et al., 2020). Social support in the context of family is dependent on the strength of family relationships and how an individual family member takes advantage of this relationship (Williams (2005). As such, choosing self-isolation brings to question the nature and impact of the available social support for older people’s social participation, especially
those living with chronic life-limiting illness related disability and frailty in rural Ghanaian societies. Further research is required to understand why communal living and social support do not adequately build resilience to increase social participation in meaningful activities among this demographic group.

Disability and perceptions of frailty and associated self-isolation from meaningful activities means that older people may be living a restrictive life. This finding is consistent with that of Chiaranai et al. (2018), who found older people living with chronic illness in Thailand lived a restricted life because emerging functional disabilities prevented them from doing things they had done previously. The social isolation that accompanies self-isolation is problematic because it accelerates disability and reinforces perceptions of frailty, increasing both physical and mental vulnerabilities among older people living with chronic illness (Guerriero & Reid, 2020). Overall, self-isolation prevents healthy ageing (Gusdal et al., 2020).

In this study, disability and limitations in meaningful activities were experienced as a loss of independence to continue self-care activities. Self-care activities have been reconceptualised to differentiate basic self-care (toileting, dressing, eating, transferring and grooming) from intermediate (bathing, walking, housework, meal preparation, shopping) and complex self-management (handling money, phone use, self-medicating) (Thomas et al., 1998). In a secondary analysis of WHO survey data for Ghana, limitations in basic self-care was more common for people with hypertension and arthritis but limitations in intermediate self-care were more common in people with strokes (Amegbor et al., 2018). Given the most commonly reported disease in this sample was hypertension and stroke, limitations in basic and intermediate self-care were commonly reported. As chronic illness increases in older Ghanaians, the nature of chronic illness related support available in Ghana requires a focus on how basic and intermediate self-care needs are met.
For chronic illness, self-care is very important for maintaining health (Riegel et al., 2012). Drawing on a middle range perspective of self-care in chronic illness, self-care is the process of maintaining physical and emotional wellbeing, such as adhering to lifestyle and treatment modifications, monitoring emerging physical and emotional changes, managing physical and emotional changes to prevent further deterioration through treatment, and evaluating treatment interventions to determine their efficacy (Riegel et al., 2012). For the older people living with chronic life-limiting illness in rural Ghana, self-care appeared to be more complex than the stated illnesses suggest, including managing financial matters, using a telephone and self-medicating. Using a middle-range theory of self-care (Riegel et al., 2012) can provide a framework for service development to support this population.

Access to multi-disciplinary chronic illness related support often impacts positively on independence in chronic illness related self-care activities (Riegel et al., 2019). Limited access to chronic illness related support for self-care, as determined in the policy analysis in Chapter 2, presents a policy concern due to increasing disability associated with chronic life-limiting illness among older populations in Ghana. This means that in assessing the personal factors, that is, disability that limits independence in chronic illness related self-care activities, access to multi-disciplinary support must also be taken into consideration.

Disability, limitations in meaningful activities and limitations in access for chronic illness related support were influenced by rurality and poverty, and poor health resource distribution also contributed to limiting access to support for the experiences associated with chronic life-limiting illness. Rurality as a precursor of access to both primary and secondary health care services is quite prevalent; it has also been found to be evident in the Ashanti Region of Ghana (Ashiagbor et al., 2020). For the older people in this study, limitations in access for chronic illness related support increased dependence on family and community support (i.e.,
chronic illness related informal care), and dependency was associated with older people feeling like they were a burden or inconvenience to others as well as challenging social identity and self-worth. It appears that older people are trying to do more for themselves, possibly to reduce the feeling of being a burden and to maintain their social identity and self-worth. Some older people, with less severe disability strived to contribute to their own care arrangements but were still unable to achieve this due to the overwhelming physical limitations associated with chronic life-limiting illness related disability. Support for intermediate self-care activities, such as walking devices, meals preparation services, and shopping assistance, is critical to the care of older people living with chronic illness in rural Ghana.

The challenges to social identity and self-worth associated with dependence found in this study resonates with the findings of a critical ethnographic study conducted among older people who experienced loss of independence due to vision loss (McGrath et al. (2016). In this critical ethnographic study, older people internally struggled with the idea of whom they had become as socially dependents (McGrath et al. (2016). The study was conducted in a Canadian city, suggesting that most older people, irrespective of the setting, may construct the meaning of loss of independence in similar ways.

In this current study, older people raised concerns about loss of financial independence to meet basic health and nutritional needs. Older people in Canada may be unlikely not to mention financial dependence due to the availability of welfare support in Canada (Salma and Salami (2020), which is not available in Ghana. Medicare and other federal sponsored support exist to help older Canadians to meet their basic health, social and economic needs. The absence of such financial support may contribute to the vulnerabilities in social identity
and self-worth of older people living with chronic life-limiting illness in rural Ghanaian communities.

In this research, independence in meeting valued social role expectations were also important for maintaining self-worth and social position in the community setting. Participants who could not accomplish their social role expectations because of living with chronic life-limiting illness questioned their self-worth and position in society.

In effect, suffering, disability, frailty, lack of resilience to cope, inadequate access to both health and social support, as well as self-isolation and challenging social identity and self-worth were the disadvantaged experiences associated with living with chronic life-limiting illness vulnerability in the Gomoa West District of Ghana. These disadvantaged experiences may represent the domains within which chronic illness related informal care occurred.

Just as the findings of the integrative review indicated that the cultural obligation to informal care was dependent on the availability of people and resources in African communities (Adonteng-Kissi et al., 2020), the findings presented in Chapter 6 on experiences with informal care showed that the availability of care for older people living with chronic life-limiting illness was inconsistent. Availability of care was dependent on availability of people and resources. Based on these findings, the answer to the second research question of, “What are the structures and processes of informal care for older people living with chronic life-limiting illness in rural Ghana?” is that with chronic life-limiting illness and rapid social change, upholding historical traditional care arrangements is a way of supporting older people but serves to marginalising older people’s family carers at the structural, or policy, level.

Traditionally, care occurred within four main social structures: the immediate family, extended family, neighbourhood acquaintances and religious societies. First, the immediate
family was the most active care group, with specific emphasis on nuclear family care. This was dependent on the common compound house cohabitation practice, such as grandparents, parents and children as well as grandchildren living together on the same compound in the community. The common compound house cohabitation practice offered the structure for greater capacity and flexibility in immediate family care, with different family members available at different times of the day and night. In addition, although socio-cultural values of role expectations in shared family responsibility and contributions existed in immediate family care, it was not shared equally. Immediate family care was dependent on availability and willingness of the individual immediate family member.

Secondly, the findings on extended family care suggested that socio-cultural responsibility underpinned the extended family care. However, such a sense of responsibility was also found to be changing. As with the immediate family members, care was heavily dependent on the willingness of the individual family member. With regards to the third structure, care from older people’s neighbourhood acquaintances was unpredictable. Changes in the extended family structure, the value of respect, interaction and community living made neighbour provided care for intermediate self-care needs quite substantial, although inconsistent. The fourth structure was religious groups. This structure was the weakest support network for older people in the community.

The first two structures, the immediate family and the extended family relied heavily on availability and willingness of family members. This is a common finding in the chronic illness literature (Awuviry-Newton et al., 2020; Kusi et al., 2020). While neighbours may offer support, the inconsistency of neighbourly support suggests that by employing innovative perspectives on neighbourhood cohesion maximum support can be harnessed from older people’s neighbours, since older people are likely to spend more time with neighbours.
The limited participation of the church community in support was a surprising finding. This is contrary to the findings of the integrative review which suggested that in some African communities, the presence of a church community was an adequate support system for older people and their family carers in the community (Adonteng-Kissi et al., 2020). Further research into informal networks of support in rural Ghanaian communities may assist with better understanding how each of these structures might be better supported through policy.

For family carer participants in this study, the conditionality of informal care availability, sometimes put the responsibility on one nuclear family member. The reduction in numbers of family members to share responsibility reflects observations that weakening cultural values (Aboderin, 2004; Avendal, 2015; Yankuzo, 2014) as well as industrialisation, migration and urbanisation (Apt, 2001) were changing the extended family care structure. Neighbourhood and religious support were used to supplement immediate family care, but their inconsistency in supply further put the responsibility to provide care on the older person’s nuclear family. The informal care practices did address basic self-care but were less consistent for intermediate and complex self-care management. These limitations may account for the exposure of individuals to more physical, financial and emotional burden but also account for their share of the vulnerability of isolation through the work of informal care processes.

In the same way as discussed on loss of independence to maintaining self-care among older people, the processes of informal care were related to supporting chronic illness related disability and needs of older people, including ADLs, IADLs and socio-emotional needs. The multiple roles in chronic illness related informal care showed that the severity of illness or disability determined the level of care requirement and the potential physical, economic and psycho-emotional burden to which family carers are exposed. The overarching role
performed in informal care was that of care manager, although, family carers appeared to model their roles in chronic illness related care requirements after professional nurses. In a recent hospital-based exploratory descriptive phenomenological study conducted among family carers of older people living with advanced breast cancer in Ghana, the findings showed that the family carers also ascribed their roles in wound care, pain and medication management routines to the nursing role in the home setting (Kusi et al., 2020). Although this research is not about breast cancer, the similarities in the home-based nursing processes should not be understated, as the carer role supports complex self-management for older people living with chronic illness in Ghana.

The processes of informal care in this study were enabled by four main factors: the availability of information and education on chronic life-limiting illness, the ability of the family carer to plan ahead, the ability to delegate responsibilities to other family and community members, and carer’s perception of physical and psycho-emotional benefits. The maximisation of information and education as well as planning are determined by the level of interaction or the kind of relationship between family carers and the health care system in a long-term informal care arrangement. A poor relationship has been linked with family carers’ poor management of pain and medications in the home setting (Ullgren et al., 2018). In the Western countries where a good relationship between family carers and health care providers has been stressed, information and education as well as planning relating to advance care planning, symptoms management and palliative care, etc., enabled family carers’ management of the long-term changing heart failure needs of recipients (Swartz & Collins, 2019).

In this research, the availability of information and education as well as the ability to plan were not uniform across all family carer participants, which means not all family carers were
able to use these resources to support their caring processes. This limitation indicates that more research is needed to assess how to build good and intentional carer-provider relationships to enhance support for chronic illness related informal care, especially in the rural areas where the majority of older people live. Exploring models of care that increase access to health care professionals in rural communities in rural Ghana are required.

In this study, delegation and family carers’ perception of physical and psycho-emotional benefits extend to the perspective of social support in caregiving. It appeared that social support benefitted both older people and their family carers. While both older people and their family carers took advantage of the socio-cultural reciprocity in social support, family carers particularly took advantage of the cultural obligation to share traditional care responsibilities and the common compound house cohabitation practice to delegate their informal care activities. Socio-cultural reciprocity and physical and psycho-emotional benefits have also been cited as underlying the informal care in Ghanaian-based cancer-related informal care (Kusi et al., 2020). The influence of socio-cultural benefits suggests any chronic illness related policy support for family carers should take into considerations these socio-cultural factors.

Another critical point to consider is that the burden of care emanated from aspects of the care processes perceived to be a gendered activity. Females appeared to provide more of the physical care, and men provided more of the financial support. This finding is consistent with most of the African literature on women and caregiving in African traditional societies (Adonteng-Kissi et al., 2020; Awuviry-Newton et al., 2020; Kusi et al., 2020). Despite this financial expectation of men, in this study, some men did not honour their financial responsibilities, and the female carer became burdened with both physical and financial responsibilities in formal care for chronic life-limiting illness. As such, gendering caring
activities poses a threat to women’s economic empowerment, duly acknowledged in the African literature as the cause of gender disparity among African ageing populations (Kpessa-Whyte, 2018; Kpessa-Whyte & Tsekpo, 2020; MoESW, 2010). With an increase in the life expectancy among African populations, including Ghana, a lack of economic empowerment will continue the cycle of dependency and economic vulnerability among Ghanaian older women who forfeited paid work to provide care for their family members, contributing to a cycle of poverty.

The highest burden of care was financial, as a result of disruptions in family carers’ work life. These disruptions threatened the carer’s economic independence to meet personal responsibilities and to continue caring. Sometimes, the financial needs of the older recipients exceeded the capacity of family carers. Mayston et al. (2017) reported on the bricolage approach in informal care in the Nigerian setting to address these limited financial resources, with family members carrying a significant burden of care. The dilemma of flexibility, that is, doing what they can when they can in the care processes puts family carers on the verge of economic and social vulnerability.

It is surprising that despite the physical, financial and psycho-emotional burden, family carers continued caring. In other words, the burden of care associated with informal care did not curtail caring. This may be related to resilience. Resilience is the ability to pull together psychological, social and physical resources to enable people to thrive successfully in adverse circumstances (Bonanno, 2004). Family carers in this study demonstrated resilience when they continued caring, despite limited resources. With demographic and epidemiological changes, resilience presents an opportunity for Ghanaian social policy to explore how equipping family carers with supportive social tools can improve informal care processes in rural communities.
Marginalisation of Older People Living with Chronic Life-Limiting Illness and Their Family Carers in Rural Ghana

As already stated in Chapter 2, this thesis used Mowat (2015) conceptualisation of marginalisation to explore how older people and their family carers’ experiences of chronic life-limiting illness and informal care may constitute marginalisation. Marginalisation is a complex social phenomenon, with different and multiple enactments. Marginalisation in aging research has mostly concentrated on stereotypical constructs associated with marginalisation, such as rurality and access (Walsh et al., 2019), as well as socio-economic constructs, such as poverty and unemployment (Nwakasi et al., 2020), all of which are relevant to this research. In addition to these constructs, Mowat (2015) conceptualisation of marginalisation encompasses the idea of marginalised groups and the manifestation of marginalisation in these groups and is therefore relevant to the experiences of older people living with chronic life-limiting illness and their carers.

Focusing on how marginalisation is manifested, Mowat (2015) explains that two basic assumptions underlie a group: a conceptualisation of shared ideals and stereotypical characterisation. In this study, participants shared similar stereotypical characterisations and ideals and therefore may be marginalised.

Mowat (2015) conceptualisation of shared ideals appears to relate to how people feel about society’s ideals. Ideals are societal norms, values, preferences and social expectations that guide human behaviour in a society (Mowat, 2015). Ideals and human behaviours shape an individual’s social identity and self-worth in society. In explaining the difference between deviant and normal school children in the school environment, Mowat (2015) suggested that rules and regulations are ideals, enforced by teachers and used to determine right and wrong behaviours. In this case, a teacher serves as the authority with the power to confer the identity
of a social deviant if the teacher determines that the child has deviated from the ideals, or the identity of a normal child if that child upholds the ideals. Normal children who uphold the ideals have a sense of belongingness and self-worth. On the other hand, deviant children have a sense of isolation and low self-worth. Thus, feelings of isolation and not being able to exercise the human agency to follow the ideals of society are what make some school children identify as marginalised groups. Therefore, marginalisation is social isolation and the inability to exercise human agency to uphold societal ideals.

Although this research is based on the experiences of older people, the idea of shared societal ideals, social isolation, social identity and self-worth are relevant constructs that are related to the disadvantageous experiences of living with chronic life-limiting illness in rural settings. As already discussed in previous section in this chapter, meaningful activities necessary for self-care and social position were interpreted as valued social roles. Like school ideals, and as portrayed in the political, social and economic roles in pre-colonial Ghana in Chapter 2, high expectations were attached to the accomplishments of these social roles, inability to meet the expectations and to exercise the human agency to continue the decision processes related to self-care significantly challenged the social identity and self-worth of the older person.

In the Ghanaian society, and as the historical analysis demonstrated, roles of older people are enormous. Older people are custodians of social norms and values and the younger generations look up to them for accepted behaviour. Older people can exude the identity of power, respect and authority. The disadvantageous experiences discussed in previous sections confer on older people identities that older people perceive to be a deviation from the identities of normal older Ghanaian group. The feeling of not belonging to the normal powerful, respectful and authoritative group makes older people feel separate from society; they subsequently self-isolate and hence become marginalised. Self-isolation appears to be a
personal decision. As Mowat (2015) explains, in the fast pace of society, those who struggle to ‘fit in’ tend to isolate from society.

The factors that create disadvantaged identities are considered as risk factors for further marginalisation. One risk factor is loss of economic power due to economic globalisation as discussed in the historical analysis (p.17), causing unbalanced economic relationships between older people and their family carers. Mowat (2015) notes the unbalanced relationship in dependency, due to a shift in physical and economic power from parents to their children. Based on the concept of social exchange, Adelman et al. (2014) argue that dependency creates an unbalanced relationship between older people and their family. This unbalanced relationship increases the risk of disadvantaged identities, leading to marginalisation. This means that marginalisation in dependency can be best understood as involving the societal risk factors influencing identity and self-worth, and as more than just what arises from the unbalanced carer-recipient relationship in dependency, even though the risk factors that caused the unbalanced carer-recipient relationship in dependency cannot be discounted (Watermeyer & Watermeyer, 2017).

As already discussed, chronic illness should not be an isolating factor for older people in communities. The analysis on challenging social identity and self-worth leading to self-isolation and marginalisation is contrary to Esiaka et al. (2019), whose findings in research conducted among older African American men living with chronic illness showed that men who reported a higher sense of social identity, self-worth and active coping with chronic illness due to identification with a race or ethnicity also reported feeling included in their African American society. Older people in Ghana also have a high sense of racial and ethnic identifications, yet with chronic illness, self-isolation seem common (Gyasi et al., 2018). The difference between the African American based study and the current study may be the
demographic characteristics of participants and the advantage associated with access to resources for chronic illness management in the American-based study. Most of the men were educated, married and had access to community-based health resources. In this current study, most of the participants were women and widowed and they had limited access to community-based health resources.

For older patients in this study, there was a nuanced decision of self-isolation relative to pain. Critically, disability associated with pain, that influenced self-isolation may not be intentional. This is because, and as found by Awuviry-Newton et al. (2020), older people expressed the desire to be active and independent in meaningful activities, for example, in walking and in trading. Awuviry-Newton et al. (2020) argue that the desire to remain active in meaningful activities can be an asset; when harnessed properly, it gives an indication that re-abling support for social participation and inclusiveness will be successful (Awuviry-Newton et al., 2020). Pain in rural community-dwelling ageing populations in Ghana presents a significant public health concern; making supportive services accessible to improve physical disabilities associated with demographic and epidemiological changes could re-able older people to remain active in meaningful activities necessary for self-care, positive social identity and inclusivity in their social environment.

Older people feeling social isolation is an important element to consider in inclusive policy. Pluskota (2010) found in her analysis of aid services for marginalised groups that the feeling of social isolation is often overlooked by inclusive policy makers. At the same time, this feeling can counter social inclusion efforts of marginalised groups in society if not managed effectively (Pluskota, 2010). Combining both biological and psychosocial interventions to manage limitations in meaningful activities necessary for self-care and self-isolation are critical in this regard. Ofosu-Poku et al. (2020) have suggested in their qualitative research
that a simple palliative or multi-disciplinary management approach incorporated into the primary health care can increase access to illness and pain management and improve the quality of life of Ghanaian community-dwelling older people. However, they added, pain management or palliative care is vaguely understood among health practitioners in Ghana.

In relation to the second assumption of stereotypical characterisation underlying marginalised groups, Mowat (2015) used constructs such as vulnerability, lack of access to social resources, poverty, geographical disenfranchisement, disability, and government policy disenfranchisement as the risk factors which stereotypically characterise a group as marginalised. These risk factors were featured in the experiences, structures and processes of informal care for older people living with chronic life-limiting illness in this study and supported by the political, social and economic losses demonstrated in the historical analysis in Chapter 2. Therefore, I argue that older people and their family carers are marginalised groups, and their experiences constitute marginalisation.

Mowat (2015) conceptualisation of vulnerability is as societal risk factors that make groups susceptible to harm and poor quality of life. From the findings, chronic life-limiting illness exposed older people to physical, mental, psycho-emotional, social and economic vulnerabilities. These vulnerabilities influenced how older people felt involved in society, hence their self-isolation and associated marginalisation. Despite these vulnerabilities, inconsistent informal care was the best option for supportive care. Neither the findings, nor the policy analysis in Chapter 2, indicate known protective factors in the form of access to state-led support for older people living with chronic life-limiting illness in rural Ghana. In the previous section, the structure of flexibility between family carer groups was found to be inadequate to sustain informal care.
Although resilience was not particularly explored in this research, it emerged as a strong enabling foundation for informal care, despite the burden of care. Further research into how informal care is sustained by the inherent resilience of family carers and how social policy can enhance family carers’ capacity through resilience is required. The conceptualisation of resilience in informal care is quite limited with the limited research concentrating on family carers in the Western countries (O’Dwyer et al., 2017). Research into resilience in informal care, especially among family carers from resource poor countries like Ghana, should be explored in future research.

The discussion presented in section 1 shows that informal care is structured on protective psychosocial and environmental factors, such as generosity, flexibility and the presumption of shared responsibility, yet there is a risk of inconsistency. This suggests that dependence on an inconsistent structure of informal care is problematic for the health and wellbeing of both older people and their family carers. In the absence of a formal system, as suggested by the policy analysis in Chapter 2, the risk of inconsistency increases vulnerability and hence marginalises older people from society.

The findings indicate that family and social networks provide informal care and are sustained by sociocultural values considered important in the community. The dilemma lies in the reality of the care processes. Based on the stereotypical characterisation of rurality, poverty and lack of access evident in this study, family carers in the rural community may be unable to access the limited health services for symptoms management. Inadequate information and education about chronic illness trajectories may cause family carers to be stressed in their care processes (Rathnayake et al., 2019). Therefore, improving access to community services and can make informal care substantially easier for family carers in managing chronic illness management in rural communities.
One of the main contributions on the process of marginalisation is the influence of the loss of economic independence in the chronic illness trajectory. With the onset of disability, and despite the expressed desire to remain economically active, older people are forced to discontinue their economic activities, leaving them with limited economic options to meet their health and nutrition needs. Loss of economic independence fits into the stereotypical characterisation of poverty, as explained by Mowat (2015) and identified by Kpessa-Whyte and Tsekpo (2020). The findings demonstrated that older people in extreme poverty were at high risk of limiting access to appropriate health care service for symptoms management. The finding is confirmed by other research conducted in Ghana among rural people that found that older people experiencing functional limitations, poor health and chronic illness have increased the need for health care use, but low socio-economic status serves as a barrier to health access (Agyemang-Duah et al., 2020).

In terms of health care access, the National Health Insurance Scheme (NHIS) helps to defray part of the cost of health care services. Ghana’s NHIS is acknowledged as one of the best social protection interventions in the subregion (Zhang et al., 2019). But, as with most social services, there is room for improvement. One of the exemption packages for older people under the NHIS, as shown in the policy overview presented in Chapter 2, is there is no requirement for payment for people 70 years and above. While highly valued by those who can access this benefit, people who are below the age of 70 years and living with a chronic life-limiting condition are excluded. With poverty, the majority of older people below 70 years (most of whom live in rural areas) are not able to register for health insurance to seek medical care. When older people do not have the financial means to pay for these services, it serves as a hinderance to seeking medical help for illness management, thereby increasing the burden of health care on family carers.
Another important discussion point about Ghana’s NHIS and access to health care that needs to be addressed for demographic, epidemiological and economic changes in older people is that irrespective of their age, older people in this research reiterated previous challenges rural dwellers face with the NHIS, which have been adequately documented in both qualitative and quantitative studies in Ghana (Akazili et al., 2014; Mills et al., 2012; Nketiah-Amponsah et al., 2019). Problems included, but were not limited to, difficulty in paying the insurance premium for first time users or difficulty in renewing registrations due to poverty, essential drugs being out of stock, delays in acquiring or registering for the cards, poor treatment or services under the NHIS and delays in claims payments to health care providers (Alhassan et al., 2015; Nketiah-Amponsah et al., 2019).

In conclusion, the difference between risk and protective factors in the Ghanaian society contribute to the marginalisation of older people and their family carers. For demographic, epidemiology and social change reasons, Ghanaian social policies will require reorganising to balance the risk and protective factors. Ensuring inclusiveness of the health and social needs of older people and their family carers through social policy is a way of achieving social justice for them.

**Recommendations for Transformative Change**

The hallmark of critical social theory, as discussed in Chapter 2, is social justice. Social justice is both the process of, and an end to, achieving equity, fairness and inclusion for the socially excluded and the marginalised (Grapin & Shriberg, 2020). Therefore, the answer to the third research question, “In what ways could social structures be strengthened to enhance the quality of lives of older people with chronic life-limiting illness in rural Ghana?”, is that for demographic, epidemiology and social change reasons, Ghanaian public policies will
require reorganising to address the needs of older people and their family carers. Through policy transformation, and associated resource allocation, social justice for this marginalised group can be achieved.

In this thesis, based on the health facts presented in Chapter 1, the historical analysis and the value-critical policy analysis presented in Chapter 2 as well as the results presented in Chapter 5 and 6, a social problem of marginalisation in health and social care exists because the existing polices do not uniformly ensure the inclusiveness of older people and their family carers’ health, social and economic needs, as far as chronic life-limiting illness and informal care are concerned. In the following section, focusing on the needs of older people and their family carers and the four specific policies: National Health Policy, National Policy for the Prevention and Control of Chronic Non-Communicable Diseases in Ghana, National Ageing Policy and the National Health Insurance Scheme, I present strategies and recommendations for achieving social justice for older people and their family carers.

As demonstrated in the value-critical policy analysis in Chapter 2, restructuring goals/objectives and the forms of benefits and services of the policies can help include the needs of older people and their family carers with respect to chronic life-limiting illness and informal care in rural Ghana. The principle of aligning health services to meet the health needs of older people has also been raised in the Global Strategy and Action Plan for Ageing and Health (WHO, 2017). In addition, bridging the implementation gap can help make these current Ghanaian policies more relevant to the health, social and economic needs of older people and their families in rural communities. For example, the gap between the National Ageing Policy’s development and implementation may be bridged through policy dialogue and participation. Policy dialogue and participation are particularly uncommon in African policy development and implementation processes. Fusheini and Marnoch (2020) have
identified that the African policy process is participated in by only a few selected participants, mostly stakeholders with political interests, and not necessarily those with lived experiences of the social problem under review. Through critical education to develop critical consciousness, as presented in the critical social theory (CST) section in Chapter 2, increasing older people’s participation and dialoguing in policy can augment ownership of the National Ageing Policy and induce self-advocacy among older people and their family carers, which is necessary to influence the implementation process of the National Ageing Policy. Further to published research, such as this thesis, community-based discussions, facilitated by policy makers, can provide an opportunity for policy makers to learn first-hand about the experiences of older people. Using today’s technologies, older people and their families can share their experiences through filmed interviews that can be used to focus policy makers on the emerging issues.

Again, based on the findings and as demonstrated in the inequity of the policies’ benefits (p.43), in bridging the implementation gap, attention should be paid to the intervention logics of the policies, that is, health prevention and promotion vis a vis health management for chronic life-limiting illness. It is recommended that management frameworks must be in place to increase access and affordability to geriatric related services, multi-disciplinary self-care programmes (Wong & Wong, 2020) and community-based wellness programmes that emphasise specialised nutrition and exercise intervention (Kehoe et al., 2020), to enhance the maintenance of chronic illness related self-care activities and the experiences of older people.

In line with critical social theory, the multi-disciplinary self-care and community-based wellness programmes should use a critical education approach. While the intervention frameworks of prevention and promotion would be beneficial in the long-term, both for the youthful and older Ghanaian population alike, management frameworks are beneficial in the immediate term (Thaler et al., 2015).
Access and affordability to the geriatric related services and equipment, multi-disciplinary self-care programmes and community-based wellness programmes will also mean increasing health financing for geriatric and allied health resources to inaccessibility in the rural and remote areas in Ghana (Essuman et al., 2018). This will help the majority of older people living in rural community access community resources to assist them manage the disadvantaged experiences associated with living with chronic life-limiting illness in rural communities. It may also have an associated impact on inclusiveness, as well as improve quality of life and afford a better health outcome.

Geriatric related services and equipment, multi-disciplinary self-care programmes and community-based wellness programmes can also benefit family carers. Family carers’ health deteriorates with older people’s health, and therefore Geriatric related services, multi-disciplinary self-care programmes and community-based wellness programmes can prevent further deterioration and sustain the system of informal care (Essuman et al., 2018). The spiral effect of integrating carer’s needs in geriatric related services and multi-disciplinary self-care programmes is to re-balance both the unbalanced relationship that induces social marginalisation in the carer-recipient relationship and the impacts of that unbalanced relationship on quality of life and health outcomes for older people and their family carers (Walsh et al., 2019). More dyad research is required to determine what is culturally appropriate. The department of social welfare could set up an integrated social welfare services desk specifically targeting older people and their family carers as a way of managing the outcomes of the interventions and to meet the criterion on service delivering and administration, based on the value-critical policy analysis presented in Chapter 2.

The findings of this research re-emphasise the paradoxical presentation of the identity of an African older person: as an historically and traditionally powerful person, yet very
susceptible to marginalisation (Chirwa & Rushwaya, 2019). The first objective of WHO’s global strategy and action plan on ageing and health (WHO, 2017) is to commit to action on healthy ageing, that every country will develop age-friendly societies with social structures that seek to reduce stereotypical characterisation and the impact of inability to meet ideals.

As presented in the theoretical framework in Chapter 2, critical consciousness through critical education is key to achieving transformative change for marginalised groups (O’Neill, 2015; Pillen et al., 2019). Developing critical consciousness is a reflective process; it allows people in an oppressive group to reflect on the meaning of their experiences and to develop new meanings that will bring them liberation (Freeman & Vasconcelos, 2010).

Critical education and critical consciousness will empower older people to identify the challenges of ageing with chronic illness beyond the individual identity. Empowerment can induce self-advocacy in older people to channel their needs to authorities for support that is rightfully theirs in the constitution, and that is why research is very important. As indicated by the tenets of the transformative paradigm in Chapter 4, research should be the blueprint based on which social justice can be achieved (Creswell, 2013; Romm, 2015). The ability to communicate the output of this research to the intended population is a good starting point for transformative change and social justice.

The underlying factor in the critical educational and critical consciousness approaches used for marginalised groups is stigma reduction, because of the potential to reduce the belief of years of internalising stereotypically self-imposed identities and characterisations (Pillen et al., 2019). In other words, critical educational and critical consciousness approaches that have to do with the deconstruction of perceptions that inhibit the nurturing of healthy social identity and self-worth will go a long way to helping older people reconstruct positive perceptions in changes in the body and the disabilities that come with stereotypically self-
imposed identities and characterisations in Ghanaian rural communities (Freeman & Vasconcelos, 2010). Targeting the community, including critical education into the mandate of the social welfare system aimed towards stigma reduction against older people in local communities in Ghana will be beneficial (Wight, 2017). On the individual level, professionals who are trained in critical education, such as clinical social workers and psychologists and those who work directly with older people and their families, can be included in the available primary health system and in the special service delivering team under the social welfare department. They can provide extra support in planning and delivering interventions that promote critical education to encourage agency in chronic illness related self-care processes and to reduce stereotypically self-imposed identities and characterisations that contribute marginalisation. Currently, such services are inadequately accessible in rural Ghana (Essuman et al., 2018).

In terms of pain management, structural challenges inhibiting access to services, including lack of access to pain relievers, lack of governmental commitment to policy regulations and lack of experts to deliver the pain services (Kamonyo, 2018; Yorke et al., 2019). The Government of Ghana can increase the recruitment and training of health professionals to assess pain and prescribe appropriate pain relievers to older people living with chronic life-limiting illness in the Gomoa West District. Improving clinicians’ education and training on pain management and also exploring how Western medicines may be effectively mixed with traditional medicines for pain management can improve assessment and treatment of pain in rural communities. This will require more pain related research.

In addition, physiotherapists, social workers and psychologists can be engaged to deliver non-medical therapies, such as physical activities in the form of exercises and psychosocial intervention, such as group activities. These activities can be incorporated into multi-
disciplin ar self-care and community-based wellness programmes to supplement local interventions and to train older people how to self-manage pain in the local community. There is also the need to increase access to shared exercise and medical equipment libraries in the local communities. Health care professionals can advise on equipment and exercises to reduce further deterioration. In addition, training family carers how to assess pain and manage pain will help support their local knowledge that is already being used to manage older people’s pain in the local setting and will improve their ‘nursing’ role. Family carers will also benefit from interventions to self-manage pain associated with providing physical care. More higher education courses for Ghanaian students to learn the disciplines of physiotherapy, pharmacy, and other allied health professions is required to achieve the high levels of community support required.

The Global Strategy and Action Plan for Ageing and Health (WHO, 2017) requires member countries—Ghana is a member—to commit to implement health policies which impact on the functional capabilities of older people. The Western literature on helping older people to maintain independence and self-worth in the light of reduced meaningful activities have been grouped under the policy discourse of reablement (Bødker et al., 2019). Reablement refers to providing ongoing home-based support to help older people balance the loss of independence associated with limitations in meaningful activities (Bødker et al., 2019). Reablement can be achieved through multi-disciplinary self-care and community-based wellness programmes, suggesting the need to improve multidisciplinary education and physical resources on ageing and chronic illness to increase access in the rural area. In this research, it is argued that re-abling older people living with chronic life-limiting illness to sustain their independence in physical activities will balance the power in dependency by improving agency and independence. In addition, re-abling will reduce marginalisation in carer-recipient dependency, the burden of care on family carers, and a better social outcome will be achieved.
in the carer-recipient relationship, ultimately leading to an improved quality of life and better health outcomes in both older people and their family carers in the local setting.

It is argued in this thesis that providing geriatric related services and equipment, multi-disciplinary self-care programmes and community-based wellness programmes for older people to manage their disadvantaged experiences with ageing and chronic illness will re-able an extended contribution in a social and economic environment. It is envisaged in the National Health Policy that improvement in health will significantly contribute to socio-economic development in Ghana (MoH, 2007). With disabilities and limitations in meaningful activities, older people living with chronic life-limiting illness may not be able to contribute to socio-economic development. A multidisciplinary approach to managing disability will help reduce the negative perception of disability which affects older people’s strength to carry out economic activities. In other jurisdictions, such as in Australia, America and some Asian countries, older people still play vital roles in the economic environment. Based on the extended desire of older people to contribute economically and socially, revisiting the social values placed on old age is vital as a country, but responding to the economic vulnerability of older people through policy and action led programs will promote adequacy and equity of the policy in the long run.

Based on the evidence presented on the Ghanaian economic culture in Chapter 2, an immediate economic action on pension schemes is suggested. However, it does not only lie within the immediate realms of older people to bring about change, rather, political interest is equally paramount in this instance. That is, the onus lies with the government to commit to redistributing national resources to ensure the social and economic inclusion of older people. This research could serve as the foundation for these discussions from which to materialise. The findings of this research empowering older people can serve as a collaboration between
older people and government agencies as well as between government and other researchers and professionals to determine what is just. In the intermediate, direct cash transfer packages delivered through the welfare system can mitigate some of the economic challenges that serve as a hinderance to ensuring nutrition and health care security among older people and increasing financial vulnerability in informal care can be explored.

Restructuring the objectives of the National Ageing Policy to include chronic illness, as already identified, can make up for the exclusivity in the National Policy for Prevention and Control of Chronic Non-Communicable diseases in Ghana and the National Health Policy. With older people suffering the double burden of ageing and chronic illness (Stockwell-Smith et al., 2019), how we as a society can mitigate the impact of ageing and the chronic illness trajectory in old age by increasing accessibility and affordability of special health care services is a critical concern raised in this research.

With the expected increase in chronic illness and the associated increase in disability, as well as pain, the findings agree with the recommendations of a simple palliative approach to be included in the primary health care system (Adonteng-Kissi et al., 2020; Awuviry-Newton et al., 2020). The emphasis of a palliative approach as a support strategy is the use of a team of experts, such as medical staff, social workers, pharmacists, psychologists and sometimes spiritual leaders, to provide comfort and to improve the quality of life of people living with chronic life-limiting illness and their families (Yosick et al., 2019). NHIS challenges needs to be addressed so as to improve access to health care for both older people and family carers. As the policy analysis indicated, lowering the exemption age to 60 to include more older people and collaborating with family carers and other members of the family to explore how telehealth can successfully reach rural communities can improve access to special health care services in the rural areas.
Based on the older people and family carers’ experiences with informal care, the findings suggest an existential lack of specific policy-led active strategies and services to support family members to provide care. As already discussed, the National Ageing Policy specifically acknowledges the need to support family carers to provide traditional informal care (MoESW, 2010). Yet, there is no implementation plan. This supports the findings of the integrative review that suggests there is no available support for family members who provide informal care for older people living with chronic illness in African communities (Adonteng-Kissi et al., 2020). The idea that informal care is a gendered activity and is based on flexibility and contribution, builds on the resilience of family carers, but it is not sustainable to the health and wellbeing of both older people and their families.

Flexibility and financial contribution to care by family carers also helps to make them marginalised. This is because it limits the capacity of family carers to engage the state in matters which make their caring a burden (Moensted & Day, 2020). Global social trends have been proposed as the need to provide payment for informal care by some researchers from Ghana (Nortey et al., 2017); however, this has yet to be reflected in the National Ageing policy or any welfare strategy for that matter. As an ageing country, we have to start discussing how to implement the evidence-based recommendations to provide payment for informal care as a strategy to sustain the system, bearing in mind the growing number of older people without active family carers in communities. Based on the data, the work hours lost in providing care can be used as a measure to determine the economic cost of providing care. This can help to reduce the economic burden, which has served as a potential barrier to providing informal care.

Based on the demonstrated burden and barriers, the analysis of informal care should look beyond the context of Ghanaian culture to encompass ageing and the chronic illness
experience. Because a carer’s health worsens with older people’s health, we need to transformatively explore how we can include carer’s health in the older peoples’ care plans (Cash et al., 2019). As a society with records of resilience, we need to explore how we can nurture resilience in informal care, at the same time social and health resources should be improved for family carers (O’Dwyer et al., 2017). Judging from the complex roles in informal care, coupled with a growing number of older people living in rural communities, it is expected that older people will need formal ongoing support services to cope with the burden of chronic illness. At the same time, more family carers will be needed, which means family carers will need formal ongoing support to build their capacity to provide adequate physical and social care (Greenwood et al., 2019; Stocker et al., 2017). There is the need to explore further how to provide formal support for family carers in this category, because if the status quo does not change, family carers’ marginality will threaten the continuity of care, and older people living with chronic life-limiting illness will suffer.

The nursing/treatment reasoning underpinning the chronic illness related informal care processes suggests formal training and ongoing support. Ongoing support in planning and coordinating caring activities as well as teaching family carers how to build more connections with members of the community to expand their available ongoing social support will help reduce the burden of providing informal care single-handedly. Offering training for family members or introducing support groups activities to help family carers share their experiences in a safe environment where family carers can potentially garner support from others have been found to have a positive impact on the quality and burden of care provided by family carers (Davies et al., 2019). Family carers support groups can be localised to ensure efficiency in rural Ghanaian communities.
The Global strategy and Action Plan for Ageing and Health objectifies developing life-long equitable systems for long term-care by improving the capacity of and supporting older people’s caregivers (WHO, 2017). However, this may be a long term objective, because formal long-term care is still very new to the Ghanaian culture (Essuman et al., 2018). In the meantime, capacity building should be geared toward families who willingly take up caring roles, and this should be explicitly stated in the National Ageing Policy or related policy. However, due to the demonstrated advantages of cultural values around informal care, this research suggests consideration of how cultural values can be integrated in the policy conversation of support for family carers, as a way of making it relevant to fit the local context.

In conclusion, the recommendations made in this thesis are in relation to policy, practice, education and the training of clinicians. The challenge for transformation is to consider how older people, their families together with the policy stakeholders, including politicians, academics and practitioners, can become engaged in social and political actions, advocacy and a series of community organising to shed light on the situation. Consumer partnership with researchers can lead to a determination of what are the cultural, social and also most cost-efficient strategies to support older people. This is necessary because human agency does not occur in isolation but is based on the context created by dynamic interactions among various parts of the social system (Mowat, 2015).

**Summary of Chapter 7**

This chapter encapsulated the findings of this critical ethnographic research and discussed them in line with critical social theory, the transformative paradigm and available evidence. The findings suggested that older people’s subjective experiences with awareness of changes
in their bodies, pain and its relative effects on physical and economic activities and loss of independence due to limitations in ALDs, IADLs and pleasurable activities caused self-worth problems which limited older people’s decisions to sustain their inclusiveness and interaction in the communities. Low self-worth creates mental health problems, and it is responsible for poor health and social outcomes, and increased mortality among older people. Clinical experiences of ageing with chronic life-limiting illness suggest the need to improve the availability of geriatric services in Ghana. However, an existential problem of marginalisation exists when it comes to access to geriatric services. Inadequate access makes older people self-isolated, and their isolation causes them to self-marginalise. For transformative changes, addressing the physical, mental, social and economic factors that make older people living with chronic life-limiting illness marginalised through health policy and social welfare is a way of achieving social justice for them.

Specifically, marginalisation suggests a need for a transformative change through public policy to reflect the current needs of older people. For marginalised groups, critical consciousness through empowerment is necessary for reducing self-induced and relational marginalisation. Increasing pain management research will lead to implementing evidence-based innovative strategies to support older people in pain. The policy term of reablement could be adopted as being supportive measures to assist older people manage limitations in physical activities, while reorganising existing health policies and expanding access to include the special needs of older people living with chronic life-limiting illness in the health care services. It is also important to financially support older people in chronic illness management in the local setting because of the devastating impact of global social change on older people. These recommendations are emphasised because of the historical importance attached to ageing in the local setting.
As regards the intergenerational benefit in providing care, cultural values sustained historical traditional care and support. However, an increase in the older population and chronic life-limiting illness puts the historical traditional care and support on a higher pedestal. Traditional care and support are only recognised in the ageing policy, theorised as the capitalist ideology of flexibility and cooperation, and explained to be the reason for a deliberate lack of state-led support services to assist family carers provide informal care.

An emphasis on social change puts all the responsibilities of care on the nuclear family—mostly female family members—but complexities in managing both ageing and chronic illness trajectories for older people often present barriers for family carers, and, sometimes, an inability to mitigate these barriers serves as a barrier to providing informal care. Supporting family carers is a useful strategy to sustain the system of family care, and as a matter of social justice there is a need to look beyond care as a cultural responsibility alone to focus on the complex needs of older people as well as the economics.

Gomoa West District can be described as a traditional society, and for this reason it is easy to ascribe traditional actions as the normal in the provision of care. However, epidemiological and demographical changes add another layer of burden on family carers of older people living with chronic life-limiting illness. Playing the role of a personal care manager to help with the ADLs, being the nurse, cleaner, cook, nutritionist, and home organiser to facilitate the IADLs as well as providing companionship and attachment were expressed as having a negative impact on the family carers’ wellbeing. However, cultural values act as the power that limit the power of family carers to seek support for informal care for their care recipients. Through education, training and instituted financial support, the burden of care can be reduced and both older people and family carers can have better health outcomes.
In the next chapter, I present a summary of the thesis, conclusions, implications for practice and recommendations for further research.
Chapter 8
Conclusions and Implications

In this chapter, the conclusion, contributions and limitations as well as implications for policy, practice, research and community education of the research are presented.

In this thesis, I sought to explore the experiences of older people and their family carers with references to chronic life-limiting illness and informal care in rural Ghana. Population ageing and social change are both significant global and national demographic trends, and these two trends have consequences for people and society as a whole. Most countries in Africa, like Ghana, are projected to experience an exponential increase in the aged population. At the same time, there will be a direct relationship between population ageing and an increase in chronic life-limiting illness. In Ghana and most parts of Africa, informal care is the most available form of support for older people. However, the effects of globalisation are influencing older persons’ access to informal care, and this creates an alarming situation because of population ageing and an increase in chronic life-limiting illness in Ghana.

Central to this research project is the predisposition that the experiences of older people and their family carers concerning chronic life-limiting illness and informal care may constitute marginalisation. This idea informed the selection of critical social theory, the transformative paradigm and the critical ethnographic research design utilised in this research. Three research questions were answered to achieve the aim. They were (1) “What are the experiences of older people with chronic life-limiting illness in rural Ghana?”; (2) “What are the structures and processes of informal care for older people living with chronic illness in rural Ghana?”; and (3) “In what ways could social structures be strengthened to enhance the quality of lives of older people living with chronic life-limiting illness in rural Ghana?”. 
An ethnographic interview method was used to collect data from 15 older people and their corresponding family carers from seven villages in Goma West District, and five health care professionals each from St. Luke Catholic Hospital in Apam and a Palliative Care Clinic of the Korle Bu Teaching Hospital in Accra. Data was managed by the ATLAS.ti version 7.1 software. A thematic analysis process, suggested by (Clarke & Braun, 2013), was used to analyse the data. The analysis led to the development of three themes depicting the experiences of chronic life-limiting illness and five themes depicting informal care.

Using a critical approach, the answers to the research questions provide a novel insight to the socio-cultural, historical and political factors which contribute to how older people and their family carers’ experiences encompass marginalisation when it comes to managing chronic life-limiting illness with informal care in the Gomoa West District of Ghana.

**Summary of the Key Research Findings**

Older people’s experiences with chronic life-limiting illness were mostly negative. The findings showed an increasing awareness of illness in the body, in relation to the suffering associated with physical changes, physiological deteriorations and pain in the body, led to a nuanced decision to self-isolate from society as illness progressed. Disabilities associated with physical changes, physiological deteriorations and pain led to increased limitations in meaningful activities (ADLs, IADLs and pleasurable activities). Disability and limitations in meaningful activities were explained as a loss of independence. A loss of independence challenged older people’s ability to continually meet their high personal role expectations, including their physical and socio-cultural positions or social roles, increasing their vulnerability in health, social and economic needs. The vulnerabilities of older people are further increased by the lack of adequate chronic illness management services in the locality.
Inadequate access to state sponsored support triggered a necessary upsurge on the dependence on family and other members of the community for support for these needs; however, the perception of being dependents caused more challenges to older people’s already challenging social identity and self-worth.

There was an indication of an inconsistent informal care and the susceptibility to revealing abuse, neglect, loneliness, isolation and feelings of uncertainty with available support. An answer to the first research question, therefore, is that older people living with chronic life-limiting illness experienced inadequate accessibility to community-based health and social support services to manage the limitations associated with chronic life-limiting illness, and these experiences increased vulnerability to self-isolation, challenging social identity and self-worth.

Historical traditional care and support still exist for older people, irrespective of chronic illness, and it is sustained by shared cultural values in love, respect, appreciation, relationships, responsibility towards one another, reciprocity and community engagements. Changing family systems put the responsibility of care very strongly on the nuclear family, and specifically on female nuclear family members. Other support networks provided care, but care from these groups was inconsistent. When it comes to informal care specifically for older people living with chronic life-limiting illness, there is existential differences between traditional care and informal care, because of the complexities with chronic life-limiting illness. Family carers performed both the traditional and other illness specific roles.

These roles correspond to the physical changes, physiological deterioration and pain experience in older people’s bodies and limitations in meaningful activities. Given that there are limited support services for family carers, informal care becomes a burden on family
carers. Where family carers are not able to exhibit resilience, the burden of care becomes a barrier to providing informal care. So, the answer to the second research question is that with chronic life-limiting illness and rapid social change, upholding historical traditional care arrangements is a way of supporting older people but serves to marginalising older people’s family carers at the structural, or policy, level. In addition to the gaps identified in relevant Ghanaian social policies reviewed, older people and their family carers’ experiences require transformative action. Therefore, the answer to the third research question is that for demographic, epidemiology and social change reasons, Ghanaian public policies will require reorganising to address the needs of older people and their family carers. Through policy transformation, and associated resource allocation, social justice for this marginalised group can be achieved.

**Contributions of the Research**

Prior to the conduct of this research, little was known about informal care for chronic life-limiting illness in Ghana. It is the first research utilising critical ethnography as a research approach to examine the experiences of older people and their family carers when it comes to using informal care to manage chronic life-limiting illness in Africa, and specific rural Ghana. The findings presented in this research help to build on available knowledge on health care and clinical experiences on chronic life-limiting illness in Ghana. The findings also build on the global problems of ageing, health and social care identified in the World Health Organisations (WHO) global strategy and action plan for ageing and health. In line with the WHO’s global strategy and action plan for ageing and health, the recommendations for policy reorganising and bridging the gap between policy development and policy implementation will ensure inclusiveness and social justice for older people, by providing a basis for the
development of culturally sensitive symptoms management and a palliative approach for people living with chronic life-limiting illness and their family carers. The findings also speak to the need to increase access to life-saving resources for older people in Ghana in general, but specifically to those dealing with chronic life-limiting illness on a daily basis on rural communities.

The findings of this research add to the body of literature that finds that due to globalisation, social change is affecting the economic and social power of Ghanaian older people, changing family systems in Africa is limiting active care and support for older people and chronic life-limiting illness is complex but access to formal support services are limited for community-dwelling older people and their family carers (Adonteng-Kissi et al., 2020). The findings make useful recommendations to support family members who provide informal care to manage the clinical experiences of older people living chronic life-limiting illness.

This research had a strong and consistent philosophical base. A good philosophical underpinning shows a researcher’s line of theoretical thinking, and it increases the researcher’s self-awareness necessary for the design, conduct and analysis of the research and the interpretation of results and outcomes (Moon & Blackman, 2014). The processes used to conduct the research have been used among participants with similar characteristics from different settings. Criteria for ensuring methodological rigour have been outlined and justified. I used reflexivity as a guide to distinguish my preconceptions from the experiences of older people and their family carers. The analysis of the research and ultimately the themes generation and interpretation of results utilised a democratic process where a team of experts in qualitative research and PhD supervision were involved. The results of this research have significant implications for research, policy and practice.
Limitations of the Research

This research was conducted in a rural district in Ghana. The characteristics and experiences of older people and their family carers in relation to chronic life-limiting illness and informal care presented in this study may not be a representation of all older people and their family carers in urban centres or other rural parts of Ghana on the same subject. Hence, generalisability of the data may not be possible. The relationship between older people and their family carers can be considered dyadic. Although the interviews were conducted separately, the presence of the other participants may have limited the ability of the other participants to express themselves freely. This may be a marginalising effect and have an impact on the outcome of the research. Again, presenting the results together may have an impact on confidentiality of the participants. Data was collected in both English and Akan language. The Akan data were translated into English during transcription. Because of differences in languages, loss of meanings of some words during translation is possible.

Conclusion

In Ghana, and Africa at large, informal care for older people is assumed, occurring within the context of the family. The historical care narrative stems from the social roles older people play in societies. Older people are supposed to be custodians of culture, norms and community resources, and as such, their identities are carved out of the respect they exude, reflected in the care provided them in old age. However, societal changes caused by globalisation can render older people less powerful, which make them susceptible to poor self-identities, low self-worth, abuse, neglect and isolation. This means that the current African setting presents older people in a paradoxical way (Chirwa & Rushwaya, 2019).
Older people still have a lot to offer to society, and there is a need to support older people to restore them to their original position in society.

From the findings, we can assume that the historical culture of care for older people is still intact, based on shared community beliefs on the provision of care and support. However, what is critical about the culture of care is the processes and the factors which act as burdens and barriers to providing quality care for older people, specifically for older people living with chronic life-limiting illness. Amidst social, epidemiologic and demographic changes, older people living with chronic illness are more vulnerable. If available evidence suggests that the Ghanaian health care system does not have the requisite resources to provide health care services for ageing and chronic disease management (Minicuci et al., 2014; Tenkorang & Kuuire, 2016), then, invariably, family members do not have the requisite resources to provide informal care for this category of older people. This makes older people and their family carers marginalised groups. It is imperative that as a society, we ascribe the same importance of resourcing the health care system to supporting family carers to provide informal care, since both support systems work hand in hand to enhance the quality of life of older people. With this conclusion, the aim of this research is successfully achieved.

Through this research, I have introduced or emphasised a societal discussion on informal care and have made recommendations that are relevant to Ghanaian society. During my fieldwork, I saw how people responded to, and discussed among themselves the importance of my research in agreement to my introduction and my explanation of the purpose of my being in the district. In addition, the transformative paradigm helps in the production of evidence-based knowledge, which may serve as an added voice to the ongoing demand for the development and implementation of palliative care policy as well as informal carer support strategies in Ghana. This is because, as Andrew and Halcomb (2009) explain, the continuous
social change, advanced population ageing and the complexity of chronic illnesses impact the way contemporary health care is advanced; hence, research should be the bedrock for contemporary health care policies.

**Implications of the Study**

As already indicated, the results of this research have implications for policy, practice and community education. These are discussed below.

**Implications for Policy**

The findings suggest the need to build on the National Ageing Policy to include chronic illness and identify frameworks to monitor the policy implementations and where resources are allocated. This can contribute to significantly meeting the health, social and economic needs of older people and their family carers when it comes to chronic life-limiting illness and informal care. This will require the state to commit financial resources to bridge the gap between policy development and implementation for the intended benefits of the National Ageing Policy to be achieved. Also, reorganising public policies will require realigning the existing health polices to fit the health needs of older people living with chronic life-limiting illness. Addressing the structural challenges identified with the implementation of the National Health Insurance Scheme (NHIS) will improve access to vital health care services for the rural poor older people. This will mean reducing the payment exemption year to 60 years to broaden the scope of access and making vital geriatrics related pharmacological therapies covered under the NHIS. Self-worth and identity challenges will require mental health services to be included in existing health policies. Affordable pain and other chronic
illness services as well as geriatrics services would have to be made available for the benefit of older people living in rural communities. Both pharmacotherapy and non-pharmacotherapy interventions are necessary to re-enable older people to maintain their independence in ADLs and IADLs through public policy and community wellness programs implementations.

Moreover, acknowledging the increasing needs of an older population ageing with chronic life-limiting illness and the need for specific health interventions suggests that National Ageing Policy needs to increase education and human resources in geriatrics and chronic illness services in Ghana. Extending these services to the rural hinterlands will ensure health service inclusiveness for marginalised older people in these areas. To guarantee economic inclusiveness, economic system restructuring will be required, necessitating the pension scheme be extended to the informal sector to ensure income security in old age in the long term so that people who retire as petty traders can also have a reliable source of income during pension. In the intermediate and immediate term, also in response to the inconsistent family and community support, direct cash transfer packages delivered through the social welfare system can ensure health and nutrition security among vulnerable older people. This will require more demographic research to determine what is appropriate. Finally, the National Ageing Policy would have to recognise informal care as being beyond only a cultural responsibility, owing to the challenges of providing informal care amid demographic, epidemiology and social changes.

**Implications for Practice**

The application of a critical approach to this research presents an opportunity for social work professionals working with older people and their family carers in communities to reflect on how everyday living in the communities are influenced by complex health, socio-cultural,
historical, economic and political domains. A social justice focus will enhance social workers’ advocacy roles to engage policy, community institutions such the Chief and his elders, church leaders and other opinion leaders in communication for development and implementation of policies, strategies and services necessary to reduce marginalisation of older people and their family carers. The transformative lens gives social workers the opportunity to explore how critical education can empower older people and their family carers to engage the state in discussing how current social trends affects their wellbeing and the need to provide support.

Social work professionals can engage community organising techniques and action research methods to gather local resources to make exercise equipment available and accessible to older people and their family carers in the local community. This will help reduce feelings of no sense of belongingness and to maintain their social identities and self-inclusiveness in physical and social activities.

Health care professionals working with older people need to educate them about the ageing body and accompanied changes in functioning as well as link them to available equipment and exercises resources in the community to limit further deterioration.

The transformative action approach highlights how the system of flexibility and cooperation can be changed by enhancing families’ capacities to engage the state in critical communications regarding care at the policy development and implementation levels. Social support groups that offer a safe environment for family carers to share experiences on care and to learn new coping skills and to manage the emotional responses from their recipients will improve care-recipient relationships and health outcomes. This will eliminate vulnerability to isolation, which threatens the resilience of family carers. Critical education can assist family carers to acknowledge, assess and treat pain for older people.
Finally, the outcome of this research provides an opportunity for professionals to work with the Health Ministry as well as the Gender, Children and Social Protection Ministries and other researchers in Ghana to devise ways of developing and implementing decentralised and integrated service delivery agencies in Ghana.

**Implications for Further Research**

This is qualitative research, and it has been based on the experiences of a small number of participants in a geographically small area in Ghana. In addition, quantitative research involving large sample sizes could be conducted to determine the spread of the problem in Ghana. Nevertheless, the outcome of this research provides an opportunity to build on available gerontological knowledge and to collaborate with the appropriate Ghanaian ministries and geriatrics, palliative and allied health care professionals to develop, implement and monitor evidence-based interventions for older people and their family carers in Ghana.

The most common chronic illness reported by participants was hypertension. I recorded their self-reported diagnoses as they were shared with me, recognising that the participants’ symptoms could be more complex than hypertension. For example, hypertension may be connected with cardiovascular disease, frailty and weakness. Based on the transformative perspective taken by this thesis, older peoples’ self-diagnoses may present an opportunity for further investigation. Finally, since this is a novel research exploring the marginalisation of older people and their family carers in relation to chronic life-limiting illness and informal care, future research collaborations with older people and their family carers in Ghana should take into considerations the factors that make them marginalised.
Implications for Community Education

The findings have implications for community education. People in rural communities, and for that matter all communities in Ghana, should be educated about the impact of prejudices and stereotypes on older people’s mental health and overall quality of life through public campaigns. Community awareness on the need to prepare for old age is necessary for economic, health and nutrition security.

Summary of Chapter 8

This is an original study utilising a critical approach to examine the experiences of older people and their family carers with regards to chronic life-limiting illness and informal care in Ghana. In this chapter, a summary of the literature gaps, the method and analysis process were presented. Contributions and limitations of the study were also presented. A summary of the major findings has been included. The conclusion presented in this chapter shows that the original aim and objectives of this research have been achieved. Based on the conclusion, implications for policy, practice and community education have also been presented.
References


Braun, V., & Clarke, V. (2013). *Successful qualitative research: a practical guide for beginners*. SAGE. http://griffith.summon.serialssolutions.com/2.0.0/link/0/eLyHCXMwpV07CwIxDA4-FsHBJ76tmw6Kl3paZ1HcdZfeXYuDuKj_3_Qhdyi6OIZCS0PT9Av5vgJwnM2n b3eCVIIHdA-qOlpWXKDULBsCqSg5RSitdvV_1QzTrmNQUJ7gnoNgaaWFmw7KwPHH6xyGIIgzzBnKv_JQZZnr4wb1xuWdXgYLhI1Qhp641aDs6LfMheWNjrxs9qePw8L C_H-rHhTmupBX1Zl7P59vA0573ovnr2VOfsen18bW2ISvYN3v17vlxiUtYP52kpp SrKZXiKol-sIEyGFxIWXCeGbeh8n7Dza7ALJb1FphsQw-KmkjB9YM3DKyHn11Vg6k


Administration and Policy in Mental Health and Mental Health Services Research, 44(1), 92-102. https://doi.org/10.1007/s10488-015-0703-4


work in health care, 58(5), 471-493.
https://doi.org/https://doi.org/10.1080/00981389.2019.1587660


https://doi.org/https://doi.org/10.1111/hsc.12946


https://doi.org/https://doi.org/10.1177/1474904115589864


Salma, J., & Salami, B. (2020). “We are like any other people, but we don’t cry much because nobody listens”: The need to strengthen aging policies and service provision for minorities in Canada. *The Gerontologist*, 60(2), 279-290. [https://doi.org/https://doi.org/10.1093/geront/gnz184](https://doi.org/https://doi.org/10.1093/geront/gnz184)


Westby, C., Burda, A., & Mehta, Z. (2003). Asking the right questions in the right ways: Strategies for ethnographic interviewing. *The ASHA Leader, 8*(8), 4-17. [https://doi.org/10.1044/leader.FTR3.08082003.4](https://doi.org/10.1044/leader.FTR3.08082003.4)


Appendices

Appendix 1: Participant Information Sheet for Older People

Project title: Informal care for the terminally ill in Ghana: experiences of older people and their family carers

<table>
<thead>
<tr>
<th>Research Team</th>
<th>Menzies Health Institute Queensland and School of Nursing and Midwifery, Griffith University and Gold Coast Hospital and Health Services</th>
<th>+61 (0) 7 5552 9558 <a href="mailto:l.grealish@griffith.edu.au">l.grealish@griffith.edu.au</a></th>
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</tr>
</tbody>
</table>

Why this research is being conducted

This research is being conducted to explore the experiences of older people and their family carers on chronic life-limiting illness and informal care in rural Ghana. This study is a postgraduate research requirement for the award of Doctor of philosophy Degree (PhD). The study is partially supported by a Griffith University, Australia scholarship. The study has been reviewed and approved by the Griffith University Human Research Ethical Committee.
Why you have been chosen to participate

You have been chosen to participate in this research because you are 60 years of age or older, are living in rural Ghana and receiving informal support from your family members. Your insights into the at-home care that you and other older people living with chronic disease might need is important to us.

What you will be asked to do

You are invited to participate in this research in three ways.

Firstly, you will be asked to participate in two or three interviews of approximately one hour per session. The interviews will focus on your experience of living with a chronic life-limiting illness and how your care needs are met. All interviews will be digitally recorded. Once these have been transferred to a written record, the digital recordings will be deleted.

Secondly, the researcher will undertake some observations. She will observe how your family carer provides care and the interaction between you both. The researcher will observe how your care needs are achieved in relation to your daily activities such as feeding, toileting, bathing, selecting proper attire, grooming, walking and transferring as well as managing finances, handling transportation, shopping, preparing meals, and using telephone, managing medication and home maintenance. The observations will occur within an approximate time of two hours and will be completed during the time your family carer is present in your home.
Thirdly, the researcher will take some photographs of you and things observed in your surroundings. The photographs will be used as reflective photos which will be discussed in subsequent interviews with you. Interviews will be in English or Akan. Some photographs may be used in future publications about the research. You will be invited to approve photographs that can be used in public.

If we use Akan in the interview, up to 500 words de-identified portion of your interview may be made available to a professional translator for the purpose of checking translations. All data collection will be conducted in your home and will take place up to a period of two months. You will be invited to sign an informed consent form which will indicate that you are willing to participate in this research at the beginning of the first interview and assent to indicate your continual commitment to be part of the research in subsequent observations, photographs and interviews.

Please read the information sheet and the consent form carefully and ask any questions you want before signing the form.

**Voluntary participation**

Your participation is voluntary, and you can decide to participate or not. If you choose to participate, you can decide to discontinue at any time without providing any reason. If you consent to participate in this research, kindly complete the informed consent sheet and submit it to the interviewer at the beginning of the first interview.
**Benefits**

Your continued participation over the two-month period would help us to understand the challenges for older people living with chronic illness. The understanding of the challenges will lead to advocating for services, which may help improve the quality of services for older people in the community.

**Risk**

There is no foreseeable physical risk associated with participation in this research. There may be a minimal level of emotional risk as this research will seek the views of participants in relation to their experiences with living with chronic illness and the nature of care provided by their family members. This situation is based on the notion that everyone has different and unique life experience. You may choose to reveal only what they are comfortable with. Should any emotional discomfort arise, you may nominate a person you trust and consult with him/her for help. You can also choose to discontinue your participation.

**Confidentiality**

Participants’ confidentiality will be strictly maintained throughout the study. Although data collection will be conducted in the homes of participants, the privacy of participants will be maintained. The interviewer will seek your permission before entering your home each time. You will be given the due respect accorded to older people in the Ghanaian cultural setting. The data generated from interviews, observation and photographs will not be made available to a third party without your prior permission. Pseudonyms will be used to represent you and
the final reports will be written in general terms so that it does not directly identify any participant. At the completion of this research, data will be stored with Griffith University for a period of five years, within which a third party can use with ethical approval for the University. After five years, the data will be destroyed.

Availability of report

A short summary of the research will be made available to participants at the end of the study. Please provide a mailing address on the consent form if you would like a copy of the report summary.

The ethical conduct of this research

Ethical approval was sought from Griffith University before the commencement of this research. Griffith University conducts research in accordance with the *National Statement on Ethical Conduct in Human Research*. If participants have any concerns or complaints about the ethical conduct of the research project they should contact Professor Ama de-Graft Aikins on +233 0 289 601 744, Associate Professor Laurie Grealish on +61 (0) 7 5552 9558 and Professor Wendy Moyle on +61 (0) 7 3735 5526. You can also contact the Manager, Research Ethics on +61 (0) 7 3735 4375 or research-ethics@griffith.edu.au.
Appendix 2: Consent Form for Older People

Project title: Informal care for the terminally ill in Ghana: experiences of older people and their family carers

Research Team

<table>
<thead>
<tr>
<th>Name</th>
<th>Organization</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Associate Professor Laurie</td>
<td>Menzies Health Institute, Queensland and School of Nursing and Midwifery, Griffith University and Gold Coast Hospital and Health Services</td>
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<td>+61 (0) 452 570 398 <a href="mailto:barbara.adonteng-kissi@griffithuni.edu.au">barbara.adonteng-kissi@griffithuni.edu.au</a></td>
</tr>
</tbody>
</table>

By signing below, I confirm that I have read and understood the information package and in particular:

- I understand that my involvement in this research will include multiple ethnographic interview sessions, permission for observation and photographs to be taken in my home over a period of 2 months
- I have had any questions answered to my satisfaction
• I understand the risks involved; I have nominated ……………………………… to consult on any emotional issues. Signature …………… Date……………….

• I understand that my participation in this research is voluntary

• I understand that if I have any additional questions, I can contact the research team

• I understand that I am free to withdraw at any time, without explanation or penalty

• I understand that my name and other personal information that could identify me will be removed or de-identified in publications or presentations resulting from this research

• I understand that I can choose or not for my face to show in conference presentations and publications

• I understand that the study has been reviewed and approved by the Griffith University Human Research Ethical Committee (GU ref no: 2018/423) and KBTH Development and Research Unit (KBTH ref no: 2018/TBA)

• I understand that I can contact Professor Ama de-Graft Aikins on +233 0 289 601 744, Associate Professor Laurie Grealish on +61 (0) 7 5552 9558 and Professor Wendy Moyle on +61 (0) 7 3735 5526 and the Manager, Research Ethics, at Griffith University Human Research Ethics Committee on 3735 4375 (or research-ethics@griffith.edu.au) if I have any concerns about the ethical conduct of the project; and

☐ I agree to participate in the project

☐ I agree for my interviews to be digitally recorded

☐ I agree for photos of me and my home to be taken as part of the research.

☐ I agree for photos to be included in conference presentations and publications.
☐ I agree to use of my data in future research projects that are an extension of, or closely related to, this research

☐ don’t show my face in conference presentations and publications.

☐ show my face in conference presentations and publications.

Name
Signature
Date

If you wish to have a copy of the summary report, please provide your contact details below:

Name: .................................................................

Address: ..............................................................

Email: ...............................................................
Appendix 3: Information Sheet for Family Carers

Project title: Informal care for the terminally ill in Ghana: experiences of older people and their family carers

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</tr>
</tbody>
</table>

Why this research is being conducted

This research is being conducted to understand how family members care for older people with chronic life-limiting illness in Ghanaian rural communities. The aim is to understand the needs of older people and the challenges associated with care. This study is a post graduate research requirement for the award of Doctor of philosophy Degree (PhD). The study is partially supported by a Griffith University, Australia scholarship. The study has been reviewed and approved by the Griffith University Human Research Ethical Committee (GU ref no: 2018/423) and KBTH Development and Research Unit (KBTH ref no: 2018/TBA)
Why you have been chosen to participate

You have been chosen to participate in this research because an older person living with a chronic life-limiting illness has nominated you as his/her family care giver and you have also indicated an interest in learning more about this research.

What you will be asked to do

You are invited to participate in this research in two ways.

Firstly, you will be asked to participate in two or three interviews on the topic of providing care to your older family member. Each interview will last about an hour. Once these have been transferred to a written record, the digital recordings will be deleted.

Secondly, the researcher will undertake some observations. She will observe how you provide care for the older person and the interaction between the two of you. The researcher will observe how you help with daily activities such as feeding, toileting, bathing, selecting proper attire, grooming, walking and transferring as well as managing finances, handling transportation, shopping, preparing meals, and using telephone, managing medication and home maintenance. The observation will be done during the time you are in the person’s home.

All data collection will be conducted over a two-month period. Interviews will be in English or Akan. If we use Akan in the interview, up to 500 words de-identified portion of your interview may be made available to a professional translator for the purpose of checking the translation. You will be invited to sign a consent form which will indicate that you are willing
to participate in this research. Please read the information sheet and the consent form carefully and ask any questions you want before signing the form.

**Voluntary participation**

Your participation is voluntary, and you can decide to participate or not. If you choose to participate, you can decide to discontinue at any time without providing any reason. If you consent to participate in this research, kindly complete the informed consent sheet and submit it to the interviewer before the first interview.

**Benefits**

Your continued participation over the two-month period would help us to understand the challenges for older people living with chronic illness. The understanding of the challenges will lead to advocating for services, which may help improve the quality of services for older people in the community.

**Risk**

There is no foreseeable physical risk associated with participation in this research. There may be a minimal level of emotional risk as this research will seek the views family members in relation the nature of care, their motivation in providing care and the challenges they face in providing care. This situation is based on the notion that everyone has different and unique
life experience. You may choose to reveal only what they are comfortable with. Should any emotional discomfort arise, you may nominate and consult a person you trust for help.

Confidentiality

Participants’ confidentiality will be highly maintained throughout the study. Although data collection will be conducted in the homes of participants, the privacy of participants will be maintained. You will have to give your permission before the interviewer enters your home and you will be rendered the due respect accorded to older people in the Ghanaian cultural setting. The data generated from the interviews observations and photographs will not be made available to a third party without the prior permission of participants. Pseudonyms will be used to represent you so the final reports will be written in general terms so that it does not directly identify any participant. At the completion of this research, data will be stored with Griffith University for a period of five years, within which a third party can use with ethical approval for the University. After five years, the data will be destroyed.

Availability of report

A short summary of the research will be made available to participants at the end of the study. Please provide a mailing address on the consent form if you would like a copy of the report summary.
The ethical conduct of this research

Ethical approval was sought from Griffith University before the commencement of this research. Griffith University conducts research in accordance with the *National Statement on Ethical Conduct in Human Research*. If participants have any concerns or complaints about the ethical conduct of the research project they should contact Professor Ama de-Graft Aikins on +233 0 289 601 744, Associate Professor Laurie Grealish on +61 (0) 7 5552 9558 and Professor Wendy Moyle on +61 (0) 7 3735 5526 and the Manager, Research Ethics on +61 (0) 7 3735 4375 or research-ethics@griffith.edu.au.
Appendix 4: Consent Form for Family Carers

Project title: Informal care for the terminally ill in Ghana: experiences of older people and their family carers

By signing below, I confirm that I have read and understood the information package and in particular:

- I understand that my involvement in this research will include participating in two or three interview sessions and permission for observations to be recorded within the home within a period of 2 months
- I have had any questions answered to my satisfaction
• I understand the risks involved; I have nominated ………………. to consult on any emotional issues. Signature …………… Date……………….

• I understand that my participation in this research is voluntary

• I understand that if I have any additional questions I can contact the research team

• I understand that I am free to withdraw at any time, without explanation or penalty

• I understand that my name and other personal information that could identify me will be removed or de-identified in publications or presentations resulting from this research

• I understand that I can choose or not for my face to show in conference presentations and publications

• I understand that the study has been reviewed and approved by the Griffith University Human Research Ethical Committee (GU ref no: 2018/423) and KBTH Development and Research Unit (KBTH ref no: 2018/TBA)

• I understand that I can contact Professor Ama de-Graft Aikins on +233 0 289 601 744, Associate Professor Laurie Grealish on +61 (0) 7 5552 9558 and Professor Wendy Moyle on +61 (0) 7 3735 5526 and the Manager, Research Ethics, at Griffith University Human Research Ethics Committee on 3735 4375 (or research-ethics@griffith.edu.au) if I have any concerns about the ethical conduct of the project; and

☐ I agree to participate in the project

☐ I agree for my interviews to be digitally recorded

☐ I agree for photos of me and my home to be taken as part of the research.

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☐ I agree to use of my data in future research projects that are an extension of, or closely related to, this research

☐ don’t show my face in conference presentations and publications.

☐ show my face in conference presentations and publications

Name
Signature
Date

If you wish to have a copy of the summary report, please provide your contact details below:

Name: .................................................................

Address: ..............................................................

Email: .................................................................
Appendix 5: KBTH Ethical Approval Letter

BARBARA ADON’TENG-KISSI

SCHOOL OF NURSING AND MIDWIFERY

GRIFFITH UNIVERSITY

AUSTRALIA

INSTITUTIONAL APPROVAL: KORLE BU TEACHING HOSPITAL-
SCIENTIFIC AND TECHNICAL COMMITTEE/INSTITUTIONAL REVIEW BOARD (KBTHISTC/1RB/00093/2018)

Following approval of your study entitled "Chronic life-limiting illness and informal care in Ghana: Experiences of people and their family carers" by the Korle Bu Teaching Hospital Scientific and Technical Committee/institutional Review Board. I am pleased to inform you that institutional approval has been granted for the conduct of your study in Korle Bu Teaching Hospital.

Please contact the Head of Department to discuss the commencement date of the study.

Please note that, this institutional approval is rendered invalid if the terms of the Institutional
Reviewed Board/Scientific and Technical Committee approval are violated.

Dr. Samuel Asiamah

Director of Medical Affairs

For: Chief Executive Officer

Cc: The Ag. Chief Executive
    Korle Bu
LETTER OF INTRODUCTION - BARBARA ADONTENG-KISSI
"CHRONIC LIFE-LIMITING ILLNESS AND INFORMAL CARE IN GHANA: EXPERIENCES OF PEOPLE AND THEIR FAMILY CARERS"

I have the pleasure to introduce to you the above-named Investigator from School of Nursing and Midwifery Griffith University, Australia. Barbara Adonteng-Kissi sought and has been granted approval to conduct a study entitled "Chronic life-limiting illness and informal care in Ghana: Experiences of people and their family carers" in your Department.

She is to contact you to discuss the commencement date of the study.

Please verify her identity with a Government issued National ID card and accord her the needed assistance.

Attached is the Scientific and Technical Committee and Institutional Review Board approval which specifies the terms.
Dr. Samuel Asiamah

Director of Medical Affairs

For: Chief Executive Officer

Cc: The Ag. Chief Executive
   Korle Bu
Appendix 6: Email Script for Health care Professionals from the Palliative Care of the Korle Bu Teaching Hospital

“This research invitation has been sent by KBTH IRB on behalf of the researchers in relation to the project: chronic life-limiting illness and informal care in Ghana: experiences of older people and their family carers”

Hello,

My name is Barbara Adonteng-Kissi. I am a PhD candidate in the School of Nursing and Midwifery at Griffith University, Australia. With the support of the School of Nursing and Midwifery and my supervisors Professor Wendy Moyle, Associate Professor Laurie Grealish, Professor Ama de-Graft Aikins and Doctor Nathan Davies, I am interested in knowing more about your opinion or view on palliative care in Ghana for my research in an interview of about an hour long in your workplace at a day and time convenient to you.

The purpose of my research project is to explore the experiences of older people living with chronic life-limiting illness and how informal care is used to support them in Ghana. Ascertaining the experiences of this vulnerable group will help justify strategies which professionals can employ to provide better care for them and their family, in order to improve their quality of lives during this phase of their lives. Your opinion on chronic life-limiting illness and the importance of palliative care will provide invaluable information.

If you are interested in learning more about this study, please review the attached information sheet outlining the research and what you will be asked to do. If you are interested after reading the information sheet, please contact the researcher directly by email or telephone.

It is important to know that this email is not to direct you to participate in this study. Participation is voluntary and is your decision. I will not discuss who does and does not opt to
participate with hospital management or any third party. I will also not pass any identified information to any third party. All issues discussed will remain confidential between the researcher and participant.

Refreshments will be served on the day of interview to thank you for your time.

Thank you for your time and consideration. I look forward to hearing from you.

If you have any questions or concerns about this request, feel free to contact me, Barbara Adonteng-Kissi on 0505286071 or barbara.adonteng-kissi@griffithuni.edu.au.

Many thanks,

Barbara Adonteng-Kissi

PhD Candidate, Griffith University
Appendix 7: Information Sheet for Health Care Professionals from the Palliative Care
Clinic of the Korle Bu Teaching Hospital

Project title: Informal care for the terminally ill in Ghana: experiences of older people
and their family carers

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This research is being conducted to ascertain how family members care for older people with chronic life-limiting illness in Ghanaian rural communities. The aim is to understand the needs of older people and the challenges associated with care so that service needs can be advocated for. This study is a post graduate research requirement for the award of Doctor of philosophy Degree (PhD). The study is partially supported by a Griffith University scholarship. The study has been reviewed and approved by the Griffith University Human...
Why you have been chosen to participate

You have been chosen to participate in this research because you are a health care professional providing palliative services for older people living with chronic life-limiting illness and their family carers in symptom management and you have giving an indication that you are willing to participate in this study.

What you will be asked to do

You are invited to participate in a single face-to-face interview which is aimed at understanding how palliative care is delivered in Ghana and the nature of services available for older people living with chronic life-limiting illness in rural Ghana. You will be asked to explain some of the challenges and strengths to providing palliative care in Ghana. You will also be asked to provide some of the working policies used to provide palliative services. The interview will last about half an hour, conducted at a convenient place and time chosen by you. The interview will be conducted in English or Akan. The interview will be digitally recorded. After transcriptions, the digital recordings will be stored at Griffith University and deleted after five years. If we use Akan in the interview, up to 500 words de-identified portion of your interview may be made available to a professional translator for the purpose of checking translations. You will be invited to sign a consent form which will indicate that you are willing to participate in this research. Please read the information sheet and the consent form carefully and ask any questions you want before signing the form.
Voluntary participation

Your participation is voluntary, and you can decide to participate or not. If you choose to participate, you can decide to discontinue at any time without providing any reason. The understanding of the challenges will lead to advocating for services, which will help improve the quality of the older people in the community. If you consent to participate in this research, kindly complete the informed consent sheet and submit it to the interviewer at the beginning of the interview.

Risk

There is no foreseeable physical or emotional risk associated with participation in this research.

Confidentiality

Participants’ confidentiality will be highly maintained throughout the study. The privacy of participants will be maintained. You will have to give your permission before the interviewer enters the place where you have chosen for the interview. The data generated from the interviews will not be made available to a third party without the prior permission of participants. Pseudonyms will be used to replace names and the final reports will be written in general terms so that it does not directly identify any participant. At the completion of this research, data will be stored with Griffith University for a period of five years, within which a third party can use with ethical approval from the University. After five years, the data will be destroyed.
Availability of report

A short summary of the research will be made available to participants at the end of the study. Please provide a mailing address on the consent form if you would like a copy of the report summary.

The ethical conduct of this research

Ethical approval was sought from Griffith University before the commencement of this research. Griffith University conducts research in accordance with the *National Statement on Ethical Conduct in Human Research*. If participants have any concerns or complaints about the ethical conduct of the research project they should contact Professor Ama de-Graft Aikins on +233 0 289 601 744, Associate Professor Laurie Grealish on +61 (0) 7 5552 9558 and Professor Wendy Moyle on +61 (0) 7 3735 5526 and the Manager, Research Ethics on +61 (0) 7 3735 4375 or research-ethics@griffith.edu.au.
Appendix 8: Consent Form for the Health Professionals from the Palliative Care Professionals of Korle Bu Teaching Hospital

Project title: Informal care for the terminally ill in Ghana: experiences of older people and their family carers

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By signing below, I confirm that I have read and understood the information package and in particular:

- I understand that my involvement in this research will include participating in a single face-to-face interview session
- I have had any questions answered to my satisfaction
- I understand the risks involved
• I understand that my participation in this research is voluntary

• I understand that if I have any additional questions I can contact the research team

• I understand that I am free to withdraw at any time, without explanation or penalty

• I understand that my name and other personal information that could identify me will be removed or de-identified in publications or presentations resulting from this research

• I know that the study has been reviewed and approved by the Griffith University Human Research Ethical Committee (GU ref no: 2018/423) and KBTH Development and Research Unit (KBTH ref no: 2018/TBA)

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☐ I agree to participate in the project

☐ I agree to use of my data in future research projects that are an extension of, or closely related to, this research

Name
Signature
Date

If you wish to have a copy of the summary report, please provide your contact details below:
Name: .......................................................... 

Address: ....................................................... 

Email: .........................................................
**Appendix 9: Information Sheet for Health Care Professionals of St. Luke Catholic Hospital**

**Project title: Informal care for the terminally ill in Ghana: experiences of older people and their family carers**

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**Why you have chosen to participate**

You have been chosen to participate in this research because you are a health care professional helping older people living with chronic life-limiting illness and their family carers in symptom management and you have giving an indication that you are willing to participate in this study.

**What you will be asked to do**

You are invited to participate in a single face-to-face interview which is aimed at understanding how palliative care is delivered in Ghana and the nature of services available for older people living with chronic life-limiting illness in rural Ghana. You will be asked to explain some of the challenges and strengths to providing palliative care in Ghana. You will also be asked to provide some of the working policies used to provide palliative services. The interview will last about an hour, conducted at a convenient place and time chosen by you. The interview will be digitally recorded. If we use Akan in the interview, up to 500 words de-identified portion of your interview may be made available to a professional translator for the purpose of checking translations. After transcription, the digital recordings will be stored at Griffith University and deleted after five years. You will be invited to sign a consent form which will indicate that you are willing to participate in this research. Please read the information sheet and the consent form carefully and ask any questions you want before signing the form.
Voluntary participation

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Appendix 10: Consent Form for Health Care Professionals of St. Luke Catholic Hospital

Project title: Informal care for the terminally ill in Ghana: experiences of older people and their family carers

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☐ I agree to participate in the project

☐ I agree to use of my data in future research projects that are an extension of, or closely related to, this research

Name
Signature
Date

If you wish to have a copy of the summary report, please provide your contact details below:
Appendix 11: First Interview Questions for Older People

Demographic information

1. Can you please tell me about yourself? (Probe: age, marital status, number of children, religion)
   Age ____
   Marital status ____
   Male ___. Female ____
   Children ____
   Occupation ______

2. How do you describe your health? (Probe: illness suffering from, number of years being diagnosed)

Experience with chronic life-limiting illness

1. Please tell me about your life experience before you became ill.
2. Please tell me about your experiences of living with the illness. What kinds of symptoms do you experience? How do the symptoms affect your activity?
3. You have been selected to participate in this study because you are over 60 years of age. Tell me more about what it is like to be living with chronic illness when you are older? How would it be different if you were younger?
4. What kinds of things do you need help with? How do you feel about needing help from others?
5. In regard to your health, have you ever needed help with anything that was not available? What happened?

6. In regard to your health, what things would you need at home that will make you feel better?

7. How often do you go to your GP/clinician with regards to your sickness? What kind of help does he/her provide?

8. Sometimes when people have lived with chronic illness for a long time, the palliative care team will become involved to help with symptom management. Has your GP discussed a palliative clinic for symptom management? Can you tell me more about your symptoms?

9. Planning for the future: What do you see happening in the next two weeks in relation to your health and needs?

Experience with informal care

1. Who is taking care of you? Is this more than one person?

2. What is your relationship with him or her?

3. Who do you turn to if you need something? How often would you need to turn to this person? Are there other people you might contact? How often?

4. What does s/he help you with?

5. Tell me about your experiences with help from your family carer (What did they do? probe: happy with the help? Do you receive everything you need from him or her?)

6. How often is care provided? Is it enough?

7. What do people or your family carers think about your illness?
8. Do you think that the care you are receiving is the same or different to your parents’ generation? In what ways?

9. How has the change (if any) affected you?

**Strengthening informal care**

1. In what ways do you think government can support your family carer to help you?
Appendix 12: First Interview Questions for Family Carers

Demographic information

1. Please tell me about yourself (Probe: age, marital status, number of children, occupation)
   
   Age ____
   
   Marital status ____
   
   Male ___. Female ____
   
   Children ____
   
   Occupation ______
   
   2. What is your relationship with the older person?
   
   Son_____ 
   
   Daughter_____ 
   
   Friend ___
   
   Spouse____
   
   Sister or brother ____
   
   Other ______

3. What is your understanding of [name of person] illness?
4. How do you know [name person] wants to be cared for at home?
5. How often do you provide care for [name person]?
6. What do you find beneficial in caring for [name person]? What makes you feel good?
7. What do you find hard to do in caring for [name person]?

8. Have you had any positives consequences in caring for [name person]? Please explain

9. Have you suffered any negative consequences as result of caring for [name person]?
   Please explain.

10. How have you dealt with these negative consequences?

11. How has caring for older people in communities changed in the last ten years? Please explain

12. How has the change affected you?

Resources and available support

1. What are the things other people help you with when caring for [name person]? How have these things helped you in caring for [name person]?

2. What type of community-based services have you used in the last six months? Who provides those services?

Planning for the future:

1. What do you see happening in the next two weeks [in relation to [name person] care]?

2. What measures have you put in place to deal with future adversities?
Appendix 13: Second Interview Questions for Older People

1. The last time we met, you described who takes care of you. What kinds of things does she/he help you with?

2. What do other members of your family and community do to help you? (probe financially, socio-emotionally)

3. What differences are there in the care and support you receive from your family carer and other members of your family from the care and support to older people in your age cohort in this community?

4. Reflect on a particular day you were sick. Explain to me how your family carer took care of you (probe process of care)

5. What things did she/he do right? What things did she/he not do right? How did these make you feel?

6. How have your family carer and other members in the community showed interest in things that concerns you in the last three months? (probe how they show concern for heath, comfort and during difficult times)

7. What are the things your family carer does that are important to you? What are the things your family carer does that are not important to you?

8. How do you communicate dissatisfaction with care with your family carer (or other members of your family/community)? What are their reactions/responses to your communications and concerns?

9. Why do you always sit in this position? Which position are you comfortable with? What do you like about sitting outside?

10. How much time do you spend outside? Is there anywhere else you would rather be?

11. Please give me a description of your room. What are the things there? What are the things you need in your room to improve your quality of life?
12. How would you explain your quality of life?

13. What social structures in your environment support you best and improve your quality of life? What structures do not support you and limit your quality of life? (Probe: structures at the micro/family level, mezzo/community level and macro/district or state level, that is, employment system; health system; social organisations such as religious groups, clubs; market or shopping centres; transport systems; drug stores, housing structures, financial institutions, government interventions for older people)

14. What changes in your social structure do you think would improve your quality of life?

15. How do we implement these changes to best support you and improve your quality of life?

16. If you had lots of money today, what would you use it for?
Appendix 14: Second Interview Questions for Family Carers

Focus on the structure

1. The last time we met, we talked about what you do to take care of [name of older person]. Please describe what kinds of things you do in the caring? (Probe ADLs and IADLs)

2. Reflect on a particular day [name of older person] was sick. Explain to me how you took care of him/her (probe process of care, knowledge on health condition, relevance of care)

3. In the past, how have you or members of your family cared for and supported older people who are living with chronic life-limiting illness in your family? What need do they express and how have you or members of the family present met those needs

4. What things does [name of older person] wants you to do more? What prevents you from doing more? What will help you to meet all the needs of [name of older person]?

Extended family processes

1. What do other members of your family do to help you with in caring for [name of person]? (probe financially, socio-emotionally)

2. What enhances or prevents other members of your extended family to help you in caring for [name of person]? (probe financially, information on health status, relationship and interactions)
Community processes

1. How have other members in the community showed interest in your caring process and activities of care for [name of older person] in the last three months? (probe how they show concern for health, comfort and during difficult times)

2. How does the care and support you give to [name of person] compare with those provided by other family carers in your community?

3. How does social systems influence care and support for older people in this community? (Probe people/families, religion, health system, government, NGOs)
Appendix 15: Interview Questions for Health Care Professionals

1. What is the nature of palliative care in Ghana?
2. Please tell me about the services you provide in this centre.
3. Which groups of people usually come to seek the services here? How often do they come for services?
4. What do you say or do when you consider a person to be near the end of life? or What is the management plan for a person approaching the end of life?
5. When do you decide if a person can’t be cared for at home and has to be in the hospital?
6. What policies do you use to provide care for people approaching the end of life?
7. What are some of the challenges you face as a centre? What challenges do you face as a health care professional?
8. In what ways can these challenges be met?
9. What types of considerations would be made for an older person approaching the end of life as compared to a younger adult?
10. How do you ensure that people from rural areas get palliative services they require?
    How are resources distributed in rural areas?
11. What your ideas about providing appropriate care for older people living with chronic illness in Ghana?
12. Does rurality have any impact on palliation or ageing?
13. How do you involve family members in the process of providing palliative care services or symptoms management for older people that present chronic diseases in the clinic?

Is there any other information you think the research team should know?
Appendix 16: Griffith University Human Research Ethics Committee Approval Letter

I am pleased to advise that this research has approval to commence from the Griffith Ethics Committee, a committee established and operating in accordance with the standards and principles of the Australian National Statement on Ethical Conduct in Human Research (2007).

For any queries regarding this ethical approval please contact the Committee Secretary on tel: 07 3735 4375.